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Technology Access and Preferences for Smartphone App Interventions to Optimize Iron Chelation Therapy Adherence Among Adolescents, Young Adults, and Parents of Children Receiving Chronic Transfusions: Cross-Sectional Survey Study

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Abstract

Background: Iron chelation therapy (ICT) is essential for people with hematological disorders requiring chronic transfusions to minimize the risk of iron overload, yet suboptimal adherence is prevalent. Widespread use of personal technology makes mobile health (mHealth) an attractive platform to promote adherence.

Objective: This study aimed to examine access to mobile technology and preferences for an mHealth intervention to improve adherence to ICT.

Methods: A cross-sectional survey that included 63 items assessing technology access, mHealth preferences, and demographics was administered through REDCap (Research Electronic Data Capture), a digital research data tool, during packed red blood cell transfusion visits. Parents of children receiving chronic transfusions, as well as adolescents and young adults receiving chronic transfusions, were enrolled between August 2018 and June 2019. Patients had to have a hematologic diagnosis requiring chronic transfusions, be receiving ICT, and be aged 12 years or older to complete the survey. Parents were required to have a child aged 24 months who met these criteria.

Results: A total of 60 participants were included (median age 31.5, IQR 20-39 years; n=40, 67% female), with 29 (48%) being parents and 31 (52%) being patients. All parents and patients owned an electronic tablet, a smartphone, or both. The most endorsed mHealth app features among all participants included laboratory test monitoring (55/60, 92%), reminders to take iron chelation medication (50/60, 83%), and education about ICT (49/60, 82%). Parents' most endorsed features included laboratory test monitoring (27/29, 93%) and education about ICT (25/29, 86%). Patients' most endorsed features included laboratory test monitoring (28/31, 90%) and reminders to take iron chelation medication (28/31, 90%). There were no substantial differences between parents and patients in their preferences.

Conclusions: Both parents and adolescents and young adults reported a strong interest in multiple mHealth app features. Participants provided valuable insights into optimal strategies and preferred app features for developing a multifunctional technology-based behavioral intervention to promote ICT adherence.

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KEYWORDS

thalassemia; sickle cell disease; medication adherence; iron chelation therapy; behavior change; technology access; mobile health; mHealth

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Introduction

Iron overload is the major cause of morbidity and mortality in transfusion-dependent hematological disorders such as thalassemia [1]. One of the cornerstones of treatment for refractory anemia is packed red blood cell transfusions. Over time, transfusions can lead to excess iron accumulation in the heart, liver, and spleen, among other tissues, leading to a wide array of complications, including endocrinopathies, cardiomyopathies, and hepatic failure.

Iron chelation therapy (ICT) is essential for people with thalassemia and other hematological disorders requiring long-term red blood cell transfusion to minimize the risk of iron overload. Previous work has shown that adherence varies widely and is often suboptimal [2-5]. Suboptimal adherence to iron chelation medication is prevalent and has been associated with an increased risk of iron overload, resulting in increased morbidity, mortality, and health care use. Thus, interventions to improve ICT adherence are important to investigate and essential to improving morbidity and mortality.

Medication adherence is complex and multifaceted [6,7] Studies of adherence among patients taking iron chelation medication often report multiple factors contributing to low adherence, and it is difficult to compare and establish rates of adherence among patients taking iron chelation medication [2,3]. One potential avenue to address and improve adherence to medications is through the development of mobile health (mHealth) tools, that is, the use of mobile and wireless applications (eg, SMS text messaging, apps, wearable devices, remote sensing, and social media) in the delivery of health-related services [7,8]. The most recent (2021) Pew Research Center survey found that 97% of adult US residents owned a mobile phone, with 85% owning a smartphone [9]. Similarly, the vast majority of adolescents have access to digital devices, including smartphones (95%), and 97% of all adolescents report using the internet daily [10].

However, while the Pew Research Center surveys are designed to sample a population that reflects the demographics of the United States, they do not necessarily reflect the demographics of individuals with chronic medical conditions such as thalassemia and their families. There is a known “digital divide” in the United States, with disparities in access to technology correlated with a variety of factors, including household income, educational level, and geography [11]. It is important to ensure that pediatric patients, adolescents, and young adults receiving chronic transfusions, as well as parents, have access to technology when considering mHealth interventions.

Moreover, there is a variety of potential avenues and tools that can be integrated into mHealth interventions. Observational studies have shown that sharing health care experiences online can lead to decreased isolation, increased support, an exchange of coping strategies, and health care learning from shared experience [12]. There is also some evidence that both healthy adolescents and those with chronic health conditions who develop skills to monitor their symptoms and self-manage their health may experience improved outcomes in disease knowledge and adherence specifically through SMS text messaging and mobile phone apps [13-16]. A pilot study of a medication reminder app demonstrated the feasibility and potential usefulness of mHealth in adolescents and young adults receiving chronic transfusions [17]. In addition to access to mHealth and the efficacy of these features, it is important that mHealth interventions have high engagement. While adolescents in general are avid smartphone users, only 2% of adolescents report frequent use of an mHealth app [18]. Thus, it is crucial that mHealth interventions are designed with accessibility and engagement in mind.

Involving users in the early development process has been shown to promote engagement [19,20]. User-centered app design is a method of designing mobile apps that begins with a needs assessment followed by iterative cycles involving the intended end user. Apps involving end-user input throughout the development, testing, and dissemination process are more likely to be perceived by users as useful as well as easy to use [21].

Thus, this study was a needs assessment for an mHealth adherence app as the first step in a user-centered design process. First, we aimed to evaluate patients’ and parents’ access to technology-based (mHealth) interventions. Second, we aimed to assess interest in and preferences for an mHealth intervention to promote ICT adherence. We hypothesized that adolescents and young adults and parents of children receiving chronic transfusions would have high interest in an mHealth app and that adolescents and young adults and parents may have different preferences and priorities for mHealth. Ultimately, this study is the first step in developing an mHealth tool to promote medication adherence and optimize health outcomes among patients receiving chronic transfusions.

Methods

Recruitment

This was a cross-sectional, single-institution study. Participants completed a cross-sectional survey that was administered through REDCap (Research Electronic Data Capture; Vanderbilt University; a secure, web-based tool for research data capture used for collecting data and surveys) using tablet computers during packed red blood cell transfusion visits at a single institution. Eligibility criteria for patients included (1) having a hematologic diagnosis requiring chronic transfusions, (2) being on ICT, and (3) being aged 12 years or older to complete the survey. Parents were required to have a child aged 24 months or older who met these criteria. Potential study participants (parents of children receiving chronic transfusions and adolescents and young adults receiving chronic transfusions) were approached during transfusion appointments between August 2018 and June 2019. Data were collected on electronic tablets through REDCap supported by the Northwestern University Clinical and Translational Sciences Institute. This study aimed to accrue 50 to 100 patients based on feasibility and patient volume at our infusion center. By the end of the accrual period, a total of 60 participants were enrolled.

Ethical Considerations

The institutional review board at the Ann and Robert H. Lurie Children’s Hospital of Chicago approved this study, and all procedures were conducted in accordance with the current

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version of the Declaration of Helsinki. Informed consent was obtained from all participants, and they were aware of their ability to opt out. Survey data were anonymous and did not contain identifying information. All participants were compensated with a US $25 gift card upon successful completion of the study survey.

Study Measures

Our study instrument included 63 items assessing technology access, mHealth preferences, and demographics. These items were based on current literature investigating technology-based interventions and medication adherence among patients with chronic conditions in adult and pediatric populations based on previous studies conducted at our institution [6,16,22-24].

The technology access portion of the survey included 7 questions about access to electronic devices, as well as 8 questions about SMS text message and call limits and home or school internet signal strength. The mHealth portion of the survey included 8 yes-or-no questions, 1 rank-order question, and 6 multiple-choice questions that evaluated interest in general mHealth features and notification preferences, which have been previously reported in studies conducted at our institution [16,23].

Statistical Analysis

Descriptive statistics for categorical data were reported in frequencies and percentages. Chi-square tests were run to determine the significant associations among variables and different subgroups. All tests were 2-sided, and a *P* value of <.05 was considered statistically significant. Statistical analysis was conducted using Microsoft Excel.

Results

Demographics and Technology Access

A total of 60 participants were included, with 29 (48%) being parents and 31 (52%) being patients (Table 1). The median age of the participants was 31.5 (IQR 20-39) years, and 67% (n=40) were female. The most common diagnoses included thalassemia (n=31, 52%) and sickle cell disease (n=21, 35%). Reported ICT medications varied, with 65% (n=39) taking deferasirox in oral formulation, 27% (n=16) taking deferasirox in tablet form, 8% (n=5) taking deferiprone, and 5% (n=3) taking deferoxamine. All participants' characteristics are summarized in Table 1.

All parents and patients owned an electronic tablet, a smartphone, or both. Most parents and patients owned cell phones (28/29, 97% and 28/31, 90%, respectively), but tablet ownership was less pervasive (19/29, 66% and 10/31, 32%, respectively). Most parents and patients had unlimited plans for SMS text messaging (27/29, 93% and 25/31, 81%, respectively) and data (21/29, 72% and 21/31, 68%, respectively), as well as a fast home internet connection (24/29, 83% and 23/31, 74%, respectively).

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Table . Participants' characteristics and demographics as self-reported on a cross-sectional survey (N=60).

	Values
Age (y), median (IQR)	31.5 (20-39)
Age group, n (%)	
Parents	29 (48)
Patients	31 (52)
Adolescents (12-17 y)	10 (17)
Young adults (≥18 y)	21 (35)
Female sex, n (%)	40 (67)
Race or ethnicity, n (%)	
Asian	23 (38)
Black	16 (27)
Hispanic	4 (7)
White	17 (28)
Diagnosis, n (%)	
Thalassemia	31 (52)
Sickle cell disease	21 (35)
Other hematological disorders[a]	8 (13)
Iron chelation medication, n (%)	
Exjade (deferasirox)	16 (27)
Jadenu (deferasirox)	39 (65)
Ferriprox (deferiprone)	5 (8)
Desferal (deferoxamine)	3 (5)
Other medications, n (%)	
Hydroxyurea	1 (2)
Penicillin	13 (22)
Folic acid	3 (5)
Insulin	3 (5)
Multivitamins	4 (7)
Amiloride	3 (5)
Others[b]	16 (27)
Insurance, n (%)	
Private	34 (57)
Public or Medicaid	18 (30)
Unsure	3 (5)
None	5 (8)

[a]Other hematological disorders among participants included sideroblastic anemia (1/60, 2%), Diamond-Blackfan anemia (3/60, 5%), congenital dyserythropoietic anemia (2/60, 3%), Fanconi anemia (1/60, 2%), and pyruvate kinase deficiency (1/60, 2%).

[b]Other medications included ibuprofen (1/60, 2%), betamethasone ointment (1/60, 2%), risedronate (1/60, 2%), levothyroxine (1/60, 1.7%), hormonal replacement therapy (1/60, 2%), medroxyprogesterone (1/60, 2%), wellbutrin (1/60, 2%), venlafaxine (1/60, 2%), enalapril (1/60, 2%), hydrocortisone (1/60, 2%), hydroxychloroquine (1/60, 2%), oral contraceptive pills (1/60, 2%), aspirin (1/60, 2%), and unspecified medications (3/60, 5%).

Interest in mHealth Features

All 8 proposed mHealth features were endorsed by over 50% (30/60) of the participants, including parents (15/29, 52%) and patients (16/31, 52%; Table 2). The median number of features endorsed by both parents and patients was 7 (IQR 6-8). The most endorsed mHealth app features among parents and patients included laboratory test monitoring (55/60, 92%), reminders to take iron chelation medication (50/60, 83%), and education

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about ICT (49/60, 82%). In particular, parents' most endorsed features included laboratory test monitoring (27/29, 93%) and education about ICT (25/29, 86%). Patients' most endorsed features included laboratory test monitoring (28/31, 90%) and reminders to take iron chelation medication (28/31, 90%). There were no significant differences between parents and patients in their preferences (Table 2).

Table . Frequency of participants' reported interest in general mobile health features as assessed via a cross-sectional survey (N=60).

App feature	All participants, n (%)	Parents (n=29), n (%)	Patients (n=31), n (%)	*P* value
Medication reminders	50 (83)	22 (76)	28 (90)	.13
Medication log	45 (75)	23 (79)	22 (71)	.46
Positive feedback	47 (78)	20 (69)	27 (87)	.09
Adherence SMS text message prompt	48 (80)	21 (72)	27 (87)	.16
Social media	39 (65)	20 (69)	19 (61)	.53
Diagnosis education	45 (75)	23 (79)	22 (71)	.46
Medication education	49 (82)	25 (86)	24 (77)	.38
Laboratory test monitoring	55 (92)	27 (93)	28 (90)	.70

The cumulative ranking of the proposed smartphone app features among parents and adolescents and young adults is summarized in Figure 1. Medication reminders (8/29, 28%) were most frequently ranked as most important among parents, followed by the ability to review laboratory test results (7/29, 24%) and social media features (3/29, 10%). Patients also most prioritized medication reminders (12/31, 39%), followed by laboratory test results (6/31, 19%) and social media features (3/31, 10%).

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Figure 1. Cumulative ranked preferences for a thalassemia smartphone app among all participants (parents and adolescents and young adults) as ranked via a cross-sectional survey: (A) all participants, (B) parents, and (C) patients.

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Discussion

Principal Results

Our study aims were to evaluate patients' and parents' access to technology-based (mHealth) interventions and assess interest in and preferences for an mHealth intervention to promote ICT adherence. These findings highlight that parents and adolescents and young adults had high rates of technology access and reported strong interest in multiple mHealth app features, including features that specifically focused on medication adherence, education, and connection with the community.

Our participants' high rate of technology access is comparable to that in reports of the general population and supports that mHealth interventions may be an accessible, useful tool to promote adherence [10,12]. Our study adds to the existing literature by demonstrating a strong interest in multiple mHealth app features by patients receiving chronic transfusions. Participants provided important insights into preferred app features for developing a technology-based behavioral intervention (mHealth app). These findings can help guide the development of an effective mHealth tool to promote ICT adherence for adolescents and young adults with thalassemia or other chronic transfusion–dependent conditions.

While there are some limited mHealth apps currently available, the strong interest from both patients and parents in mHealth features in our study suggests that there may be some features and tools that would be more beneficial and engaging to users than those that currently exist. This further highlights the importance of user-centered development in ensuring that these apps prioritize features that are of interest to the populations that are intended to use them. One international study in 2018 found that, although there are currently many mHealth apps available for use, they often do not match patients' expectations due to lack of user-centered development [24]. Our study represents the starting point of user-centered design and assessment of interest in mHealth interventions and features among patients receiving ICT and their parents. User-centered design should continue throughout the phases of development, including creation, deployment, testing, implementation, and dissemination [21].

Of the app features highlighted in our study, there was particularly strong interest in laboratory test monitoring, medication reminders, and social media or virtual connections with other patients with transfusion-dependent illnesses. Of note, there was no statistically significant difference between the mHealth preferences of parents and patients surveyed, with a nonsignificant but slightly greater proportion of patients preferring positive feedback when taking medications compared to parents. Prior literature has often highlighted the ways in which barriers to adherence may vary from adolescence to adulthood and the ways in which adolescents may have unique preferences for mHealth interventions due to their relative use of technology compared to other age groups [25-27]. One possible explanation for the lack of discrepancy between the preferences of parents and patients is that most participants had interest in multiple mHealth features, with a median number of features endorsed of 7 out of 8. An mHealth tool with multiple features may be beneficial to both patients receiving ICT and parents.

This study builds on previous literature examining adherence interventions for patients receiving ICT [2-4,17]. In particular, a 2017 study highlighted a pilot intervention using a medication reminder app and demonstrated the feasibility and potential usefulness of mHealth in adolescents and young adults receiving chronic transfusions. Our study was focused more on the development stages of an mHealth intervention, particularly on obtaining user-centered feedback on which features might be preferred and promote adherence. Moreover, our study examined not only adolescents and young adults but also parents, who are also a potential user group for an mHealth intervention.

The results of this study are consistent with the literature on technology access and preferences among patients with other complex chronic conditions, including cystic fibrosis, diabetes, sickle cell disease, and acute lymphoblastic leukemia [16,23,28-30]. This further supports that an mHealth app with multiple features could be a promising tool to promote ICT adherence in patients receiving chronic transfusions.

Strengths

Our study had several strengths. We were able to conduct a thorough evaluation of access to technology, assessing both access to multiple modes of technology and barriers to technology use, such as data plans and Wi-Fi access. Moreover, this study examined both patients' and parents' preferences for an ICT mHealth app, allowing us to effectively examine a group of all potential users of this mHealth intervention while also comparing preferences. Lastly, our patient population was diverse, both racially and ethnically and in terms of ICT medications used, as well as in insurance status.

Limitations

There are several limitations worth noting in this study. First, this was a single-institution study with a relatively small sample size. While our survey items were not validated, they have been used in other published studies [16,22]. Additionally, as we adapted existing survey items, we did not provide an exhaustive list of potential mHealth interventions and app features. Finally, we did not survey our participants about prior experience with mHealth apps, which may have been helpful to note in participants' perceptions of mHealth and preferences for mHealth features.

Conclusions

In conclusion, parents and patients reported high accessibility to mobile technology. Overall, there was a high level of interest in mHealth interventions, as well as in features specifically intended to promote medication adherence. These findings support an interest in and need for the development of a user-centered mHealth intervention as a tool to promote medication adherence among patients with thalassemia and other conditions requiring chronic transfusions, as well as among their parents. Parents and patients reported similar preferences for mHealth features centered on medication reminders, education, and connection with the broader community of individuals requiring chronic transfusions and their families. In

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the future, continuing to center user experiences and feedback will be important in maximizing engagement with and utility of an app as an intervention to improve adherence and health care outcomes among patients receiving ICT.

Next steps may include developing and designing an app for an mHealth intervention integrating participant preferences. Throughout development and implementation, centering user experience will continue to be important. Future studies could then use participant feedback to assess the effectiveness of these tools in promoting medication adherence and optimizing health outcomes while also modifying the mHealth tools to be more effective among patients and parents of individuals receiving chronic transfusions.

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Data Availability

The data supporting the findings of this study are available from the corresponding author on reasonable request. Data requests will be reviewed by the research team and the institutional review board at Ann and Robert H. Lurie Children's Hospital of Chicago to ensure compliance with participant privacy protections and institutional data sharing agreements. Due to the sensitive nature of health information and the potential for participant reidentification in this specialized patient population, individual participant data cannot be made publicly available.

Authors' Contributions

PR, ML, and SB were involved in the conceptualization, investigation, formal analysis, and interpretation of the data. SB was involved in funding acquisition and mentorship. PR and ML were involved in the drafting of the paper. SB was involved in revising the paper critically for intellectual content. PR, ML, and SB approved the final version to be published, and all authors agree to be accountable for all aspects of the work.

Conflicts of Interest

SB serves as editor-in-chief for *JMIR Pediatrics and Parents*. He has been completely blinded to and not involved in any way with the peer review process. All other authors declare no conflicts of interest.

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Abbreviations

ICT: iron chelation therapy
mHealth: mobile health
REDCap: Research Electronic Data Capture

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Healthy Lifestyle Practices, Online Health Information–Seeking Behaviors, and Internet Usage Among Pregnant Women: Multigroup Structural Equation Modeling Approach

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Abstract

Background: Singapore is a multicultural society characterized by a diverse array of ethnic groups, including Chinese, Malay, Indians, and others. A considerable percentage of Singaporeans are active users of the internet. The internet has become a significant resource for health education, particularly for women who wish to learn about a healthy lifestyle during pregnancy. However, it is still unclear how pregnant women search for information online, particularly within specific groups.

Objective: This study aimed to explore the relationship between healthy lifestyle practices, online health information-seeking behaviors, and internet usage (IU) among 1905 pregnant women.

Methods: Structural equation modeling (SEM) was used to evaluate the relationships between the appropriate intake of food groups, healthy diet practices (HD), internet for dietary advice (ID), internet for physical activity advice (IP), and IU, based on 5 hypotheses rooted in theoretical concepts. We used a multigroup SEM approach to examine these hypotheses across various ages, ethnicities, BMI, and categories of pregnant groups.

Results: Our results confirmed 5 hypotheses, indicating significant relationships among the variables: appropriate intake of food groups was positively linked to HD (β=0.262; *P*<.001); HD was positively linked to ID (β=.168; *P*<.001); ID was positively linked to IP (β=0.185; *P*<.001); IP was positively linked to IU (β=0.190; *P*<.001); and HD was negatively linked to IU (β=−0.208; *P*<.001). The multigroup SEM analyses yielded significant differences in Hypotheses 2 and 3 when comparing different age groups (*P*=.009), BMI categories (*P*=.03), and number of pregnancies (*P*=.003).

Conclusions: Our findings offer valuable insights into developing customized online interventions aimed at encouraging a healthy lifestyle during pregnancy.

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KEYWORDS

healthy lifestyle practices; online health information-seeking behaviors; internet usage; pregnant women; multigroup structural equation model

Introduction

A healthy lifestyle during pregnancy, including physical activity along with a healthy diet, is beneficial for pregnant women in terms of reducing the risk of maternal and fetal complications [1,2]. With the recent rapid advancement of information and communication technology over the past 2 decades, the internet has emerged as a prominent health education resource for women seeking to learn about dietary and lifestyle modifications during pregnancy [3]. In Singapore, 92.3% of residents are internet users, as indicated by statistics from Global Digital Insights 2025 [4]. Evidence indicates that pregnant women actively use the internet to seek out pregnancy-related information and engage in discussions with peers [5]. Given that the internet serves as a medium for health education, there is a notable lack of investigation into how healthy lifestyles impact online health information-seeking behaviors and internet usage (IU) among pregnant women.

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The selection of appropriate food group intake is essential during pregnancy because pregnancy heightens nutritional awareness; thereby, it can help establish healthy dietary practices [6]. Given that the internet serves as a valuable resource for seeking information, pregnant women rely on it to make informed lifestyle choices, encompassing physical activity and healthy eating [7]. A systematic review observed that health information-seeking internet behaviors among pregnant women, especially first-time and young pregnant women, were more likely to find internet-based information [5]. Furthermore, a systematic review revealed that internet use was positively correlated with an increased likelihood of being overweight and obese in the general population [8]. However, it remains unclear whether this conclusion applies to pregnant women.

There are inconsistent findings concerning the relationship between IU and the lifestyle of pregnant women across various countries and ethnic groups, including Iran [9] and Qatar [10]. We found that there is a significant positive relationship between using the internet for healthy behaviors and positive lifestyle changes in Qatari pregnant women [10]. However, 1 study showed no statistical correlation between online health information and a healthy lifestyle in Iranian pregnant women [9]. This discrepancy may be associated with the unique cultural values and beliefs of different ethnic groups. Singapore is a multiracial and multicultural nation, comprising Chinese, Malay, Indian, and various other ethnic groups, all of which contribute to its rich and diverse cultural landscape. Since Singapore is a multicultural country, various ethnic groups may impact these relationships.

This study aimed to investigate the connections among the appropriateness of food group intake, use of online resources for diet and exercise, and IU among pregnant women. A hypothetical model was developed based on protection motivation theory (PMT) [11] and self-control theory (SCT) [12]. The PMT was used to elucidate how pregnant women determine whether to engage in protective behaviors when confronted with a threat by examining the cognitive processes involved in threat and coping appraisal [13]. Pregnant women may pose risks to their unborn babies during pregnancy, yet they are often more inclined to adopt a healthy lifestyle to ensure the safety and development of their child [14]. PMT suggests that pregnant women are more likely than the general population to be motivated by protection, prompting them to actively seek health-related information online regarding a healthy diet and lifestyle [11].

According to the SCT, self-control is the ability to regulate current thoughts, feelings, and behavior to secure future benefits [15], which is very important for health and well-being and involves the repeated act of overriding a dominant response [16]. This trait can manifest in behaviors such as adopting an unhealthy lifestyle prior to pregnancy or spending excessive time browsing irrelevant information online [17]. Pregnant women who exhibit high self-control may prioritize an optimal lifestyle by exerting efforts in self-regulation [15,17]. Therefore, pregnant women who intentionally seek the internet for healthy diets may benefit from the deliberative control process, allowing them to more effectively resist the temptation of high-energy foods and irrelevant online information [12]. Based on these theories, we concluded that there could be potential relationships between IU and healthy lifestyles among pregnant women (Figure 1). It is still unclear whether the hypothetical relationships operated in the same way across different groups, particularly among those of varying ages, ethnicities, BMIs, and numbers of pregnant individuals.

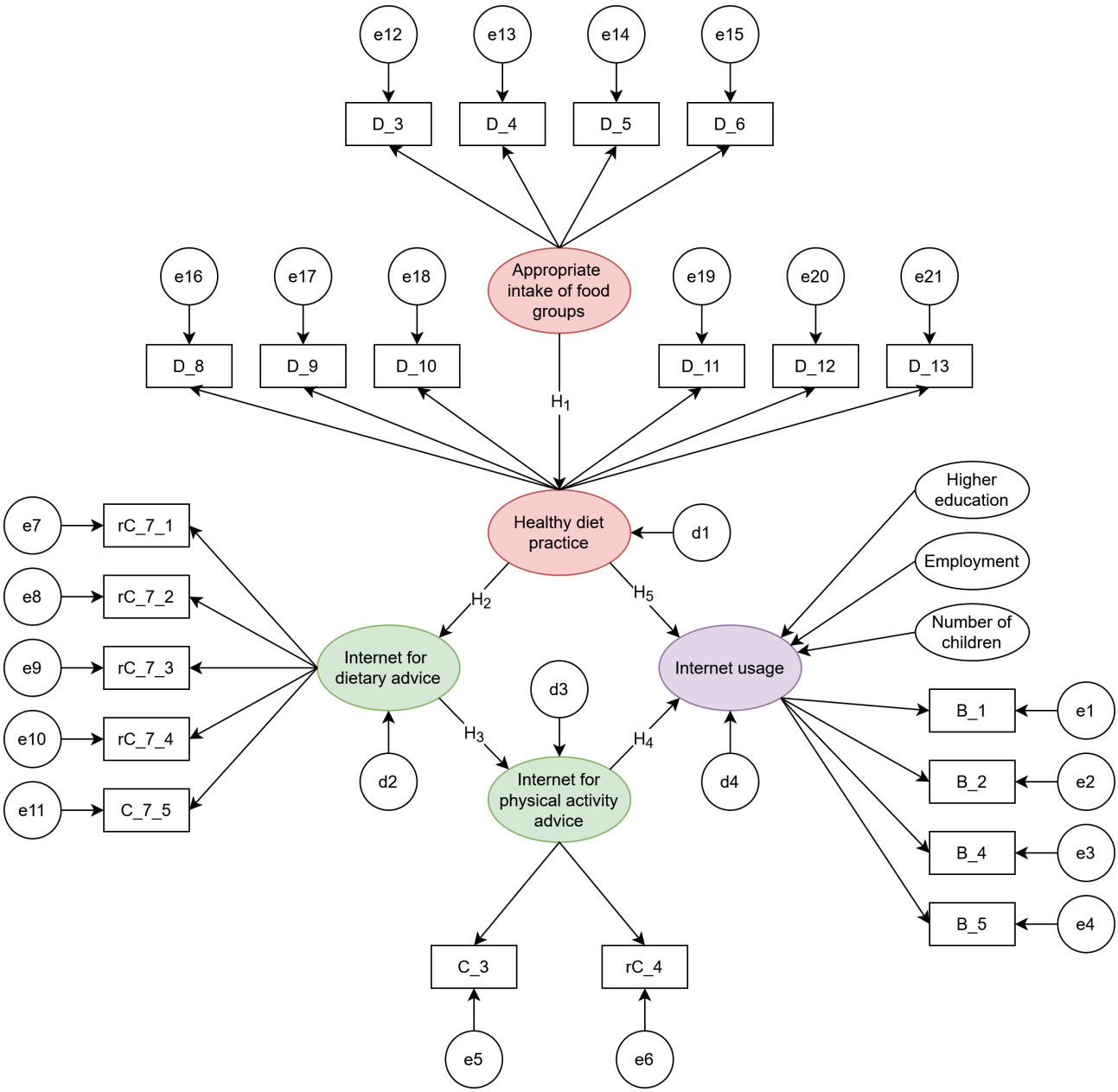
Thus, our study sought to assess these relationships based on five hypotheses (H):

1. Hypothesis 1: Appropriate intake of food groups is linked to healthy diet practice
2. Hypothesis 2: Healthy diet practice is linked to seeking dietary advice on the internet
3. Hypothesis 3: The internet's advice on diet is linked to the pursuit of physical activity advice found on the internet
4. Hypothesis 4: The internet's advice on physical activity is linked to IU
5. Hypothesis 5: Healthy diet practice is linked to IU

Furthermore, we also compare these hypotheses across various ages, ethnicities, BMIs, and numbers of pregnant groups. Such information is crucial for obtaining insights that can guide future targeted interventions for pregnant women.

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Figure 1. A hypothetical model of the relationships among study variables (appropriate intakes of food groups, healthy diet practice, internet for dietary advice, internet for physical activity advice, and internet usage) in pregnant women. Arrow (→): direct impact; B: Items of Internet Frequency Usage Scale; C: Items of Internet for Physical Activity and Nutrition Scale; D: Items of the Rapid Eating and Activity Assessment for Participant Short Version; d: residue term; e: error term; H_1:Hypothesis 1; H_2: Hypothesis 2; H_3: Hypothesis 3; H_4: Hypothesis 4; H_5: Hypothesis 5; r: reversed item. *P < .05; **P < .01; ***P < .001.



Methods

Study Design and Data Collection

We conducted this explanatory cross-sectional study among pregnant women who visited 2 antenatal clinics at a university-affiliated hospital in Singapore. There was a public antenatal clinic that served individuals from various economic backgrounds and a private antenatal clinic that catered to those from middle and upper economic classes. We collected data from both clinics, representing a range of socio-economic classes. Data collection occurred while pregnant women were waiting at both clinics. A convenience sampling method was used because of resource constraints. The inclusion criteria were as follows: (1) a minimum age of 21 years, (2) pregnancy in the second trimester (12 to 24 wk of gestation), (3) proficiency in English, and (4) regular access to the internet. A sample size of 1054 was deemed necessary, taking into account a margin of error of 2%, a confidence level of 95%, and a presumed population size of 20,000 [18]. The final anticipated sample size was 1270, which further accounted for a presumed response rate of 83% [19].

Two experienced research assistants (SHW and WWA) recruited all eligible participants in both clinics during the waiting period for their scheduled antenatal follow-up. The research assistants identified moments that were less stressful and more conducive to thoughtful responses, such as right after registration, after checking vital signs, or while participants were waiting for examination results. The research assistants offered a thorough

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explanation of the study and invited participants to pose any questions they might have. The research assistants made it clear that choosing not to participate would not impact their antenatal care, and participation was entirely voluntary. We allowed sufficient time for each participant to consider their participation in the study. We acquired their written informed consent prior to the commencement of data collection. A self-administered structured questionnaire was designed to be completed in approximately 10 to 15 minutes. This research was carried out in accordance with the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guideline to guarantee the quality of the study (Checklist 1).

Measurements

The study used a package of questionnaires that included demographic and obstetric characteristics, such as age, pre-pregnancy weight and height, race, educational level, employment status, method of conception, number of pregnancies, and number of children, along with 3 validated measures. Classification of BMI groups was based on Singaporean adults [20]: underweight (BMI <18.5 kg/m^2), normal (BMI 18.5 - 22.9 kg/m^2), overweight (BMI 23 - 27.4 kg/m^2), and obese (BMI ≥27.5 kg/m^2).

The Rapid Eating and Activity Assessment for Participants Short Version

The diet was assessed using the 16-item Rapid Eating Assessment for Participant-Shortened version (REAP-S) [21]. The REAP-S questionnaire was designed for adequacy and excess intake of fat, cholesterol, fiber, sugar, and selected food groups [21]. The questionnaire contains 16 items featured with a binary scale (ie, yes or no), a 3-point scale (ie, from usually or often to rarely or never), and a 5-point Likert scale (ie, from not at all to very willing). A higher score indicated healthy diet intake. The scale has been validated with the Block 1998 food frequency questionnaire [21]. Good internal consistency (Cronbach α=.72) [22] and good test-retest reliability (r=0.86) were reported [23]. Our study indicated a Cronbach α value of .7.

Internet for Physical Activity and Nutrition Scale

A 7-item Internet for Physical Activity and Nutrition Scale (IPAS) was adopted to investigate associations between healthy lifestyles and internet use from 1 session of a survey instrument [24,25]. The question types included both dichotomous (yes or no) and ordinal 5-point Likert scales. The items included both positives and negatives. We reversed the negative items before conducting the data analysis. A higher score indicated greater levels of physical activity and adherence to a healthy diet obtained from the internet. We found that this scale demonstrated acceptable internal consistency (Cronbach α=.7).

Internet Frequency Usage Scale (IFUS)

We created a 6-item Internet Frequency Usage Scale (IFUS) to evaluate the frequency of internet use, drawing on the concepts of the existing IU scale [26]. We adjusted the items to assess the frequency of internet access across various activities, including social media, gaming, emails, and online messaging applications. The sample item was, “On average, how many hours do you spend on social media (Facebook, Twitter, or others) every day?” The scale was designed to be self-completed by answering to what extent they had accessed the internet every day on a 5-point Likert scale from <1 hour (1) to >4 hours (5). The higher the score, the longer the duration of the IU. Cronbach α was calculated to be .7 in this study, indicating an acceptable level of internal consistency.

Statistical Analysis

R software (version 4.3.2; R Core Team) [27] was used for descriptive and inferential statistical analysis, including Bonferroni-corrected chi-squared tests and 2-sample 2-tailed t tests. SAS (version 9.4; SAS Institute Inc) [28] was used for simultaneously examining the hypothesized associations through a structural equation modeling (SEM) approach [29]. Given that there were dichotomous responses in the IPAS, we applied the Satorra-Bentler corrections to the chi-square statistic and standard errors to address the non-normality of our data, in conjunction with the normal-theory maximum likelihood estimator [30]. We addressed missing data using two methods: listwise deletion and imputation. For the demographic data, we opted for listwise deletion to handle the missing information effectively. For each item in the questionnaire, we used imputation to tackle the missing data. Binary response items were imputed using the discriminant function method [31], while all other response items were imputed through regression [32].

A series of exploratory factor analyses was used to identify the structure of variables, while confirmatory factor analyses (CFA) were adopted to test a prespecified theoretical model [33]. Items with a factor loading <0.30 or a communality <0.10 were excluded due to inadequate explanation of the proposed constructs [34]. Modification indices (MI) were used to improve the fitness of models. Goodness-of-fit criteria for the model fit included a ratio of chi-square to its degree of freedom <5, an incremental fit index >0.90, a Tucker-Lewis index >0.90, a comparative fit index >0.90, and a root mean square error of approximation <0.06 [35,36].

A multigroup SEM was performed to compare our 5 hypotheses across different ages (<30, ≥30 - 34, or >35), ethnicities (Chinese, Malay, Indian, or others), BMIs (underweight, normal, overweight, or obese), and numbers of pregnant (primigravida or multigravida) groups. We quantified these relationships as standardized coefficients (β), estimating them with equal factor loadings across the multigroup by establishing metric equivalence to ensure accurate comparisons through chi-squared tests [37]. A P value of .05 indicates statistically significant differences among the multiple groups.

Ethical Considerations

The National Health Care Group Domain Specific Review Board (NHG DSRB Ref: 2017/00423) conducted a review and granted approval for this study on May 17, 2017. We provided each participant with S $5 (US $3.9) as a token of appreciation for their time. We emphasized the voluntary nature of participants’ involvement and the confidentiality of the information collected. All data were stored in an encrypted file protected by 2-factor authentication. Access to the data was restricted to research

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team members only. All participants provided written informed consent.

Results

We approached 2700 women in total, and 2206 of them agreed to participate in our study (response rate=81.7%). The reasons for nonparticipation included fatigue, busy schedules, and commitments to other business activities. Among these participants, 1905 fully disclosed their demographic information. The process of selection is illustrated in Figure 2. Table 1 summarizes the demographic and obstetrical characteristics of participants. The prevalence of underweight, normal weight, overweight, and obese women was 10.18% (194/1905), 48.56% (925/1905), 28.24% (538/1905), and 13.02% (248/1905), respectively. The mean age was 31.24 (SD 4.05) years. The majority were Chinese (800/1905, 41.99%), followed by Malay (466/1905, 24.46%), Indian (364/1905, 19.11%), and others (275/1905, 14.44%). Main participants obtained bachelor's degrees or above (1319/1905, 69.24%) and were full-time workers (1483/1905, 77.8%). We observed significant differences in BMI comparison in ethnicity, education, and number of pregnancies and children.

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Table . Demographic and obstetric characteristics of participants by comparisons of underweight, normal, overweight, and obese groups (N=1905).

Demographic variables	Entire (N=1905), n (%)	Underweight[a] (n=194), n (%)	Normal[a] (n=925), n (%)	Overweight[a] (n=538), n (%)	Obese[a] (n=248), n (%)	*P* value
Age (years), mean (SD)	31.24 (4.05)	30.62 (3.99)	31.30 (4.01)	31.30 (4.11)	31.37 (4.07)	—
Comparisons						
UW[b] vs NM[c]	—[d]	—	—	—	—	.20[e]
UW vs OW[f]	—	—	—	—	—	.26[e]
UW vs OB[g]	—	—	—	—	—	.03[e,h]
NW[c] vs OW	—	—	—	—	—	≥.99[e]
NW vs OB	—	—	—	—	—	≥.99[e]
OW vs OB	—	—	—	—	—	≥.99[e]
Ethnicity groups						
Chinese	800 (41.99)	125 (64.43)	476 (51.46)	164 (30.48)	35 (14.11)	—
Malay	466 (24.46)	34 (17.52)	177 (19.14)	155 (28.81)	100 (40.32)	—
Indian	364 (19.11)	16 (8.25)	138 (14.92)	134 (24.91)	76 (30.65)	—
Others	275 (14.44)	19 (9.79)	134 (14.49)	85 (15.80)	37 (14.92)	—
Comparison						
UW vs NM	—	—	—	—	—	.03[i,h]
UW vs OW	—	—	—	—	—	<.001[i,j]
UW vs OB	—	—	—	—	—	<.001[i,j]
NW vs OW	—	—	—	—	—	<.001[i,j]
NW vs OB	—	—	—	—	—	<.001[i,j]
OW vs OB	—	—	—	—	—	<.001[i,j]
Education levels						
≥ Bachelor's degree	1319 (69.24)	149 (76.80)	698 (75.46)	348 (64.68)	124 (50.00)	—
< Bachelor's degree	586 (30.76)	45 (23.20)	227 (24.54)	190 (35.32)	124 (50.00)	—
Comparison						
UW vs NM	—	—	—	—	—	≥.99[i]
UW vs OW	—	—	—	—	—	.02[i,h]
UW vs OB	—	—	—	—	—	<.001[i,j]
NW vs OW	—	—	—	—	—	<.001[i,j]
NW vs OB	—	—	—	—	—	<.001[i,j]
OW vs OB	—	—	—	—	—	<.001[i,j]
Employment status						
Full-time	1483 (77.85)	157 (80.93)	716 (77.41)	423 (78.62)	187 (75.40)	—
Others	422 (22.15)	37 (19.07)	209 (22.59)	115 (21.38)	61 (24.60)	—
Comparison						
UW vs NM	—	—	—	—	—	≥.99[i]
UW vs OW	—	—	—	—	—	≥.99[i]

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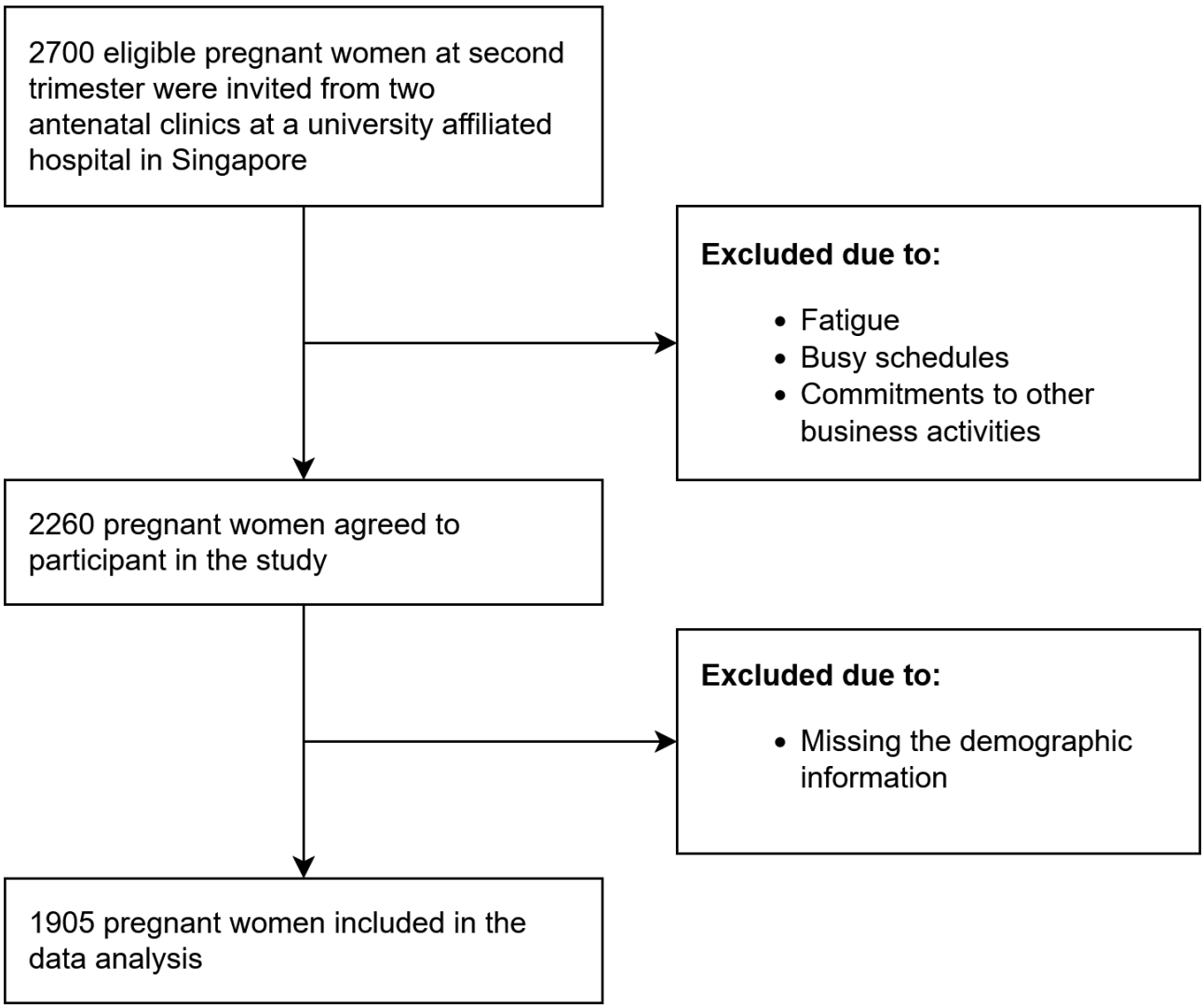
Demographic variables	Entire (N=1905), n (%)	Underweight[a] (n=194), n (%)	Normal[a] (n=925), n (%)	Overweight[a] (n=538), n (%)	Obese[a] (n=248), n (%)	*P* value
UW vs OB	—	—	—	—	—	≥.99[i]
NW vs OW	—	—	—	—	—	≥.99[i]
NW vs OB	—	—	—	—	—	≥.99[i]
OW vs OB	—	—	—	—	—	≥.99[i]
Obstetric variables						
Conceptive method						
Spontaneous	1729 (90.76)	184 (94.85)	832 (89.95)	489 (90.89)	224 (90.32)	—
Ovulation drugs	61 (3.20)	2 (1.03)	26 (2.81)	22 (4.09)	11 (4.44)	—
In vitro fertilization	115 (6.04)	8 (4.12)	67 (7.24)	27 (5.02)	13 (5.24)	—
Comparison						
UW vs NM	—	—	—	—	—	.55[i]
UW vs OW	—	—	—	—	—	.62[i]
UW vs OB	—	—	—	—	—	.54[i]
NW vs OW	—	—	—	—	—	.68[i]
NW vs OB	—	—	—	—	—	≥.99[i]
OW vs OB	—	—	—	—	—	≥.99[i]
Number of pregnancies, mean (SD)	1.73 (0.99)	1.56 (0.86)	1.69 (0.99)	1.76 (0.94)	1.98 (1.12)	—
Comparison						
UW vs NM	—	—	—	—	—	.60[e]
UW vs OW	—	—	—	—	—	.10[e]
UW vs OB	—	—	—	—	—	<.001[e,j]
NW vs OW	—	—	—	—	—	≥.99[e]
NW vs OB	—	—	—	—	—	<.001[e,j]
OW vs OB	—	—	—	—	—	.03[e,h]
Number of children, mean (SD)	0.64 (0.88)	0.53 (0.88)	0.59 (0.83)	0.68 (0.86)	0.85 (1.04)	—
Comparison						
UW vs NM	—	—	—	—	—	≥.99[e]
UW vs OW	—	—	—	—	—	.22[e]
UW vs OB	—	—	—	—	—	.001[e,k]
NW vs OW	—	—	—	—	—	.36[e]
NW vs OB	—	—	—	—	—	<.001[e,j]

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Demographic variables	Entire (N=1905), n (%)	Underweight[a] (n=194), n (%)	Normal[a] (n=925), n (%)	Overweight[a] (n=538), n (%)	Obese[a] (n=248), n (%)	*P* value
OW vs OB	—	—	—	—	—	<.001[e,j]

[a]BMI classification for Singaporean adults.
[b]UW: underweight.
[c]NW: normal weight.
[d]Not available.
[e]Pairwise 2-sample *t* test with Bonferroni correction
[f]OW: overweight.
[g]OB: obese.
[h]*P*<.05.
[i]Pairwise χ^2 test with Bonferroni correction
[j]*P*<.001.
[k]*P*<.01.

Figure 2. Respondents' selection process.



The results of exploratory factor analyses and CFAs identified and confirmed a 1-factor structure of IFUS (IU), a 2-factor structure of IPAS (internet for dietary advice and internet for physical activity advice), and a 2-factor structure of REAP-S (appropriate intake of food group and healthy diet practice) after removing inadequate factor loadings. We found that the initial model did not fit well because of model misspecification. Hence, we performed MI by correlating error terms of interpretable covariances based on the evidence. Table 2 presents the median, range, mean, and SD of the IFUS, IPAS, and REAP-S, along with their factor loadings for each item, as determined through the CFAs. The mean (SD) scores for the IFUS, IPAS, and

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REAP-S were 9.85 (SD 3.62), 11.99 (SD 2.36), and 23.49 (SD 3.17), respectively. The factor loadings for items across 3 scales ranged from 0.327 to 0.942.

Table . Mean (SD) and median (range) of Internet Frequency Usage Scale, Internet for Physical Activity and Nutrition Scale, and the Rapid Eating Assessment for Participant Shortened Version and subscales, and factor loadings of the items of Internet Frequency Usage Scale, Internet for Physical Activity and Nutrition Scale subscales, and Rapid Eating Assessment for Participant Shortened Version subscales in a series of confirmatory factor analyses.

Scales	Mean (SD)	Median (range)	Structure	Subscales	Mean (SD)	Median (range)	Items	Factor loadings
IFUS[a]	9.85 (3.62)	9 (3.18 - 20)	1-factor	IU[b]	9.85 (3.62)	9 (3.18 - 20)	B_1	0.646
							B_2	0.777
							B_4	0.71
							B_5	0.327
IPAS[c]	11.99 (2.36)	12 (7-17)	2-factor	IP[d]	4.14 (1.33)	4 (2-7)	C_3	0.525
							rC_4[e]	0.782
				ID[f]	7.85 (1.74)	8 (5-10)	rC_7_1	0.719
							rC_7_2	0.5
							rC_7_3	0.386
							rC_7_4	0.477
							C_7_5	0.942
REAP-S[g]	23.49 (3.17)	24 (10 - 31.62)	2-factor	AI[h]	8.67 (1.90)	9 (4 - 12.66)	D_3	0.378
							D_4	0.743
							D_5	0.732
							D_6	0.44
				HD[i]	14.83 (2.22)	15 (6 - 20.13)	D_8	0.489
							D_9	0.634
							D_10	0.652
							D_11	0.372
							D_12	0.485
							D_13	0.335

[a]IFUS: Internet Frequency Usage Scale.

[b]IU: internet usage.

[c]IPAS: Internet for Physical Activity and Nutrition Scale.

[d]IP: Internet for physical activity advice.

[e]r: reversed item.

[f]ID: Internet for dietary advice.

[g]REAP-S: Rapid Eating Assessment for Participant Shortened Version.

[h]AI: Appropriate intakes of food groups.

[i]HD: Healthy diet practice.

Afterwards, we examined the relationships among appropriate intake of food groups (AI), healthy diet practice (HD), internet for dietary advice (ID), internet for physical activity advice (IP), and IU using an SEM approach, as shown in Figure 3. We also added employment, education levels, and the number of children in the SEM for adjustment. Table 3 presents the goodness-of-fit criteria before and after MI for 3 measures and an SEM. The SEM model demonstrated satisfactory goodness-of-fit indices [35,36], with the following results: χ^2/df=3.766 (<5), incremental fit index=0.930 (>0.90), Tucker-Lewis index=0.908 (>0.90), comparative fit index=0.930 (>0.90), and root mean square error of approximation=0.038 (<0.06). Figure 3 suggests that AI was positively linked to HD (β=0.262; *P*<.001); HD was positively linked to ID (β=0.168; *P*<.001); ID was positively linked to IP (β=0.185; *P*<.001); IP was positively linked to IU (β=0.190; *P*<.001); and HD was negatively linked to IU (β=−0.208; *P*<.001). We concluded that the results supported hypotheses H_1–H_5.

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Table . Goodness-of-fit indices of three tools and the final structural equation model.

Models	χ^2 (*df*)	χ^2/df	IFI[a]	TLI[b]	CFI[c]	RMSEA[d] (90% CI)
Internet Frequency Usage Scale						
Initial model	473.724 (10)	47.372	0.775	0.782	0.774	0.121 (0.109-0.133)
Modified model	12.864 (2)	6.432	0.992	0.992	0.992	0.054 (0.028-0.083)
Internet for Physical Activity and Nutrition Scale						
Initial model	1109.979 (43)	25.813	0.775	0.753	0.774	0.112 (0.107-0.118)
Modified model	68.483 (9)	7.609	0.987	0.982	0.987	0.057 (0.044-0.070)
The Rapid Eating Assessment for Participant Shortened Version						
Initial model	706.915 (103)	6.863	0.821	0.799	0.82	0.054 (0.050-0.058)
Modified model	169.321 (33)	5.131	0.949	0.939	0.949	0.044 (0.038-0.051)
A structural equation model						
Initial model	836.018 (222)	3.766	0.93	0.908	0.93	0.038 (0.035-0.040)

[a]IFI: incremental fit index.

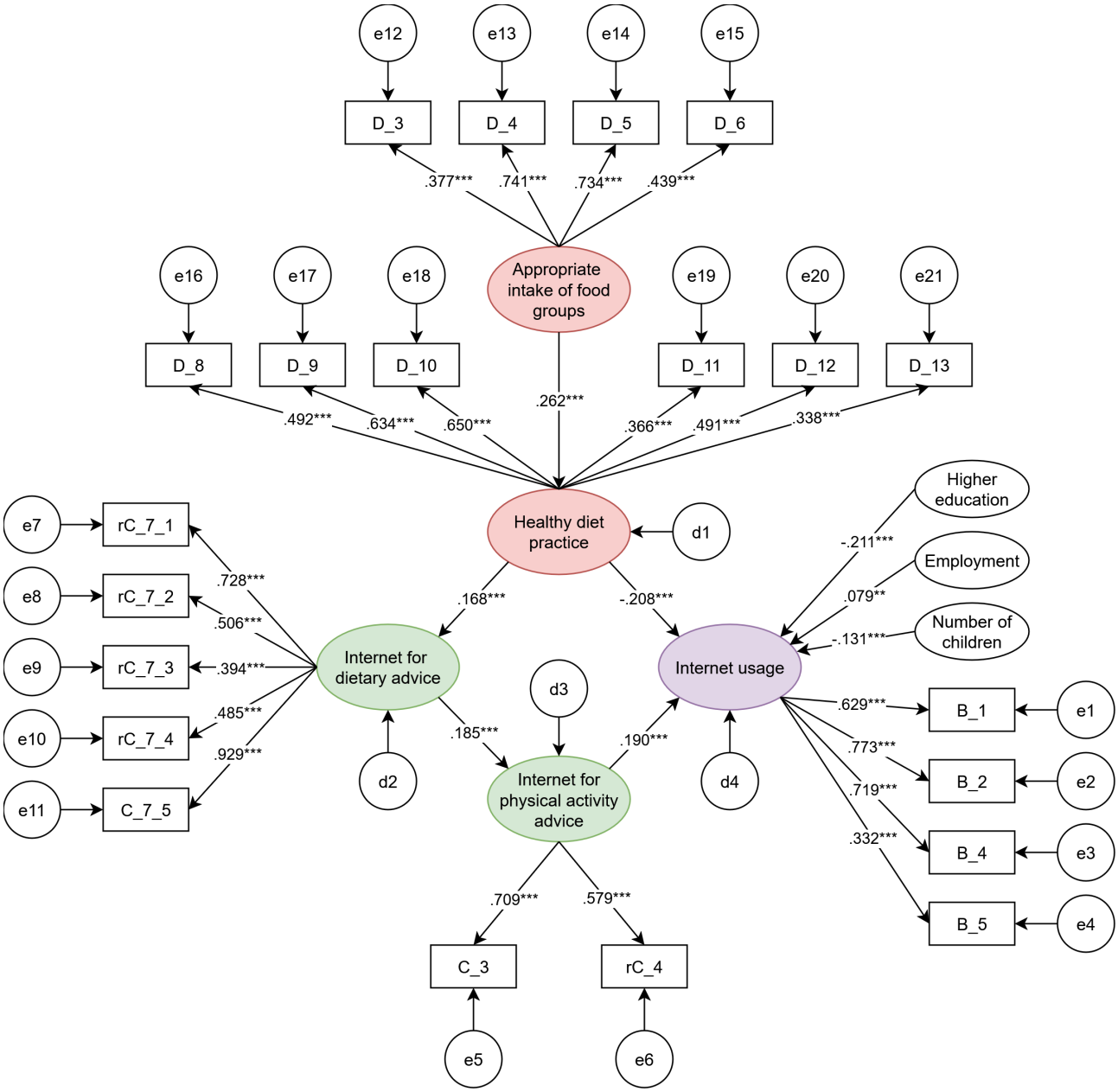
[b]TLI: Tucker-Lewis index.

[c]CFI: comparative fit index.

[d]RMSEA: root mean square error of approximation.

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Figure 3. A structural equation model of the relationships among study variables (appropriate intakes of food groups, healthy diet practice, internet for dietary advice, internet for physical activity advice, and internet usage) in pregnant women after adjustment of education level, employment status, and number of children. Arrow (→): direct impact; B: Items of Internet Frequency Usage Scale; C: Items of Internet for Physical Activity and Nutrition Scale; D: Items of the Rapid Eating and Activity Assessment for Participant Short Version; d: residue term; e: error term; r: reversed item. * $P < .05$; ** $P < .01$; *** $P < .001$.



In Table 4, we performed 4 multigroup SEMs to test these 5 hypotheses by comparing different ages, ethnicities, BMIs, and numbers of pregnant groups. All multigroup SEM analyses yielded significant results concerning the relationship from AI to HD (Hypothesis 1). For the relationship from HD to ID (Hypothesis 2), nonsignificant findings were observed in underweight pregnant women (P=.94) aged 30 to 34 (P=.05) from other ethnic groups (P=.95). There were notable differences between age groups (<30 vs 30–34, P=.009) and BMI groups (underweight vs overweight, P=.03). For the relationship from ID to IP (Hypothesis 3), no significant results were found in underweight women (P=.27) or first-time pregnant women (P=.30) from the Indian ethnic group (P=.11). We found a significant difference (P=.003) between primigravida and multigravida. Although we observed nonsignificant findings in Hypothesis 4 and Hypothesis 5 for specific ethnic and BMI groups, the comparisons between these groups were insignificant.

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Table . Using four multigroup structural equation modeling to compare five hypotheses by age, ethnicity, BMI, and number of pregnancy groups.

Group comparison	H_1:[a] AI[b] →[c] HD[d]		H_2:[e] HD → ID[f]		H_3:[g] ID → IP[h]		H_4:[i] IP → IU[j]		H_5:[k] HD → IU	
	β (95% CI)	*P*[l] value	β (95% CI)	*P*[l] value	β (95% CI)	*P*[l] value	β (95% CI)	*P*[l] value	β (95% CI)	*P*[l] value
All (N=1905)	0.262 (0.201-0.323)	<.001[v]	0.168 (0.110-0.226)	<.001[v]	0.185 (0.127-0.243)	<.001[v]	0.190 (0.124-0.255)	<.001[v]	–0.208 (–0.268 to –0.148)	<.001[v]
Age (years)										
<30 (n=693)	0.235 (0.137-0.334)	<.001[v]	0.282 (0.190-0.374)	<.001[v]	0.135 (0.046-0.225)	.003[u]	0.118 (0.023-0.213)	.02[s]	–0.201 (–0.297 to –0.105)	<.001[v]
30-34 (n=813)	0.251 (0.155-0.347)	<.001[v]	0.087 (0-0.174)	.05	0.178 (0.087-0.269)	<.001[v]	0.257 (0.149-0.364)	<.001[v]	–0.183 (–0.277 to –0.088)	<.001[v]
≥ 35 (n=399)	0.315 (0.179-0.452)	<.001[v]	0.156 (0.021-0.292)	.02[s]	0.262 (0.125-0.400)	<.001[v]	0.192 (0.031-0.352)	.02[s]	–0.201 (–0.342 to –0.060)	.005[u]
Group comparison[m]										
<30 vs 30-34	—[t]	.93	—	.009[u]	—	.75	—	.10	—	.58
30-34 vs ≥ 35	—	.84	—	.28	—	.65	—	.90	—	.54
<30 vs ≥ 35	—	.78	—	.50	—	.47	—	.93	—	.84
Ethnic groups										
Chinese (n=800)	0.277 (0.172-0.383)	<.001[v]	0.178 (0.088-0.268)	<.001[v]	0.137 (0.050-0.224)	.002[u]	0.237 (0.138-0.336)	<.001[v]	–0.207 (–0.307 to –0.107)	<.001[v]
Malay (n=466)	0.224 (0.111-0.336)	<.001[v]	0.225 (0.118-0.333)	<.001[v]	0.245 (0.123-0.366)	<.001[v]	0.068 (–0.059 to 0.195)	.29	–0.055 (–0.170 to 0.059)	.34
Indian (n=346)	0.219 (0.087-0.350)	.001[u]	0.144 (0.003-0.285)	.045[s]	0.110 (–0.026 to 0.246)	0.112	0.118 (–0.035 to 0.271)	.13	–0.248 (–0.398 to –0.099)	.001[v]
Others (n=275)	0.233 (0.058-0.407)	.009[u]	0.006 (–0.166 to 0.179)	.95	0.331 (0.175-0.487)	<.001[v]	0.324 (0.161-0.487)	<.001[v]	–0.216 (–0.374 to –0.057)	.008[u]
Group comparison[m]										
Chinese vs Malay	—	.82	—	.81	—	.21	—	.12	—	.06
Malay vs Indian	—	.45	—	.32	—	.30	—	.72	—	.06
Chinese vs Indian	—	.27	—	.43	—	.91	—	.26	—	.66
Chinese vs Others	—	.46	—	.10	—	.06	—	.21	—	.72
Malay vs Others	—	.63	—	.08	—	.46	—	.03[s]	—	.09
Indian vs Others	—	.86	—	.32	—	.11	—	.06	—	.98
BMI[n]										

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Group comparison	H_1:[a] AI[b] →[c] HD[d]		H_2:[e] HD → ID[f]		H_3:[g] ID → IP[h]		H_4:[i] IP → IU[j]		H_5:[k] HD → IU	
UW[o] (n=194)	0.253 (0.045-0.462)	.02[s]	0.006 (–0.163 to 0.176)	.94	0.106 (–0.083 to 0.295)	.27	0.122 (–0.072 to 0.315)	.22	–0.290 (–0.464 to –0.116)	.001[v]
NW[p] (n=925)	0.254 (0.163-0.344)	<.001[v]	0.161 (0.077-0.246)	<.001[v]	0.167 (0.080-0.253)	<.001[v]	0.247 (0.155-0.340)	<.001[v]	–0.207 (–0.293 to –0.121)	<.001[v]
OW[q] (n=538)	0.243 (0.132-0.354)	<.001[v]	0.239 (0.009-0.319)	<.001[v]	0.255 (0.155-0.356)	<.001[v]	0.106 (–0.025 to 0.237)	.11	–0.148 (–0.268 to –0.029)	.02[s]
OB[r] (n=248)	0.317 (0.159-0.475)	<.001[v]	0.164 (0.130-0.348)	.04[s]	0.217 (0.070-0.365)	.004[u]	0.160 (–0.010 to 0.330)	.06	–0.276 (–0.424 to –0.129)	<.001[v]
Group comparison[m]										
UW vs NW	—	.79	—	.10	—	.63	—	.22	—	.53
NW vs OW	—	.89	—	.41	—	.14	—	.11	—	.42
UW vs OW	—	.86	—	.03	—	.18	—	.96	—	.26
UW vs OB	—	.45	—	.24	—	.34	—	.70	—	.81
NW vs OB	—	.18	—	.64	—	.44	—	.44	—	.65
OW vs OB	—	.23	—	.26	—	.78	—	.62	—	.29
Number of pregnancies										
Primigravida (n=979)	0.273 (0.185-0.360)	<.001[v]	0.200 (0.121-0.279)	<.001[v]	0.043 (–0.038 to 0.123)	.30	0.158 (0.070-0.246)	<.001[v]	–0.204 (–0.287 to –0.122)	<.001[v]
Multigravida (n=926)	0.250 (0.166-0.334)	<.001[v]	0.121 (0.037-0.205)	.005[u]	0.241 (0.162-0.320)	<.001[v]	0.215 (0.121-0.310)	<.001[v]	–0.203 (–0.293 to –0.114)	<.001[v]
Group comparison[m]										

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Group comparison	H_1:[a] AI[b] →[c] HD[d]		H_2:[e] HD → ID[f]		H_3:[g] ID → IP[h]		H_4:[i] IP → IU[j]		H_5:[k] HD → IU	
Primigravida vs Multigravida	—	.70	—	.39	—	.003[u]	—	.45	—	.91

[a]H_1: Hypothesis 1.

[b]AI: appropriate intakes of food groups.

[c]Arrow (→): direct impact.

[d]HD: healthy diet practice.

[e]H_2: Hypothesis 2.

[f]ID: Internet for dietary advice.

[g]H_3: Hypothesis 3.

[h]IP: Internet for physical activity advice.

[i]H_4: Hypothesis 4.

[j]IU: Internet usage.

[k]H_5: Hypothesis 5.

[l]*P* value from *t* test.

[m]*P* value from the χ^2 test.

[n]BMI classification for Singaporean adults.

[o]UW: underweight.

[p]NW: normal weight.

[q]OW: overweight.

[r]OB: obese.

[s]$P<.05$.

[t]Not available.

[u]$P<.01$.

[v]$P<.001$.

Table 5 presents a summary of the outcomes related to 5 hypotheses and 4 comparisons across various age groups, ethnicities, BMIs, and numbers of pregnancies. Based on our study, we supported 5 hypotheses within our hypothetical model that was grounded in the PMT [11] and SCT [12]. To extend our knowledge, we discovered that the hypothetical relationships varied significantly across different age and BMI groups for Hypothesis 2, the number of pregnancies for Hypothesis 3, and ethnic groups for Hypothesis 4.

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Table . Summarizing results of hypotheses.

Hypotheses	Entire group	Age group comparisons	Ethnic group comparisons	BMI group comparisons	Primigravida vs multigravida
H1: Appropriate intake of food groups is linked to healthy diet practice.	√	ns[a]	ns	ns	ns
H2: Healthy diet practice is linked to seeking dietary advice on the internet.	√	<30 > 30-34	ns	OW[b]>UW[c]	ns
H3: The internet's advice on diet is linked to the pursuit of physical activity advice found on the internet.	√	ns	ns	ns	Multigravida > Primigravida
H4: The internet's advice on physical activity is linked to internet usage.	√	ns	Others > Malay	ns	ns
H5: Healthy diet practice is linked to internet usage.	√	ns	ns	ns	ns

[a]ns: not significant.

[b]OW: overweight.

[c]UW: underweight.

Discussion

Principal Findings

This study confirmed the 5 hypotheses among pregnant women. For Hypothesis 1, our findings support the relationship between the intake of food groups and healthy diet practice regardless of different groups of age, ethnicity, BMI, and number of pregnancies. Our results revealed that women who had an appropriate intake of various food groups were more likely to maintain a healthy diet, which aligns with the results of a previous study [6]. The findings aligned with the concepts of the PMT [14], indicating that pregnant women adopted protective behaviors to ensure the safety and development of their unborn babies. The pregnant women perceived poor eating habits as a threat to their pregnancy outcomes and used the internet to assist them in maintaining a healthy diet. They did this by choosing appropriate food groups and engaging in healthy dietary practices [11]. Pregnancy offers a valuable opportunity to embrace health-promoting lifestyle behaviors [38], as this is essential for safeguarding the baby's health.

For Hypothesis 2, we supported that women who follow healthy dietary practices are inclined to seek dietary advice from the internet. This result is consistent with a previous narrative review [7]. The potential explanation may relate to the fact that most pregnant women find the internet to be the most convenient source for accessing nutritional information tailored specifically for pregnancy, enabling them to connect their healthy eating behaviors [39]. This finding supports the concept of SCT [12], suggesting the pregnant women regulate thoughts, feelings, and behaviors to secure future benefits of their pregnancy by optimizing their lifestyle [15]. Consequently, pregnant women actively sought online health-related information to guide their dietary choices as part of a control process aimed at making informed decisions [12].

However, Hypothesis 2 became insignificant in underweight women aged 30 to 34 when compared to overweight women aged less than 30, and our multigroup comparisons were significant. The finding may suggest that these women are more cautious about their screen time [40]. In contrast, the use of the internet was found to have a significant positive correlation with overweight and obesity [8]. Additionally, younger women were increasingly inclined to use the internet [5].

For Hypothesis 3, our results confirmed that pregnant women who sought online diet advice were more likely to seek online physical advice. One possibility for these observations was that pregnant women sought to ensure a healthy pregnancy and to make informed decisions about their health and the well-being of their unborn children [7]. Physical activity and healthy eating could help pregnant women achieve the recommended gestational weight gain while minimizing the risk of pregnancy complications [41]. This pattern was consistent with the PMT's theoretical principles [11]; expectant mothers confronted with the threat of pregnancy sought health-related information to ensure a healthy pregnancy [13]. As a result, pregnant women are driven to protect their unborn children by actively seeking internet information about a good diet and lifestyle [14].

Notably, our multigroup SEM comparison revealed a significant difference between primigravida and multigravida. The finding supports previous results indicating that multigravida experience positive outcomes from pregnancy exercises, including improved sleep, reduced stress, decreased back pain, and shorter labor

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[42]. Another study suggested that primigravida were more likely to be physically inactive than multigravida, as they tended to pay extra caution regarding their pregnancy [43].

For Hypothesis 4, we found that women who received online physical advice were likely to use the internet. The pattern of this result seems to align with findings from a prior study indicating that more than half of pregnant women use the internet to seek information regarding physical activities [10]. Online platforms enable pregnant women to obtain health advice from various sources, prompting them to invest time in seeking reliable information to ensure safe exercise during pregnancy [5], in accordance with the principle of PMT [14].

Although the multigroup comparisons were not significant, we observed that Hypothesis 4 became nonsignificant in both the Indian and Malay groups. Regional variations and cultural differences may account for the observed disparities in physical activity levels during pregnancy, as suggested by a rapid review [44] and 2 studies [45,46]. Malay and Indian Women from the Malay and Indian communities in Singapore each possess distinct sociocultural environments, characterized by significant variations in cultural practices [47]. For both Indian and Malay pregnant women, cultural values place a strong emphasis on rest and modesty during pregnancy, which may restrict physical activities. It was possible that Malay and Indian women might have been dissuaded from participating in antenatal physical activity due to insufficient and contradictory information stemming from cultural beliefs about exercise and physical activity [45,46].

Multigroup comparison also showed that Malay women who sought advice on physical activity from the internet were significantly less likely to be associated with IU compared to women from other ethnic groups. The possibility is associated with socio-economic disadvantages and limited digital literacy [48], particularly affecting certain Malay households in Singapore [47]. In these households, Malay pregnant women faced challenges stemming from restricted digital access. Malay women may exhibit a lack of confidence in interpreting digital information, which aligns with findings observed in Iran [9].

We found that women in the normal-weight group who received online physical advice were significantly more likely to use the internet than those in the underweight, overweight, and obese groups, according to our multigroup analyses. Underweight pregnant women may experience fatigue and decreased motivation for engaging in physical activities [49]. Overweight and obese pregnant women may exhibit lower motivation to participate in online activities, potentially due to feeling overwhelmed by recommendations for lifestyle changes [50].

For Hypothesis 5, our results revealed that participants with healthy diet practice were significantly negatively associated with IU. This may occur because pregnant women who follow a healthy diet are less likely to rely on the internet for dietary information, as they have already established habits and knowledge about nutrition [51]. Additionally, some individuals who maintain a well-balanced diet may prefer to seek guidance from health care professionals, read books, or consult offline resources instead of browsing online [52]. Some pregnant women expressed that the online information available to them failed to instill the confidence required for effectively managing their health [9].

Another potential reason was that they focused on mindful eating and aimed to decrease screen time for the sake of their overall well-being [53]. All usage of the internet is classified as screen time. Screen watching during meals can distract individuals from truly enjoying their food, potentially hindering their ability to recognize satiety signals, which is an essential aspect of intuitive eating [53]. Hence, limiting screens while eating is often associated with mindful and intuitive eating, which can help develop awareness of hunger and satiety signals [54]. Mindful eating may enhance awareness of daily consumption of nutritious and balanced foods, aid in preventing overeating, and promote better digestion [54].

We observed that Hypothesis 5 became nonsignificant in the Malay group. This pattern indicates that cultural factors and personal habits may influence IU [55,56]. A study indicated that individuals in Malaysia express greater concern for their privacy on social networking platforms; consequently, it was probable that they would also have similar privacy concerns when engaging with IU [55]. Personal habits, like limiting screen time or prioritizing offline activities (reading books or participating in outdoor hobbies), could affect IU [56]. Hence, cultural values and personal preferences play a role in influencing IU.

Strengths and Limitations

This study has several notable strengths. To the best of our knowledge, this study is the first to assess the structural relationships between healthy lifestyle practices, online health information-seeking behaviors, and IU among pregnant women. This evaluation is grounded in the theoretical frameworks of the PMT [11] and SCT [12]. We used multigroup SEM to analyze the structural relationships among various groups. We had a sufficiently large sample size to enhance accuracy, increase statistical power, and bolster confidence in the results.

However, we recognized several limitations in this study. First, because the study is cross-sectional, the findings indicate a temporal relationship rather than a cause-and-effect relationship. Second, using a self-administered questionnaire may introduce recall, informational, and social desirability biases. Furthermore, the reliance on self-reported dietary data lacked objective validation, which could address issues such as portion size misestimation and variability in dietary habits from day to day. Third, since this study only included pregnant women who had made 2 antenatal clinic visits at a hospital, it may not be generalizable to the whole population of pregnant women. Fourth, our study used convenience sampling, which may restrict representativeness and introduce selection bias due to the potential for sampling error. Fifth, while we used validated tools for measuring study variables from other countries, it was essential to culturally adapt them for the local population. Finally, the participants were restricted to women who were proficient in English, which may have resulted in the exclusion of non-English-speaking women. This limitation could potentially affect the generalizability of the findings.

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Implications

Our findings have several important implications. A positive relationship exists between healthy lifestyle practices and online health information-seeking behavior, highlighting the specific needs of pregnant women to seek online information that supports their healthy lifestyle choices. Our findings provide important insights into the effectiveness of online interventions designed to promote a healthy lifestyle during pregnancy. A negative relationship exists between healthy dietary practices and IU. This observation highlights the importance of credible online information, as well as cultural values and personal preferences, in shaping how pregnant women use the internet. Monitoring online content by regulatory bodies is important [57]. Health care professionals ought to be equipped to assist pregnant women with retrieving, interpreting, and using online resources [9]. Various age groups, BMI categories, ethnicities, and numbers of pregnancies exhibited alterations in these relationships. These findings assist in designing targeted interventions tailored to specific groups.

Future Research

Future research should adopt a longitudinal multisector design to examine the causal relationships between study variables and enhance the generalizability of the findings. Future research could explore the use of objective measurement tools and probabilistic sampling techniques to reduce biases and errors. To gain a comprehensive understanding of healthy lifestyle practices, online health information-seeking behavior, and IU among pregnant women, there is a need for additional qualitative studies. Future research should explore healthy eating and IU among pregnant women during the first and third trimesters, thereby broadening the understanding beyond the second trimester.

Conclusions

Our study confirms 5 hypotheses and reveals that there are significant structural relationships between healthy lifestyle practices, online health information-seeking behaviors, and IU among pregnant women. The multigroup SEM indicated that age, BMI, ethnicity, and number of pregnancies play a role in affecting these hypotheses. Future research should explore the potential for a longitudinal study to examine causal relationships between the appropriate intake of food groups, adherence to healthy dietary practices, online dietary advice, online physical activity, and IU.

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Data Availability

The datasets analyzed in the study are available from the corresponding author upon request.

Authors' Contributions

YL, YTTL, and SHW conceptualized the study. YL and SHW designed the methodology. YY and ZT designed the software. YL, YY, and ZT validated the study. YL, YY, and ZT performed the formal analysis. YL and SHW performed the investigation. YL managed the resources. YL and SHW performed the data curation. YTTL, YY, and YL wrote the original draft. YL, YY, YTTL, ZT, and SHW wrote reviews and editing. YTTL, YY, and YL performed the visualization. YL supervised the project, undertook the project administration and funding acquisition.

Conflicts of Interest

None declared.

Checklist 1
STROBE checklist.
[PDF File, 134 KB - pediatrics_v9i1e80637_app1.pdf]

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Abbreviations

AI: appropriate intake of food groups
CFA: confirmatory factor analyses
HD: healthy diet practice
ID: internet for dietary advice
IFUS: Internet Frequency Usage Scale
IP: internet for physical activity advice
IPAS: Internet for Physical Activity and Nutrition Scale
IU: internet usage
MI: modification indices
PMT: protection motivation theory
REAP-S: Rapid Eating Assessment for Participant-Shortened version
SCT: self-control theory
SEM: structural equation modeling
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

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Brazilian Immigrant Parents' Perspectives on Oral Health in Early Childhood and Suggested Strategies for Education, Access, and Care: Qualitative Study

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Abstract

Background: Oral health in early childhood is vital for long-term well-being, yet dental caries is highly prevalent among young children in the United States, especially in low-income and immigrant families. Brazilian immigrants, a rapidly growing Latin American population in the United States, face distinct barriers to oral health care, such as language differences, limited access to care, and a lack of culturally tailored resources. Despite this, Brazilian immigrants are understudied in public health research. Understanding Brazilian immigrant parents' perspectives is essential to advancing oral health equity through culturally responsive strategies.

Objective: This study aims to understand (1) parents' views on the best ways to support their children's oral health, (2) perceived barriers to oral health care, and (3) preferred methods and strategies for addressing barriers and receiving oral health education and care.

Methods: This qualitative study usedin-depth, semistructured interviews with Brazilian immigrant parents. Guided by the social ecological model, the data were thematically analyzed to identify multilevel influences on oral health behaviors as well as intervention preferences.

Results: Forty-eight Brazilian immigrant parents (29 mothers and 19 fathers) participated. Most had low acculturation levels and lived in primarily Portuguese-speaking households. Parents stressed the need for early, community-based oral health education in schools and daycares. They preferred visual and digital materials, such as videos, apps, and cartoons in Portuguese to overcome language barriers. Parents spoke of language and cultural challenges, limiting access and reducing confidence in navigating care. Access to affordable dental services was a major concern. Parents supported expanded school-based services and culturally welcoming care. Notably, mothers often focused on home routines and navigating systems, while fathers emphasized community outreach and structural barriers.

Conclusions: Brazilian immigrant parents called for linguistically and culturally tailored oral health programs to be offered in trusted community settings, along with improved dental care access through policy changes and expanded insurance coverage. Multilevel strategies addressing both behavioral and systemic barriers show promise in reducing disparities. Future efforts should prioritize the development and evaluation of scalable, culturally responsive models that meet the needs of Brazilian immigrant families.

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KEYWORDS

oral health disparities; oral health promotion; preschool-aged children; Brazilian immigrant families; qualitative methods; culturally tailored interventions; community-based education; access to dental care

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Introduction

Oral health in early childhood is a critical component of overall child well-being, with lifelong implications for physical, emotional, and social development [1-3]. Despite national efforts to reduce oral health disparities, dental caries is the most common chronic disease among young children in the United States, disproportionately affecting low-income and racial or ethnic minority populations, including immigrant families [4]. According to a recent report by the Centers for Disease Prevention and Control, approximately 11% of children aged 2 to 5 years have one or more primary teeth with untreated decay, and this prevalence is higher among Latino children (eg, Mexican Americans, 18%) [4].

Brazilian immigrants are one of the fastest-growing Latin American populations in the United States yet remain largely understudied in public health research [5]. In recent years, the Brazilian immigrant population in the United States has grown significantly. According to the US Census Bureau, the Brazilian population nationwide has nearly tripled over the past 2 decades, making it one of the fastest-growing immigrant groups [5,6]. Massachusetts is home to approximately 130,323 Brazilian residents—the second-largest Brazilian population in the United States, surpassed only by Florida [5].

Despite this growing presence, Brazilian immigrants often face unique challenges that may not always be addressed in broader Latinx immigrant health research [5,7]. One key distinction is linguistic: Brazilian immigrants primarily speak Portuguese, which sets them apart from other Latin American populations who speak Spanish. This language difference creates specific communication challenges in accessing health care services, including oral health care. It also limits the effectiveness of educational materials and interventions designed for Spanish-speaking populations [5,7].

Much of the existing research on immigrant oral health in the United States focuses on Spanish-speaking communities [8-12], and there remains a limited body of research focused specifically on the oral health of Brazilian immigrant families [6]. Emerging evidence suggests that cultural norms, language barriers, limited access to care, and lack of familiarity with the US health care system can present significant challenges to maintaining oral health among children in Brazilian immigrant households [6].

This research gap presents a significant barrier to developing effective, culturally tailored interventions. Given that cultural and linguistic factors play a critical role in shaping health behaviors and outcomes, especially in oral health, addressing this gap is essential for improving health equity among Brazilian immigrants [6,13,14].

Parents play a central role in shaping their children's oral hygiene behaviors and use of dental services [15-18]. Immigrant parents often face unique systemic and structural barriers that may undermine even strong intentions to support their children's oral health [19-22]. Moreover, public health messaging and health care delivery systems often fail to accommodate the linguistic and cultural needs of Portuguese-speaking immigrant communities [7]. For Brazilian immigrant families in the United States, the intersection of cultural practices, acculturation stress, language barriers, and service inaccessibility creates distinct oral health challenges that are not addressed by most health education efforts [7,23-25].

Community-based and culturally responsive approaches are essential to advancing oral health equity for immigrant populations [19-22]. Frameworks, such as the social ecological model (SEM), provide a valuable lens for understanding how individual, interpersonal, organizational, community, and policy factors influence oral health behaviors and access to dental care [26]. While much of the existing literature has focused on knowledge deficits or service utilization patterns, fewer studies have explored immigrant parents' ideas and recommendations for improving oral health, especially through multilevel intervention strategies addressing education, access, and culturally appropriate care [27-30].

To address noted gaps, this study explored the perspectives of Brazilian immigrant parents living in Massachusetts regarding the challenges and opportunities for promoting early childhood oral health. Specifically, we aimed to understand: (1) parents' views on the best ways to support their children's oral health, (2) perceived barriers to oral health care, and (3) preferred methods and strategies for addressing barriers and receiving oral health education and care. Grounded in the SEM, this qualitative study provides insights that can inform the design of effective, community-based interventions to promote oral health and health equity among Brazilian immigrant populations.

Methods

Study Design

This qualitative study used in-depth, semistructured interviews. In line with qualitative research traditions, this approach enabled the collection of rich, contextualized narratives illuminating how cultural values, parenting practices, and systemic barriers shape health-related behaviors and decision-making in immigrant communities [31,32].

Participant Eligibility and Recruitment

ligibility criteria included (1) self-identifying as a Brazilian immigrant parent, (2) being at least 21 years old, (3) having at least 1 child aged 2 to 5 years, (4) residing in Massachusetts, and (5) having lived in the United States for at least 6 months to ensure sufficient exposure to local health care and cultural systems. This 6-month minimum was required to help ensure participants had adequate time to engage with the US health care system and broader social environment. We aimed to capture insights from parents who had begun navigating pediatric and dental care, encountered potential access barriers, and could reflect on how US-based experiences compared with those in Brazil. Additionally, only 1 parent per household was eligible to participate, ensuring that each interview represented a distinct family unit.

Participants were recruited using purposive sampling, in partnership with local organizations that conducted community-based outreach by distributing study flyers in Portuguese and posting in Brazilian-focused Facebook and WhatsApp groups [33]. Additionally, participants were recruited

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using snowball sampling [33]. Interested individuals contacted the research team by text message to confirm eligibility and schedule an interview [33].

Data Collection

Two native speakers with postgraduate training in public health and maternal and child health and extensive experience in qualitative research and engaging with immigrant communities conducted all interviews in Portuguese. One interviewer is a Brazilian immigrant to the United States and a nonpracticing dentist, while the other is a nurse with strong professional ties to the Brazilian community in Massachusetts. Their cultural fluency and professional backgrounds supported a respectful, informed, and empathetic approach to interviewing, contributing to the credibility and depth of the data collected [34].

Interviews were conducted between December 29, 2023, and March 31, 2024. All interviews were conducted via Zoom, a secure video conferencing platform, to ensure participant flexibility and minimize common logistical barriers, such as transportation and childcare. This approach enabled participants to join from a location of their choice, fostering comfort and convenience while maintaining face-to-face interaction, which can increase rapport-building in qualitative research. Before the start of each interview, the interviewer informed participants in Portuguese of the study's purpose, procedures, and their rights, including the voluntary nature of participation and their ability to withdraw at any time without penalty. Verbal informed consent was obtained in Portuguese before proceeding with data collection.

Interviews were conducted using a guide developed based on the SEM and previous research on immigrant health [26,35]. The guide was pilot tested for cultural relevance and clarity. The interview guide was designed to explore three domains: (1) parents' views on the best ways to support their children's oral health, (2) perceived barriers to oral health care, and (3) preferred methods and strategies for addressing barriers and receiving oral health education and care [36-41].

Before each interview, and after obtaining informed consent, participants completed an interviewer-administered sociodemographic questionnaire. The questionnaire, previously validated and used in studies with Brazilian immigrants in the United States, captured key information including age, marital status, educational attainment, annual household income, number of children aged 2 to 5 years, primary language spoken at home, and length of US residency [7]. The interviewer used Qualtrics to access the survey and enter the data.

To assess acculturation, the survey also included the 12-item Short Acculturation Scale for Hispanics (SASH), adapted for Portuguese-speaking populations [42]. The SASH is a validated tool that measures acculturation through 3 subscales: language use, media preferences, and ethnic social relations [42]. Responses are scored on a 5-point Likert scale, with average scores of 2.99 or higher indicating higher levels of acculturation [42,43]. This scale has demonstrated strong reliability across domains (eg, α=.92 overall, .89 for language use, .88 for media preference, and .72 for social relationships) [42,43].

Each interview lasted approximately 40 to 60 minutes and was audio-recorded with the participants' consent. Field notes were also taken to document nonverbal cues, contextual observations, and interviewer reflections [32]. This supplemental information enriched the analytic process and contributed to the rigor of the qualitative approach. Data collection continued until thematic saturation was reached, when no new insights or themes emerged from subsequent interviews [32].

Data Analysis

Transcripts were deidentified to ensure confidentiality and checked for accuracy against the original audio recordings by a bilingual member of the research team. A thematic analysis approach was used to identify and interpret patterns within the data [44]. This method was selected for its flexibility and ability to capture both manifest (explicit) and latent (underlying) meanings in participants' narratives [44,45].

The analytic process began with repeated readings of the transcripts to allow for immersion in the data and develop a holistic understanding of participants' experiences [32,44,45]. A preliminary codebook was developed using a hybrid approach, which incorporated deductive codes informed by the study's theoretical framework (SEM) alongside inductive codes that emerged directly from participants' responses [26,32,44,45]. This approach allowed the team to remain theoretically grounded and open to new or unexpected insights.

Two bilingual researchers independently coded the transcripts line by line using MAXQDA qualitative analysis software (VERBI Software GmbH), which facilitated the application, retrieval, and organization of codes [46]. Coding was conducted in Portuguese to preserve cultural nuance and linguistic fidelity. Following initial coding, the researchers met regularly to compare coding decisions, discuss discrepancies, and refine the codebook through consensus [32,44,45]. Throughout the analysis, the team used a constant comparison method, revisiting previously coded transcripts in light of emerging data to ensure consistency and depth [44,45]. Codes were grouped into broader categories and synthesized into overarching themes that captured the core elements of participants' perspectives and lived experiences. Analytic memos were written throughout the process to document decision-making, emerging insights, and the evolution of thematic interpretations [44,45]. After identifying the themes, we examined them for differences based on family income, acculturation level (measured by length of stay in the United States), and gender.

To enhance the trustworthiness of the findings, we used several validation strategies [44,45]. These included the use of dual independent coders, regular consensus meetings to resolve discrepancies, and ongoing analytic memo writing to reflect on interpretations and researcher positionality. Although we did not conduct member checking or formal data triangulation, the analysis was further strengthened by the constant comparative approach and by the cultural and linguistic concordance between the researchers and participants, which supported nuanced interpretation and contextual sensitivity.

Selected quotes were translated into English for reporting purposes. To ensure linguistic and cultural accuracy, a

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back-translation process was used: a second independent bilingual researcher translated the English quotes back into Portuguese, and any discrepancies were reviewed and resolved by consensus. This process helped preserve the original meaning and cultural nuances of participants' statements.

Sociodemographic data were summarized using descriptive statistics, including means, standard deviations, frequencies, and percentages. These analyses were conducted using SAS version 9.4 [47].

Ethical Considerations

This study was approved by the University of Massachusetts Boston Institutional Review Board (IRB protocol number 3541, approved June 26, 2023). All participants provided informed verbal consent. The data were stored securely and accessed only by the research team. Participant confidentiality and the right to withdraw without penalty were emphasized throughout the study. Participants received a US $40 gift card in appreciation of their time and contribution to the study.

Results

Sociodemographic Characteristics of the Sample

In total, 48 Brazilian immigrant parents (29 mothers and 19 fathers) participated in the study. As seen in Table 1, the participants' mean age was 36.5 years (SD 6.6 years), with fathers being older on average (39.1, SD 6.8 years) than mothers (33.9, SD 6.5 years). Most (n=28, 58.3%) participants identified as mixed race, followed by White (n=15, 31.3%) and Black (n=5, 10.4%).

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Table . Sample characteristics.

Variables	Total (N=48)	Fathers (n=19)	Mothers (n=29)
Age, mean (SD)	36.5 (6.6)	39.1 (6.8)	33.9 (6.5)
Race, n (%)			
White	15 (31.3)	6 (31.6)	9 (31)
Black	5 (10.4)	1 (5.3)	4 (13.8)
Mixed race (pardo or mestizo)	28 (58.3)	12 (63.1)	16 (55.2)
Marital status, n (%)			
Married or living with partner	41 (85.4)	19 (100)	22 (75.9)
Divorced or separated	3 (6.3)	0 (0)	3 (10.3)
Single	4 (8.3)	0 (0)	4 (13.8)
Educational attainment, n (%)			
Less than high school diploma	10 (20.8)	6 (31.6)	4 (13.8)
High school graduate	23 (47.9)	7 (36.8)	16 (55.2)
More than high school	15 (31.3)	6 (31.6)	9 (31)
Household income per year (US $), n (%)			
<45,000	14 (29.1)	6 (31.6)	8 (27.6)
≥45,000 to <65,000	25 (52.1)	11 (57.9)	14 (48.3)
≥65,000	9 (18.8)	2 (10.5)	7 (24.1)
Number of children between 2 and 5 years old in the household, n (%)			
1	34 (70.8)	9 (47.4)	25 (86.2)
2	14 (29.2)	10 (52.6)	4 (13.8)
Born in Brazil, n (%)			
Yes	48 (100)	19 (100)	29 (100)
States of origin, n (%)			
Minas Gerais	28 (58.2)	8 (42.1)	20 (69)
São Paulo	4 (8.3)	2 (10.5)	2 (6.9)
Espírito Santo	5 (10.5)	2 (10.5)	3 (10.2)
Paraná	2 (4.2)	0 (0)	2 (6.9)
Amazonas	1 (2.1)	0 (0)	1 (3.5)
Rio Grande do Norte	1 (2.1)	0 (0)	1 (3.5)
Bahia	4 (8.3)	4 (21)	0 (0)
Rondônia	1 (2.1)	1 (5.3)	0 (0)
Alagoas	1 (2.1)	1 (5.3)	0 (0)
Rio de Janeiro	1 (2.1)	1 (5.3)	0 (0)
Years of residence in the United States, n (%)			
<5	27 (56.3)	13 (68.5)	14 (48.3)
>5 to <10	16 (33.3)	4 (21)	12 (41.4)
>10	5 (10.4)	2 (10.5)	3 (10.3)
Primary language spoken at home, n (%)			
Portuguese	48 (100)	19 (100)	29 (100)
SASH[a], n (%)			
Low acculturation (<2.99)	47 (97.9)	19 (100)	28 (96.6)
High acculturation (>2.99)	1 (2.1)	0 (0)	1 (3.4)

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Variables	Total (N=48)	Fathers (n=19)	Mothers (n=29)
Health care insurance, n (%)			
Public or government-sponsored	44 (91.7)	17 (89.5)	27 (93.1)
Private	4 (8.3)	2 (10.5)	2 (6.9)
Dental care insurance, n (%)			
Yes (MassHealth)	33 (68.7)	17 (89.5)	16 (55.2)
No	15 (31.3)	2 (10.5)	13 (44.8)

[a]SASH: Short Acculturation Scale for Hispanics.

The majority (n=41, 85.4%) of the participants was married or living with a partner. All participants were born in Brazil, with 58.2% (n=28) originating from the state of Minas Gerais. Over half (n=27, 56.3%) had lived in the United States for less than 5 years. Portuguese was the primary language spoken at home, and 97.9% (n=47) scored below 2.99 on the SASH scale, indicating low acculturation to the United States.

Educational attainment varied among participants, with 79.2% (n=38) having completed high school or more. About half reported an annual household income between US $45,000 and US $65,000 (n=25, 52.1%). Most parents (n=34, 70.8%) had one child aged 2 to 5 years, while 29.2% (n=14) had 2 children in that age range. The majority of participants (n=44, 91.7%) was enrolled in public or government-sponsored health insurance programs, and 68.7% (n=33) reported having dental insurance.

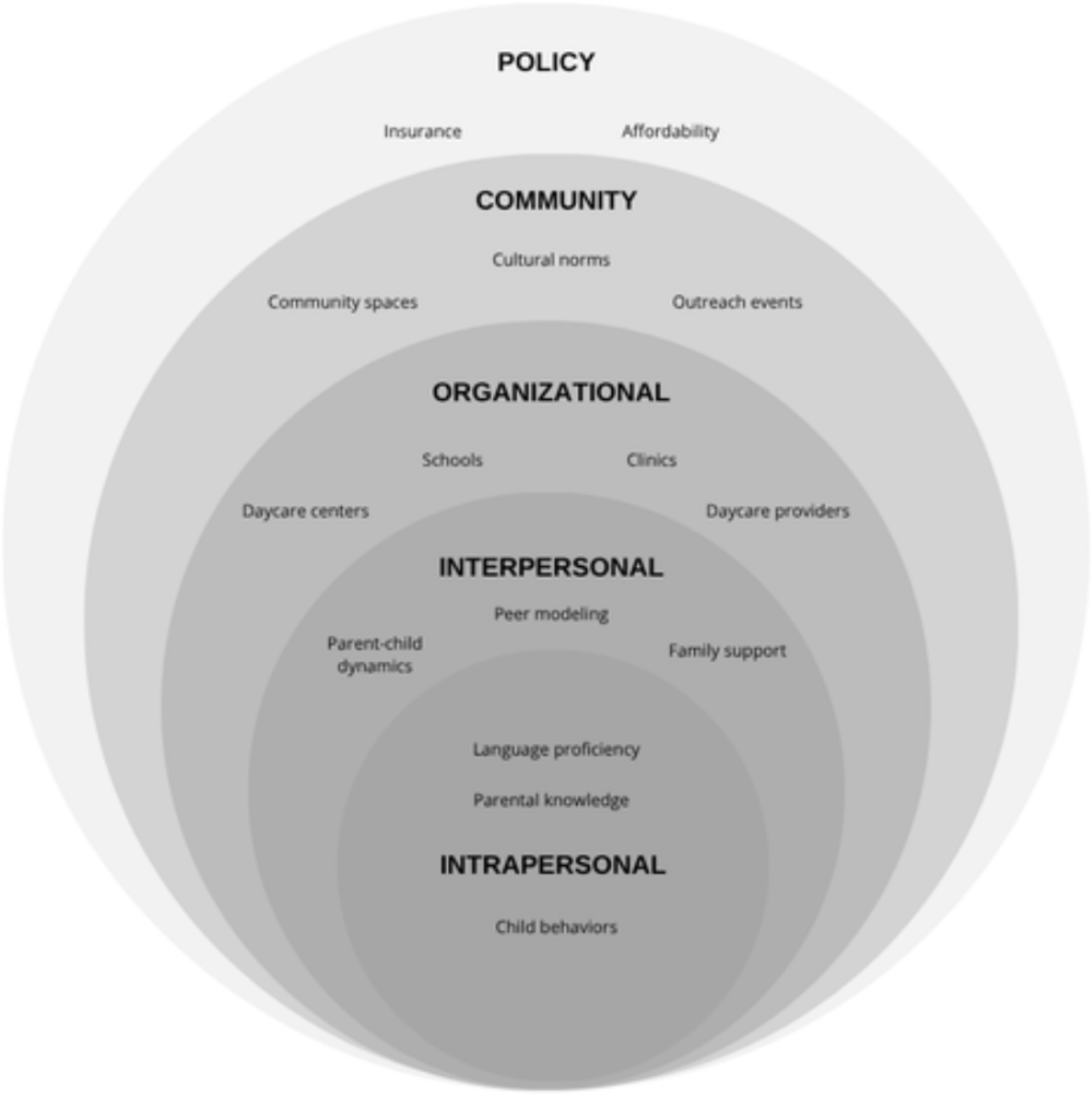
Themes

Overview

The analysis revealed a range of factors influencing Brazilian immigrant parents' perspectives on early childhood oral health. These findings are organized according to the SEM. A conceptual model (Figure 1) visually depicts the SEM levels along with the key themes and subthemes that emerged from the analysis. Representative quotes from parents are integrated throughout the text to illustrate the identified themes and highlight the diversity of perspectives. Notably, gender-based differences were observed in some thematic areas: fathers more frequently emphasized the importance of community outreach and school-based interventions, whereas mothers often focused on home-based education and the challenges associated with navigating health care systems. Differences also emerged by length of time in the United States and income, which further shaped parents' perspectives and experiences.

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Figure 1. Social ecological model of influences on Brazilian immigrant parents' perspectives on oral health in early childhood and suggested strategies for education, access, and care.



Intrapersonal Factors: Knowledge Gaps, Language Barriers, and Suggested Solutions for Oral Health

Barriers and Challenges to Children's Oral Health

Parents identified limited knowledge and language obstacles as barriers that they and other Brazilian immigrant families face in supporting their children's oral health. Several noted that caregivers often lack basic information about pediatric dental care. As one mother explained, "There are many mothers who are not educated on how to take care of their kids' teeth. They don't know what's important" (mother #12).

Language barriers were also widely reported, particularly among those newer to the United States. Participants spoke limited English proficiency made it difficult to understand dental recommendations, navigate insurance, or communicate with providers, undermining parents' confidence and ability to advocate for their children. One mother shared, "I'm not fluent in English. It would help to have information in our language" (mother #7). Another parent stressed the need for organizations that support families struggling with language challenges, "There should be places that help families like ours understand things better, especially when we don't speak the language well" (mother #14).

Parents who had lived in the United States for fewer than 5 years more frequently reported these difficulties. This highlights how language barriers and cultural unfamiliarity compounded challenges in accessing timely and appropriate dental care.

Preferred Strategies to Address Barriers

To address key gaps, parents emphasized the importance of parents and children being provided culturally tailored oral

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health education especially in Portuguese, when their children are very young to build knowledge and support home-based routines, such as brushing, limiting sugary snacks, and modeling good habits. One mother explained, "Children need encouragement, so that in the future they don't end up spending money fixing dental problems—if they take care of their teeth consistently" (mother #11).

Parents felt that community-based programs were the most likely to be effective. Parents called for "more educational programs" (mother #19), and one father described the need for initiatives "showing the importance of oral health for children and families, and the damage of not taking care of your mouth and teeth" (father #10). These programs were viewed as particularly important for families new (<5 years) to the United States.

Digital and visual learning tools were widely recommended to improve accessibility and engagement. Suggestions included "videos" (father #6), "podcasts" (father #8), "mobile brushing games" (father #14), and "cartoons for children" (mother #18). Mothers generally expressed a stronger preference for visual and interactive materials that they could use together with their children, reflecting their more active roles in day-to-day child care. In contrast, fathers preferred digital formats they could access on their own during commutes or work breaks.

Language remained a significant barrier, particularly for newer immigrants. Participants with lower English proficiency and shorter US residence were more likely to report difficulties related to language and cultural challenges when accessing dental services. Many stressed the need for materials and support in Portuguese to boost their confidence and ability to care for their children's oral health. As one father said, "If I had information in Portuguese, I'd feel more confident taking care of my kids' teeth" (father #9), while another noted, "You trust more when someone speaks your language and understands where you come from" (father #5).

Interpersonal Level: Parent-Child and Social Relationships

Barriers and Challenges to Children's Oral Health

At the interpersonal level, parents described how their relationships with their children, peers, and broader social networks influence oral health behaviors. Key themes included the role of peer modeling and school-based learning in shaping children's habits, the challenges parents face in modeling oral health behaviors due to limited knowledge, and the importance of informal social networks, particularly within immigrant communities, for sharing information and accessing support.

Many parents noted that children learn by observing and often mimic what they see at school or from peers. For example, one mother said, "When this is taught at school, kids come home wanting to do it. When it's only from parents, it doesn't always work" (mother #20). Similarly, a father shared, "Children like to imitate" (father #12), highlighting the strong influence of peer behavior on home routines.

While parents tried to serve as educators, several noted that a lack of oral health knowledge among other adults undermined their ability to model good habits. One mother explained, "... Because there are many mothers who are not educated on how to take care of their kids' teeth. They don't know what's important" (mother #12).

Parents often shared oral health experiences and information within informal community groups. One mother emphasized the role of peer support: "I usually hear about new things from other moms—like which toothpaste is best or when to take my child to the dentist. We really learn from each other" (mother #13). Another highlighted the need for greater connection among parents, stating, "… programs that bring parents together and help us support each other with our children's daily oral health care" (mother #6).

Parents who had recently arrived in the United States and those with lower household incomes or without dental insurance more frequently emphasized the need for accessible, no-cost community resources. For these families, support through free cleanings, oral hygiene kits, and multilingual education was seen not just as helpful but essential. These parents also described a greater reliance on informal community networks, such as churches or local nonprofits, to meet health-related needs, further underscoring the importance of community-based resources.

Preferred Strategies to Address Barriers

To overcome these interpersonal challenges, parents suggested strengthening culturally grounded, community-based programs that engage both families and peer groups. These programs could reinforce positive oral health behaviors by providing education and support within trusted social networks. As one mother expressed, "Programs that support us, helping with our children's daily oral health care" (mother #19), underscoring the importance of accessible, community-rooted resources.

Parents felt that offering no-cost or low-cost services, oral hygiene kits, and multilingual educational materials through informal networks, such as churches and community centers, could improve access and engagement, especially for recent immigrants and lower-income families. As a father noted about trusted community venues, "Churches already bring families together. Adding health workshops there would be very effective" (father #9).

Parents also valued school-based initiatives, seeing them as a way to promote healthy behaviors that children could bring home, helping to bridge gaps in parental knowledge and role modeling. As one mother reflected, "At my daughter's daycare, they brush her teeth after lunch. They asked me if I wanted them to do it" (mother #8), highlighting the power of early education settings in shaping habits.

Organizational Level: Institutions and Services

Barriers and Challenges to Children's Oral Health

At the organizational level, parents highlighted the important role of institutions, such as schools, daycare centers, clinics, and pediatric offices, in shaping children's oral health. However, parents also identified challenges and missed opportunities. Many parents noted missed opportunities in health care settings where oral health promotion and education could be better

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integrated. For example, some felt that dental health was overlooked during medical visits. One mother mentioned, "Sometimes when I take my child to the doctor, they only check the general health, and nobody asks about their teeth. It feels like dental health is forgotten" (mother #3). Additionally, unfamiliarity and a lack of culturally welcoming environments made navigating health care systems particularly difficult for immigrant families. One mother expressed, "First is information, for sure, but also being welcomed. That's very important. One of the hardest things when you arrive here is not knowing where to go for help" (mother #10).

Preferred Strategies to Address Barriers

Parents strongly supported embedding oral health promotion within early education settings. They praised daycare programs where children's teeth were brushed after meals, highlighting schools and daycares as critical sites for developing positive habits. For instance, a mother shared, "At my daughter's daycare, they brush her teeth after lunch. They asked me if I wanted them to do it" (mother #8). Others suggested distributing toothbrushes and toothpaste in schools alongside instruction on proper use. One mother stated, "Distribute brushes and toothpaste, and teach children how to use them at school" (mother #5). The influence of peer learning was also emphasized, with 1 parent noting, "When this is taught at school, kids come home wanting to do it" (mother #20).

Despite this enthusiasm, participants noted a lack of oral health programs in local schools. Some reflected on more robust efforts in their home country of Brazil, such as fluoride days and school visits from dentists. As 1 mother recalled, "In Brazil, we had a fluoride day and dentists visiting schools. Here, there's nothing like that" (mother #9). Parents reiterated the value of school-based efforts not only for education but also for motivating children through peer influence.

Regarding health care environments, parents recommended integrating oral health education into routine pediatric visits and offering workshops at clinics. One mother said, "Offer workshops at the same place where children are seen by doctors. Teach mothers how to prevent diseases too" (mother #12). Continuity of care and easier access to multiple clinics were also viewed as important, with parents advocating for follow-ups similar to pediatric care and more options for dental services.

Welcoming environments were especially valued. Parents appreciated when providers gave tangible tools, such as toothbrushes and toothpaste, helping children get excited about brushing. One mother reflected, "First is information, for sure, but also being welcomed. That's very important. One of the hardest things when you arrive here is not knowing where to go for help" (mother #10). Another added, "The dentist gave my son a toothbrush and toothpaste. He came home super excited to brush" (mother 23). Relational and culturally sensitive care settings were seen as essential for building trust and encouraging ongoing engagement.

Community Level: Local Environments and Cultural Context

Barriers and Challenges to Children's Oral Health

At the community level, parents identified environmental, cultural, and informational barriers that limited their ability to support their children's oral health. These included a lack of localized services, culturally appropriate education, and outreach in trusted spaces. Recent immigrants particularly noted difficulties finding oral health resources in their language or in places they frequented. One mother recommended, "A program that goes into the communities, offering free help. Not everyone has health care or dental insurance" (mother #15). Another parent emphasized the need for local programs: "A more accessible program so that children can get cleanings for free. Some kids don't even have MassHealth and can't afford cleanings" (father #7).

Preferred Strategies to Address Barriers

Parents were enthusiastic about community-based outreach efforts that could bring oral health education and services into familiar and trusted environments. Health fairs, free hygiene kits, and toothbrushing demonstrations were widely supported. "Health fairs with free kits and toothbrushing demonstrations would really help" (father #6). "The only thing that could help would be providing us with oral hygiene products" (father #3).

Trusted local institutions, such as churches and community centers, were viewed as effective platforms for education and engagement. A mother explained, "Mothers are usually responsible for health in the family. Community centers could offer this support" (mother #11). A father added, "Churches already bring families together. Adding health workshops there would be very effective" (father #9).

Parents also suggested increasing the visibility of oral health messaging through flyers, posters, and small magazines placed in culturally relevant, high-traffic areas, such as supermarkets and bus stops. "Put up posters in places Brazilians go, like supermarkets or bus stops" (father #5). Another noted, "Distribute flyers, posters, small magazines with information about oral health" (father #4).

Particularly for those newer to the United States, culturally and linguistically appropriate messaging and delivery channels were vital. In contrast, parents with longer US residency often preferred institutional sources, such as schools and clinics, for receiving health information, suggesting a need for varied community engagement strategies.

Policy Level: Structural and Systemic Barriers

Barriers and Challenges to Children's Oral Health

At the policy level, parents highlighted structural barriers, particularly related to insurance coverage, service availability, and systemic navigation challenges. Many families described difficulties using public insurance programs, such as MassHealth, due to bureaucratic complexity and long wait times. One mother expressed, "Sometimes you try to make an appointment, and they say, 'There are no slots. Your insurance isn't active. You have to call MassHealth...'" (mother #9).

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Another stated, "I never managed to book a dentist for my son through MassHealth. I think there's little support for the Brazilian community ..." (mother #12).

These experiences reflect what many parents described as system-level inaccessibility, referring to barriers that stem not from a lack of individual effort or community-based resources but from the way the health care system is designed and operates. These include complex insurance rules, difficulty finding providers who accept public coverage, long appointment waiting times, and limited language support within insurance and health systems. For many families, these challenges made it difficult to navigate oral health care, even the services that were technically available.

Preferred Strategies to Address Barriers

Parents proposed policy-level changes such as expanding public dental coverage, increasing provider availability, and simplifying the process of booking appointments. For example, one mother suggested, "They should provide more assistance to families, maybe even schedule appointments through the schools" (mother #24), showing support for integrated service delivery.

There were also calls for systemic reforms to improve support for immigrant communities, such as enhanced language access and outreach by state programs. Broader investments in affordable dental services, policy incentives for providers to accept public insurance, and improved transparency around insurance benefits were also suggested to reduce disparities and ensure equitable care. One father stated: "It's hard for families like mine to get good dental care. Sometimes we don't undertsand the forms or what the insurance covers. I wish there were programs in our language and more clinics that take public insurance (MassHealth), so everyone could get the care they need" (father #4).

Discussion

Principal Results

This qualitative study examined Brazilian immigrant parents' perspectives on promoting early childhood oral health in the United States, revealing multilevel influences that shape knowledge, skills, attitudes, and behaviors. To our knowledge, based on available literature, this is the first study focusing specifically on this population. Key themes emerged across all 5 levels of the SEM, providing a comprehensive framework to understand how individual behaviors are embedded within broader social and structural contexts. This alignment underscores the need for tailored, multilevel interventions to advance oral health equity among Brazilian immigrant families.

At the intrapersonal level, participants emphasized the critical role of their knowledge and skills in shaping oral health behaviors, highlighting the importance of culturally and linguistically tailored education delivered in Portuguese. Consistent with prior research, parents viewed early education for both children and caregivers as foundational for establishing positive oral hygiene habits [30,48-51]. Digital tools, such as videos, apps, and podcasts, were recommended to complement traditional education and accommodate diverse learning preferences and schedules.

Language proficiency emerged as a key intrapersonal and interpersonal factor influencing parents' confidence and self-efficacy in navigating oral health care. Limited English skills hindered comprehension and agency, especially among newer immigrants and those with low acculturation, as previous research demonstrates, underscoring the need for linguistically accessible materials and communication [8-12,22].

At the interpersonal level, parents reflected on family dynamics and peer influence. They acknowledged their critical role as educators and role models for their children's oral health behaviors but also reported knowledge gaps that could limit their effectiveness. Consistent with prior studies, parents noted that children's peer interactions and school-based learning reinforced positive habits, illustrating how family and social relationships work together to shape behaviors [52-55].

Informal social networks within the Brazilian immigrant community also served as valuable sources of support and information exchange for parents, particularly those recently arrived and with limited access to formal resources. Gendered caregiving roles influenced interpersonal interactions, with mothers often assuming primary responsibility for navigating health care, while fathers focused more on structural access issues. Mothers described needing providers who were patient and approachable due to their caregiving role, highlighting how interpersonal dynamics shape emotional components of provider-patient interactions.

Parents identified schools, daycare centers, clinics, and pediatric offices as key organizational settings for oral health promotion. They advocated integrating oral health education and preventive services into early childhood education environments, emphasizing these institutions' unique potential to consistently reach children and families. These findings are supported by prior research [52,53,56-59]. Clinics and pediatric providers were viewed as being underutilized and where relational, culturally sensitive care and consistent follow-up could enhance engagement and outcomes.

Participants emphasized the importance of culturally concordant care and bilingual staff, a finding that aligns with previous research highlighting how such practices strengthen patient-provider relationships and improve communication in institutional settings [60-66]. Organizational efforts to recruit Portuguese-speaking staff and create welcoming environments were seen as essential for overcoming barriers related to trust.

At the community level, participants identified trusted venues, such as churches, community centers, ethnic markets, and local events, as vital platforms for oral health outreach. Consistent with prior research, these settings leverage social capital and cultural resonance, fostering engagement and trust beyond formal health care systems [56-59,67-71]. Parents emphasized the importance of providing free or low-cost services and hygiene products within these community spaces, particularly for lower-income families and those without insurance. Participants also suggested combining in-person community initiatives with culturally tailored digital outreach embedded in familiar networks (eg, WhatsApp groups, church social media pages), enhancing accessibility and sustaining engagement across multiple community touchpoints.

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At the policy level, systemic challenges, including insurance complexities, cost barriers, and provider shortages, were viewed as major impediments to timely oral health care. Prior research shows that these structural issues disproportionately affect low-income families and recent immigrants, compounding individual and interpersonal challenges [19,21,22]. Parents called for expanded public dental coverage (eg, MassHealth), policy reforms to increase provider availability, and funding for community-based preventive services, such as oral health kits and mobile clinics. The need for bilingual, culturally competent providers and office staff and navigation assistance reflects policy imperatives to address disparities holistically [28,29,36,72].

Implications for Practice and Policy

The findings emphasize the necessity of coordinated multilevel strategies to effectively promote oral health among Brazilian immigrant families. Practical recommendations include the following:

- Intrapersonal: Deliver linguistically accessible, culturally tailored oral health education and digital resources to improve knowledge and self-efficacy, especially among recent immigrants and those with limited English proficiency
- Interpersonal: Support parental modeling and strengthen peer and family networks as channels for health promotion, while considering gendered caregiving roles and the different relational expectations of mothers and fathers
- Organizational: Integrate oral health into schools, daycare, and pediatric care settings, ensuring culturally competent providers and bilingual staff are available to foster trust and continuity of care. Utilize translation technologies where appropriate
- Community: Leverage trusted community spaces and organizations for outreach, offering free or low-cost services and distributing culturally relevant materials with attention to accessibility for low-income and uninsured families
- Policy: Advocate for expanded dental insurance coverage, increased provider availability, funding for culturally tailored preventive programs, and system navigation supports, such as bilingual oral health navigators and onboarding workshops to assist recent immigrant families.

Special attention is warranted for recent immigrants and economically vulnerable families, which face compounded barriers across all SEM levels. Tailored outreach, considering gendered caregiving roles and flexible service delivery options, such as evening or weekend hours and bundled visits, can improve accessibility and engagement.

Building on these findings, future research should prioritize developing, implementing, and evaluating culturally and linguistically tailored oral health interventions specifically designed for Brazilian immigrant families. Studies could use mixed methods approaches to assess intervention efficacy on behavioral and clinical oral health outcomes over time. Additionally, exploring the role of technology-based solutions, such as mobile health apps and tele-dentistry, may offer scalable ways to overcome language and access barriers.

Further research is also needed to examine intragroup differences by factors such as gender, acculturation level, immigration status, and socioeconomic position to better tailor interventions and policies. Longitudinal studies tracking families' oral health trajectories as they acculturate could provide valuable insights into how social determinants evolve and impact health outcomes.

At the policy level, advocacy efforts should focus on systematic evaluations of insurance programs and community dental services to identify gaps and inform equitable resource allocation. Implementation science frameworks could guide the translation of culturally competent practices into routine care within community health centers and pediatric clinics serving diverse immigrant populations.

Limitations

While this study provides rich qualitative insights, several limitations should be acknowledged. The sample consisted of Brazilian parents residing in a specific US state, which may limit generalizability to other geographic areas or immigrant communities [32]. Additionally, the perspectives of those facing the most significant barriers (eg, undocumented parents) may be underrepresented [33,36,72]. Most participants had dental insurance, which might not reflect the experiences of uninsured families. Despite these limitations, this study offers unique and novel insights into the oral health perspectives of Brazilian immigrant parents, a population that has been understudied in this context. Future research could expand to include more diverse immigrant populations and investigate the implementation and effectiveness of the interventions proposed here.

Conclusions

Brazilian immigrant parents in this study expressed a strong need for linguistically and culturally tailored strategies to support early childhood oral health. Interventions that combine education, improved access to care, and delivery through trusted community settings (eg, daycares, preschools, schools, and churches) offer a promising path to reducing disparities. Parents also emphasized the value of digital platforms, including social media, messaging apps, and online content, as accessible tools for reinforcing oral health messages. Integrating these digital approaches with in-person outreach can improve both reach and cultural relevance. Newly arrived families and those with low acculturation may require additional support in navigating the US dental system, underscoring the importance of onboarding programs and culturally concordant patient navigators. Mothers, often the primary caregivers, face unique logistical and emotional challenges that should inform the design of flexible, family-centered interventions. Policy efforts should focus on expanding access to bilingual, culturally competent providers and investing in both digital and community-based infrastructure to eliminate persistent structural barriers.

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Formal analysis: DLN, ACL, SAC
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Investigation: ACL, DLN
Methodology: ACL, MLG, DLN
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Resources: ACL, MLG
Validation: ACL, DLN, MLG
Writing – original draft preparation: ACL, DLN, MLG
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All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

SASH: Short Acculturation Scale for Hispanics
SEM: Social Ecological Model

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Maternal Screen-Related Behaviors, Toddler Screen Use, and Toddler BMI in Mexican American Families: Cross-Sectional Study

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Abstract

Background: Parents, as the most proximal influence on young children, play an important role in shaping toddler behaviors. Yet, evidence on how parents shape toddler screen use is limited. Little is also known about the relationship between toddler screen use and BMI. Given existing disparities in screen use and early childhood obesity, a focus on Mexican American families with toddlers is warranted.

Objective: This study aimed to evaluate the independent contributions of both maternal screen use and screen-related parenting practices with toddler screen use duration, for both TV viewing and mobile device use, and examine the relationship between toddler screen use duration and BMI.

Methods: This cross-sectional study enrolled 384 Mexican American mother-toddler dyads recruited from safety net clinics. Enrolled mothers completed 7-day screen use diaries and surveys on screen-related parenting practices, and toddler anthropometrics were obtained. Negative binomial regression models estimated the relationships between screen-related parenting practices and maternal screen use (predictors) with child duration of daily TV use and mobile device use (outcomes). Spearman correlations were calculated to estimate the relationship between toddler screen use duration and age- and sex-specific BMI *z* scores.

Results: Maternal duration of daily TV and mobile device use were associated with toddler duration of daily TV (adjusted rate ratios [aRRs] 1.27 - 1.28; all *P*<.001) and mobile device use (aRRs 1.17 - 1.18; all *P*<.001), respectively, even after adjusting for maternal screen-related parenting practices. Specific parenting practices, including restriction of TV time (aRR=0.86; *P*=.01), restriction of mobile device time (aRR=0.80; *P*=.02), use of TV (aRR=1.27; *P*=.003) and mobile devices (aRR=1.78; *P*<.001) for child behavior regulation, and coviewing of mobile devices (aRR=1.51; *P*<.001), were associated with toddler duration of daily screen use, adjusted for maternal duration of daily screen use. Neither toddler duration of daily TV viewing nor daily mobile device use was correlated with toddler BMI *z* scores.

Conclusions: Both the duration of maternal screen use and screen-related parenting practices, for both TV and mobile devices, should be considered when promoting healthy screen use in toddlers in Mexican American families. Interventionists should consider the family ecology when designing interventions promoting healthy screen use in early childhood.

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KEYWORDS

restriction; digital media; behavior management; technology; early childhood

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Introduction

While the American Academy of Pediatrics (AAP) and numerous other organizations have clearly outlined recommended parameters for screen use in children aged younger than 3 years [1-3], effective interventions promoting healthy screen use, such as limited duration of use and no use before bedtime, are lacking for this age group [1,4,5]. This is in part due to the limited evidence informing the design of such interventions [1,4,6,7]. Our understanding of the contributors to screen use in toddlers is lacking, even though screen use often starts in the first year of life, with early screen use behaviors often persisting throughout childhood [8,9]. Given the impact of screen use on the well-being of young children, both positive and negative, there is a need to identify modifiable factors contributing to screen use in the first few years of life [10-12].

Numerous experts have called for a focus on the family ecology around screen media use, particularly in early childhood [10,13-16]. Family systems theory [17], which recognizes the interconnectedness and interdependence of family members and the emergence of behavior patterns within a family system, further suggests the need to evaluate the relationship of screen-related parental behaviors with child screen use. Parents, as the most proximal influence on young children, play an important role in shaping their toddlers' screen use [18]. Evidence suggests that certain screen-related parenting practices (eg, restriction of use or coviewing) are associated with child screen use duration [16,19-22]. In our own previous work with Mexican American families with preschoolers, maternal restriction of duration of TV viewing was associated with fewer minutes of preschooler daily TV viewing [23]. A small study in Canada of mainly White and middle-class families with 1.5- to 5-year-olds as well as a larger study in Israel of parents of toddlers (aged 1.5 - 3 y) reported that greater maternal use of screens to manage child behaviors was associated with increased screen use duration [21,24]. While screen-related parenting practices are important, parents' own screen use, specifically the duration of their screen use, is also associated with child screen use in children younger than 5 years [25-28]. Given the interconnectedness of members within families, children may learn to use screen devices by observing parental behaviors. Moreover, in households with limited space, children may end up watching TV as a natural result of their parents deciding to watch TV themselves. Altogether, these studies suggest multiple ways in which parents shape child screen use behaviors.

Although the evidence on the influence of parent screen-related behaviors on toddler screen use is growing, important limitations of existing research need to be addressed. To start, most of these studies are limited by imprecise measurement of parent and child screen use, using global parental reports to measure screen use, which are not highly correlated with actual screen use [29-31]. Additionally, most studies use 1- or 2-item measures of screen-related parenting, which tend to have poor reliability, and for which validation studies are lacking [21,24,32]. Moreover, only 1 study, to our knowledge, has evaluated the independent associations of parental screen use and screen-related parenting practices with the duration of toddler screen use, finding that both independently predicted child screen time [33]. Parental restriction of screen time was associated with reduced toddler screen time, and parent screen time was associated with increased toddler screen time [33]. Work is needed to clarify whether interventions promoting healthy screen use in toddlers should focus on parents' own screen use in addition to the typical focus on screen-related parenting practices. Addressing these measurement and design issues is important to ensure that future interventions can be designed to focus on modifying the most important influences on toddler screen use.

An additional limitation of existing research is that most studies elucidating the role of parents in shaping screen use in toddlers measure all types of screen use as a single category, even though toddlers interact with multiple different types of screens, including television, smartphones, and tablets [34]. As a result, investigators have been unable to consider whether relationships between parental screen-related behaviors and child screen use vary by screen device type. In our previous work, we found that parental perceptions of the risks and benefits of screen devices can depend on the type of device, which may impact how they parent regarding that device [35]. For example, some parents reported that they needed to pay closer attention to the content their child views on a mobile device compared to TV, and they more commonly used mobile devices for child behavior management than TV [35]. Moving forward, measurement of screen-related parenting should consider variation in parenting across certain screen types to ensure a more nuanced understanding of parenting.

While evidence is growing regarding the impact of screen use on toddler well-being, to date, little is known about whether toddler screen use is associated with BMI [36]. Possible mechanisms for this relationship include increased sedentary time secondary to limited movement while viewing; altered dietary intake, either because screen use while eating distracts one from recognizing satiety cues or screen content (eg, food and beverage commercials) influences food preferences; and reduced sleep duration, potentially resulting from stimulation caused by screen use before bed [36,37]. In children aged 3 years and older, more screen time is associated with obesity [37]. Yet, for children aged younger than 3 years, only a handful of studies exist. Overall, findings are mixed for the studies evaluating the association of toddler screen use with BMI during the toddler years [38-42]. Longitudinal studies, however, suggest that toddler screen use duration does predict BMI years later [43-46]. Yet, again, most of these studies rely on imprecise measurement of screen use (usually a few survey questions). While obesity is multifactorial in origin, understanding the relationship between toddler screen use and toddler weight is needed to inform interventions aiming to prevent early childhood obesity [47].

Focusing future work on Latino children is important because, as a group, they are disproportionately affected by obesity starting in very early life [48-51]. Evidence suggests that approximately 15% of children younger than 2 years and approximately 16% of Latino children aged 2 to 5 years meet the criteria for obesity [48,52]. Unhealthy screen use (eg, higher duration of use) is also more common in low-income Latino children than higher income and non-Latino White children

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[53,54]. Recognizing the cultural heterogeneity of Latino populations [55,56], our work focuses on the largest subgroup of Latinos, Mexican Americans [48-51,57,58]. Approximately 16% of children in the United States are of Mexican heritage. Results of this work may therefore be generalizable to a large portion of children in the United States [59,60].

In this study, we aimed to advance our understanding of family-level contributors (ie, maternal screen use and screen-related parenting practices) to toddler screen use in Mexican American families by addressing the above-outlined limitations in the existing literature. We addressed limitations in the measurement of screen use in previous studies by using diaries to measure screen use duration. Screen use diaries are known to be highly correlated with actual screen use and allow measurement of screen use across device types [30,61]. We also used multi-item measures of screen-related parenting practices that we developed through a systematic process, applying a mixed methods approach and allowing for measurement of device-specific parenting [62]. We expected that maternal screen use and screen-related parenting practices would be independently associated with toddler screen use duration, for both TV viewing and mobile device use. Additionally, we examined the association between toddler screen use duration and BMI to expand existing evidence on this topic in toddlers. Findings will help to inform the design of interventions promoting healthy screen use in Mexican American families with toddlers.

Methods

Ethical Considerations

This study was part of a larger cross-sectional study aiming to evaluate contributors to and outcomes of early childhood screen use in Mexican American communities. The Colorado Multiple Institutional Review Board approved this study (18‐1662; initial approval 2018). All participants gave informed consent, documented with an electronic or written signature, before enrolling in the study. Data are stored securely to ensure confidentiality. Participants were compensated with gift cards: US $95 (mother) and US $45 (toddler).

Recruitment

A convenience sample of 384 families was recruited from a safety-net health care system in Denver, Colorado (November 2020 to December 2023). Spanish- and English-speaking parents of toddlers identified as Latino or Spanish-speaking in the electronic medical record and living in the greater Denver, Colorado, metropolitan area were sent an introductory letter about the study. Letters were followed by phone calls with the child's mother (inclusive of caregivers in maternal roles) to assess interest and eligibility. Mothers were eligible if they were at least 18 years old, identified as being of Mexican heritage, had screen devices at home, and denied having a condition that limited the way they used screen devices. Additionally, their 15‐ to 26-month-old child had to be ambulatory, live with them most of the time, and not have a health or developmental condition that impacted their child's sleep, physical activity, diet, or growth. Adult participants in this study are labeled "mothers" since 383 (99%) of 384 were the focal child's birth mother. Of the 773 eligible mothers, 384 (49.7%) completed data collection in this study.

Procedures

Informed consent was conducted by phone by trained bilingual and bicultural team members. Consent documents were sent electronically via text or email based on participant preference, with participant signatures being captured electronically, or in some instances, in person. Following informed consent, mothers completed a 1- to 1.5-hour phone interview in which trained bilingual and bicultural study staff administered surveys. In the days following the first survey, staff dropped off and trained mothers on the completion of the 7-day screen use diary and conducted anthropometric measurements on toddlers. Following the pick-up of the diary, staff administered another 1‐ to 1.5-hour phone interview to complete the final survey items. Survey and anthropometric data were collected and managed using REDCap (Research Electronic Data Capture) tools hosted at the University of Colorado [63]. All communication was conducted in the preferred language of the participant.

Survey items were evaluated and adapted as needed to ensure relevance and clarity for the enrolled sample. Survey items were translated by a bilingual/bicultural team member into Spanish or English as needed. We compared the 2 language versions side by side as a group consisting of bilingual investigators and research staff. We evaluated translations for conceptual equivalence and contextual and cultural relevance, applying a decentering process in which alterations were made to either language version to obtain conceptual equivalence [64,65]. We then pretested items using cognitive interviews in both Spanish and English to ensure easy comprehension as well as shared conceptual meaning across participants and the investigative team [66]. Details of this process are described elsewhere [62,67]. Finally, following in-depth training of the research team, we piloted study procedures with 7 mother-toddler dyads, prior to starting data collection.

Measures

Outcomes

Toddler Duration of Daily TV and Mobile Device Use

Mothers completed a written 7-day daily screen use diary tracking their toddler's TV and mobile device use (smartphones and tablets) in 15-minute increments from 5 AM to midnight, similar to other studies [61,68]. Daily TV and mobile device use amounts in minutes were calculated and then averaged over the number of diary days for those submitting at least 5 days of diary data. Screen use diaries are highly correlated (r=0.84) with the actual amount viewed [30,61], overcoming the limitations of most screen use research that was based on parent global estimates of screen use. Because screen use can change day to day, mothers were asked to complete a full 7-day diary.

Toddler Age- and Sex-Specific BMI *Z* Score

Trained staff measured length in children younger than 24 months or height for those 24 months or older to the nearest 0.1 cm and weight (light clothing and no shoes) to the nearest 0.01 kg, according to recommendations, using portable digital scales (Seca 354) and measuring boards (Seca 417) or stadiometers

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(Seca 217) [69]. When it was not feasible to obtain a length in those younger than 24 months or a height in those 24 months or older, we obtained the other measurement, that is, a height or length, respectively, and added or subtracted the standard 0.7 cm [69]. Age- and sex-specific BMI *z* scores were calculated based on the World Health Organization growth charts [70]. BMI is a typical measure of weight status in research studies on this age group [71-75]. Toddler BMI is associated with both adiposity and risk of future obesity [71-75]. Due to COVID-19 pandemic–related restrictions, some toddlers' anthropometrics were not collected or were collected more than 30 days following completion of the surveys and diaries. For this study, toddlers whose anthropometric data were collected more than 30 days from the date of the first survey were excluded from analyses.

Predictors: Maternal Screen-Related Behaviors

Maternal Duration of Daily TV and Mobile Device Use

Mothers completed a written 7-day daily screen use diary tracking their own TV and mobile device use (smartphones and tablets) in 15-minute increments from 5 AM to midnight. Daily TV and mobile device use amounts were calculated and then averaged over the number of diary days for those submitting at least 5 days of diary data. Mothers completed their own screen use diary the same week they completed their child's diary to capture contemporaneous patterns of mother and child screen use. To minimize the possibility of inflated associations, the diaries were designed with separate pages for mother and child and physically bound together in a way that prevented easy side-by-side comparison during completion.

Maternal Screen-Related Parenting Practices

Seven domains of screen-related parenting practices were measured; restriction of toddler screen time (TV use: 8 items, α=.82; mobile device use: 8 items, α=.84), use of screens for behavioral regulation (eg, have their child use a screen to calm down or when misbehaving, TV use: 12 items, α=.90; mobile device use: 16 items, α=.91), coviewing screens with the child (TV use: 10 items, α=.86; mobile device use: 10 items, α=.87), and restriction of content viewed on screens, with screens defined as both TV and mobile devices (8 items, α=.83). Device-related parenting behaviors were not administered to participants who said the focal child had never used the device type (TV or mobile devices), because for these children, no device-specific parenting behaviors occurred. Item response options ranged from never (0) to always (4) on a 5-point Likert scale, with higher values indicating greater endorsement of the item (ie, greater content restriction, greater coviewing). Methods for the development of these measures are described in detail elsewhere [62]. Briefly, items were developed from findings from 32 semistructured interviews with Mexican American parents of toddlers aged 15 to 26 months [35,76], followed by exploratory and confirmatory factor analyses using a split sample approach.

Covariates

Mothers reported child age in months, child gender, maternal age, education level, partnership status (ie, married/partnered or not), employment status (yes/no), number of children in the home, and acculturation. Acculturation was measured using the Bidimensional Acculturation Scale for Hispanics: non-Hispanic acculturation scale (12 items; α=.97) [77]. Scores range from 1 to 4, with higher scores reflecting higher levels of acculturation. To capture the possible impact of the COVID-19 pandemic on everyday life throughout the period of data collection, we created a binary variable that reflected whether the Denver County Department of Health had any COVID-19 pandemic–related restrictions in place at the time of data collection, coded as no restrictions in place=1 and any restrictions in place=0.

Analysis

Analyses were completed in SAS Version 9.4 (SAS Institute). From the sample of 384 participants, we removed those mother-child dyads who were missing duration of daily screen use (mothers n=2; child n=8), and those with toddler anthropometrics collected for more than 30 days following survey administration (n=61), resulting in a sample size of 313. In addition, 20% (n=62) of children did not use a mobile device, and thus, parents were not asked the mobile device–specific parenting practices questions. Accordingly, for analyses involving mobile devices, the sample size was 251. Due to the skewness of some variables, Spearman correlations were calculated between covariates, maternal screen-related behaviors, and outcomes to determine bivariate associations among variables. Because the outcome data were counts, negative binomial regression was used to estimate the relationships between maternal screen use and screen-related parenting practices (predictors) with child duration of daily TV use and mobile device use (outcomes). Regression modeling was carried out separately for TV use and mobile screen use. Three different regression models were estimated for each due to the substantial correlations between some parenting practices. All models included maternal screen use duration, with model 1 estimating restriction of time and content, model 2 estimating behavioral regulation, and model 3 estimating coviewing. Maternal restriction of time and content were included in the same model because, although they represent distinct parenting practices, they are complementary strategies widely recommended to promote healthy screen use in young children [1]. Including both practices in the same model enabled us to examine their independent associations with child screen use duration. Covariates associated with either TV or mobile use at $P<.2$ were included in all models. Final results are presented as adjusted rate ratios. Rate ratios greater than 1 indicate increased screen use for every 1 unit increase in the predictor, while rate ratios less than 1 indicate decreased screen use for every 1 unit increase in the predictor. Maternal duration of daily TV and mobile device use were converted to hours for regression modeling to improve the interpretability of the rate ratios.

Results

Mothers were on average 31 (SD 6.0) years old, and the majority were partnered (264/313, 84.3%; Table 1). Toddlers were on average 21.2 (SD 3.0) months old, and nearly half (153/313, 48.6%) were male participants. The majority of surveys were

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administered in Spanish (241/313, 77.0%). Toddler average daily TV use was 94.3 (IQR 49.3 - 173.6) minutes, and average daily mobile use was 27.9 (IQR 6.4 - 66.4) minutes. There was no significant correlation between average daily TV use and average daily mobile use (ρ=0.09; *P*=.15).

Table . Characteristics of Mexican American mother–toddler dyads recruited from safety-net clinics.

Characteristic	Values
Child characteristics (n=313)	
Age (mo), mean (SD)	21.2 (3.0)
Male sex, n (%)	152 (48.6)
Maternal characteristics (n=313)	
Age (y), mean (SD)	31.3 (6.0)
Education (y), mean (SD)	11.6 (2.5)
Partnered, n (%)	264 (84.3)
Employed, n (%)	130 (41.5)
Acculturation: non-Hispanic, median (IQR)	2.2 (1.7 to 3.2)
Number of children in home, median (IQR)	3.0 (2.0 to 3.0)
No COVID-19–related restrictions in place, n (%)	259 (82.7)
Toddler screen use	
Duration of daily TV (min; n=313), median (IQR)	94.3 (49.3 to 173.6)
Child ever used a mobile device, (n=313), n (%)	251 (80)
Duration of daily mobile device use (min; n=251), median (IQR)	27.9 (6.4 to 66.4)
Screen-related parenting practices	
Television[a] (n=307), median (IQR)	
Restrict time	2.3 (1.6 to 2.9)
Behavior regulation	0.9 (0.6 to 1.3)
Coview	2.0 (1.4 to 2.5)
Mobile device use[b] (min; n=251), median (IQR)	
Restrict time	2.5 (1.8 to 3.1)
Behavior regulation	0.7 (0.4 to 1.0)
Coview	1.2 (0.9 to 1.7)
Screen use (n=312), median (IQR)	
Content restriction	3.6 (3.2 to 4.0)
Maternal screen use (n=313), median (IQR)	
Duration of daily TV (min)	75.0 (32.1 to 145.7)
Duration of daily mobile device use (min)	145.7 (70.7 to 246.4)
Toddler anthropometrics (n=274), median (IQR)	
BMI *z* score[c]	0.7 (–0.1 to 1.5)

[a]Reported only for children who ever viewed television (n=307).

[b]Reported only for children who have ever used a mobile device (n=251).

[c]Not reported in some due to the impact of COVID-19 on ability to collect or timing of collection (>30 d from survey administration).

Spearman correlations between maternal screen-related behaviors (screen use duration and parenting practices), child screen use duration, child BMI *z* scores, and covariates included in the final regression models are presented in Table 2 for TV viewing and Table 3 for mobile device use. Neither toddler duration of daily TV viewing nor daily mobile device use was correlated with toddler BMI *z* scores. Similarly, average total duration of screen use, inclusive of TV and mobile device use, was not correlated with BMI *z* scores (ρ=0.06; *P*=.30).

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Table . Correlation matrix for screen-related parenting practices, maternal TV use, child TV use, and child BMI *z* scores (n=313).

	Screen-related parenting practices				Mother	Child		Covariates		
	Television use			Screens	Duration of daily TV (min)	Duration of daily TV (min)	BMI *z* score	Child age (mo)	Child gender	No COVID-19–related restrictions
	Restrict time	Coview	Behavioral regulation	Restrict content						
Restrict time										
r	1.00									
P value	<.001									
Coview										
r	0.21	1.00								
P value	<.001	<.001								
Behavioral regulation										
r	–0.28	0.26	1.00							
P value	<.001	<.001	<.001							
Restrict content										
r	0.39	0.18	–0.20	1.00						
P value	<.001	.002	<.001	<.001						
Mother duration of daily TV (min)										
r	–0.11	0.18	0.15	0.02	1.00					
P value	.05	.002	.009	.73	<.001					
Child duration of daily TV (min)										
r	–0.17	0.12	0.28	0	0.60	1.00				
P value	.003	.04	<.001	.99	<.001	<.001				
Child BMI *z* score										
r	–0.08	0.02	0.11	–0.07	0	0.04	1.00			
P value	.21	.77	.08	.25	.97	.47	<.001			
Child age (mo)										
r	–0.15	–0.04	0.05	–0.18	–0.01	–0.03	0.03	1.00		
P value	.007	.50	.38	.002	.88	.54	.63	<.001		
Child gender										
r	–0.08	–0.01	0	0.09	0.04	–0.06	0.03	0.07	1.00	
P value	.15	.86	.93	.12	.53	.33	.58	.19	<.001	
No COVID-19–related restrictions										
r	–0.02	0	0.09	–0.7	0.01	0.11	–0.02	0.09	0.05	1.00
P value	.67	>.99	.10	.22	.85	.06	.70	.10	.41	<.001

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Table . Correlation matrix for screen-related parenting practices, maternal mobile device use, child mobile device use, and BMI *z* scores (n=251).

	Screen-related parenting practices				Mother	Child		Covariates		
	Mobile Device Use			Screens	Duration of daily mobile use (min)	Duration of daily mobile use (min)	BMI *z* score	Child age (mo)	Child gender	No COVID-19–related restrictions
	Restrict time	Coview	Behavioral regulation	Restrict Content						
Restrict time										
r	1.00									
P value	<.001									
Coview										
r	–0.01	1.00								
P value	.93	<.001								
Behavioral regulation										
r	–0.40	0.42	1.00							
P value	<.001	<.001	<.001							
Restrict content										
r	0.42	0	–0.26	1.00						
P value	<.001	.97	<.001	<.001						
Mother duration of daily mobile use (min)										
r	–0.14	0.07	0.16	–0.10	1.00					
P value	.02	.26	.01	.12	<.001					
Child duration of daily mobile use (min)										
r	–0.28	0.29	0.38	–0.13	0.31	1.00				
P value	<.001	<.001	<.001	.04	<.001	<.001				
Child BMI *z* score										
r	–0.1	0.05	0.22	–0.06	0.04	0.06	1.00			
P value	.13	.43	.001	.37	.54	.36	<.001			
Child age (mo)										
r	–0.15	0.07	0.22	–0.15	0.01	0.20	–0.02	1.00		
P value	.02	.27	<.001	.02	.90	.001	.75	<.001		
Child gender										
r	–0.03	–0.01	0.06	0.11	0.04	0.08	0.03	0.09	1.00	
P value	.60	.93	.34	.09	.53	.20	.70	.17	<.001	
No COVID-19–related restrictions										
r	–0.02	0.02	0.11	–0.08	0.10	0.09	–0.02	0.11	0.05	1.00
P value	.76	.79	.07	.19	.10	.15	.82	.09	.41	<.001

Results of the negative binomial regression models estimating the relationships between maternal screen-related behaviors with toddler duration of daily TV use and daily mobile device use are presented in Table 4. In the regression analyses specific to television use, all models included maternal duration of daily TV (h). Model 1 included the restriction of toddler duration of TV use (restrict time) and restriction of content viewed (restrict content). Model 2 included the parenting practice of using TV for toddler behavior regulation (behavioral regulation), and model 3 included coviewing of TV (coview). Similar models were used in the analysis focused on mobile device use, with variables specific to mobile device use. Findings were similar across models for TV use and mobile device use.

Across all models shown in Table 4, maternal duration of daily screen use variables (TV and mobile device use) were associated with toddler duration of daily screen use for both TV and mobile device use, respectively, even after adjusting for maternal

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restriction of toddler screen time and restriction of content viewed, use of screen devices for behavioral regulation, and coviewing (Table 4, all *P*<.001).

Parenting practices were also associated with toddler duration of daily screen use, independent of maternal duration of daily screen use. Increased restriction of toddler screen time, for both TV use and mobile device use, was associated with decreased toddler duration of daily screen use (television use—model 1: restrict time *P*=.01 and mobile use—model 1: restrict time *P*=.02 in Table 4), adjusted for both maternal duration of daily screen use and maternal restriction of content viewed on TV or mobile devices. However, restriction of toddler content viewed on TV or mobile devices was not associated with child duration of daily screen use, when adjusted for both maternal duration of daily screen use and maternal restriction of toddler screen time (Table 4; television use—model 1: restrict content *P*=.28 and mobile use—model 1: restrict content *P*=.60). Increased maternal use of screen devices for child behavior regulation was associated with increased toddler duration of daily screen use for both TV use and mobile device use, independent of maternal duration of daily screen use (television use—model 2: behavior regulation *P*<.001 and mobile use—model 2: behavior regulation *P*<.001 in Table 4). Finally, a mother's practice of coviewing TV with their toddler was not associated with toddler duration of daily TV viewing (television use—model 3: coview *P*=.41), whereas mothers' greater coviewing of mobile devices with their toddler was associated with increased toddler duration of daily mobile use (mobile use—model 3: coview *P*<.001). Both models were adjusted for maternal duration of daily screen use.

Table . Negative binomial regression models evaluating relationships between maternal screen-related behaviors and child duration of daily TV use and mobile use (min).

Negative binomial regression models	Adjusted rate ratio (95% CI)	*P* value
Television use		
Model 1		
Maternal duration of daily TV (h)	1.27 (1.21 - 1.33)	<.001
PP[a]: restrict time	0.86 (0.77 - 0.96)	.01
PP: restrict content	1.08 (0.94 - 1.26)	.28
Model 2		
Maternal duration of daily TV (h)	1.27 (1.21 - 1.33)	<.001
PP: behavior regulation	1.27 (1.08 - 1.49)	.003
Model 3		
Maternal duration of daily TV (h)	1.28 (1.22 - 1.35)	<.001
PP: coview	0.95 (0.84 - 1.07)	.41
Mobile use		
Model 1		
Maternal duration of daily mobile device use (h)	1.17 (1.08 - 1.27)	<.001
PP: restrict time	0.80 (0.66 - 0.97)	.02
PP: restrict content	0.93 (0.69 - 1.24)	.60
Model 2		
Maternal duration of daily mobile device use (h)	1.17 (1.08 - 1.27)	<.001
PP: behavior regulation	1.78 (1.27 - 2.49)	<.001
Model 3		
Maternal duration of daily mobile device use (h)	1.18 (1.09 - 1.29)	<.001
PP: coview	1.51 (1.18 - 1.94)	<.001

[a]PP: parenting practice.

Discussion

This cross-sectional study evaluated associations between maternal screen-related behaviors and toddler screen use duration across screen types in Mexican American families recruited from safety-net clinics. Both the duration of maternal screen use and screen-related parenting practices were independently associated with the duration of toddler screen use, suggesting that interventionists should consider both domains of parent behavior when promoting healthy screen use

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in toddlers. Addressing the lack of evidence on the impact of screen use on toddler well-being, we also evaluated the relationship between toddler screen use duration and toddler BMI but found no relationship between toddler duration of TV viewing or mobile use with BMI. The methods of this study addressed many of the limitations of previous studies. Specifically, we used 7-day diaries to measure parent and toddler screen use duration and used multi-item measures of screen-related parenting practices developed through rigorous methods to reliably measure multiple dimensions of screen-related parenting practices. Given that early screen use behaviors often persist throughout childhood [8,9], interventions that support families, including parents and toddlers, in the healthy use of screen devices are needed.

This study's finding that both maternal screen use and screen-related parenting practices are related to toddler screen use duration extends previous evidence on this topic. Only 1 other study evaluated both parental screen use and screen-related parenting practices in the same model, assessing the independent effect of each on toddler screen use duration [33]. That study focused on parental restriction of toddler duration of screen use and parental limits on electronics in the bedroom in a socioeconomically diverse sample of families with 18-month-olds in Canada. They found that increased parental restriction of toddler duration of screen use and lower parental duration of screen use were associated with lower durations of toddler screen use [33]. However, their findings are limited due to the use of global estimates of parent and child screen use, inclusive of TV, computers, and video games [33]. Additionally, they did not examine differences by screen device type [33]. Numerous other studies have evaluated either parental screen use [26,33,78-80] or parenting practices in relation to toddler screen use duration, reporting findings similar to ours [16,19-22]. Our study extends the evidence on this topic by evaluating both parental practices and parental screen use together, using enhanced measures of screen use, and evaluating parenting practices specific to screen device type. Altogether, the findings underscore the need for interventions to consider ways to address both parental screen use and screen-related parenting practices in mothers in order to support healthy toddler screen use.

A strength of this study is the focus on Mexican Americans, a cultural group experiencing disparities in unhealthy screen use [53,54], as well as childhood obesity [48-51]. We used methods in this study to ensure rigorous and culturally- and contextually-relevant measurement supporting the validity of the findings [35,62]. While our results may apply to other cultural groups, the evidence provided here could inform the development of interventions aiming to promote healthy screen use in toddlers in Mexican American communities, especially those that are under-resourced. To further enhance the design of such interventions, additional research evaluating how the broader context within which families live and how the related stressors they experience might impact screen-related parenting.

An additional strength of this study is the separate consideration, in both our measurement of screen use and our analytic approach, of TV viewing and mobile device use, thus providing a nuanced evaluation of the relationships between parental screen-related behaviors and toddler screen use. The results suggest that maternal role modeling of both TV viewing and mobile device use is associated with duration of toddler TV viewing and mobile device use, respectively, independent of a variety of device-specific parenting practices. As for screen-related parenting practices, findings were similar for both TV and mobile devices for both time restriction and behavioral regulation with devices. Interestingly, coviewing of mobile devices was associated with increased mobile device use, whereas coviewing of TV was not associated with toddler duration of TV viewing. Prior qualitative work in this population suggests that this could be due to high levels of parental concern for inappropriate content exposure on mobile devices, possibly leading to more coviewing of mobile devices [35]. Moreover, it is possible that when parents are using mobile devices, their toddlers are with them more often than when watching TV. Future research should continue to consider differences in screen-related parental behaviors by type of screen device in use.

The AAP's recommendations regarding certain parental screen-related behaviors are supported by our findings. The AAP recommends limiting toddlers' duration of use as well as limiting parental use of screens for behavioral regulation, both of which were associated in our study with decreased screen use duration for both TV and mobile devices. The AAP also recommends coviewing content with children. While our findings support a link between coviewing and child duration of use for mobile devices, but not for TV, there are numerous reasons why parents should coview both TV and mobile device content with their child [1]. Coviewing of content helps parents to ensure that their child is exposed to appropriate content in addition to offering the possibility of scaffolding their child's learning [1]. The AAP also recommends the use of a "Family Media Plan," which includes parents setting guidelines for their own use [1]. Our finding that the duration of maternal media use is positively associated with child duration of use supports the need for this plan. That said, counseling parents on their parenting practices across a variety of domains is common in pediatric offices, whereas addressing the entire family's behaviors is more challenging [81]. Moreover, whether families are receptive to such counseling from their child's provider is unknown. Research is needed to understand the best approaches for promoting healthy screen use within families, especially given the instrumental support screen devices offer parents in managing child behavior [82,83]. Parental use of screens for behavioral regulation of their toddler is common, offering what is perceived by many parents as an effective way to get things done while with their child [35]. Clearly, intervention work must consider the context of families with young children, parent and child needs, as well as the timing of such intervention.

Similar to the handful of other studies in this area, we did not find a relationship between toddler duration of screen use and BMI [41,42]. Our focus on a specific population and our use of diaries to measure screen use extend the current literature in this area. Proposed mechanisms of the relationship between screen use and a child's BMI may not be as applicable in the first few years of life. For example, toddlers (1- and 2-year-olds) may not be as sedentary while using screen devices compared

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to older children. Because early screen use is associated with higher BMIs in the preschool years (ages 3 - 5 y) and beyond, intervening on screen use during the first few years of life is still warranted [36].

Limitations of this study warrant mention. To start, this work only focuses on maternal parenting practices despite research highlighting the important role of fathers in managing child screen use [24,35,84]. Second, the cross-sectional design of this study does not provide information on the direction of the relationships we evaluated. Longitudinal data collection would allow for an understanding of the factors contributing to the development of toddler screen use over time. Third, data collection occurred during different phases of COVID-19 restrictions. Other studies captured changes in multiple behaviors, including screen use, during the early stages of the pandemic [85-87]. Accordingly, we adjusted for COVID-19–related restrictions in our models to control for the possibility that COVID-19 affected these relationships. Finally, while the use of diaries for the collection of screen use is an advance over the measures used in current evidence, enhanced measurement is needed. Moreover, while we intentionally asked mothers to complete their own screen use diary during the same week they completed their child's diary to capture the contemporaneous relationship between mother and child screen use, this approach may have inflated the observed associations. As mentioned previously, we designed the diaries in such a way as to minimize this possibility. Of note, other studies using alternative measures of screen use have noted strong correlations between mother and child screen use, suggesting our finding is not solely an artifact of our measurement approach [25-28]. Recognizing the limitations of self-report measures, investigators are working to develop objective measures of screen use that are feasible and acceptable across diverse populations. One such example is the Family Level Assessment of Screen Use in the Home-Television system, which uses face detection and gaze estimation to measure TV viewing in the home [88].

In summary, both the duration of a mother's own screen use and screen-related parenting practices should be considered when promoting healthy screen use in toddlers in Mexican American families. This holds true for both TV viewing and mobile device use. While these findings support the AAP's recommendations for families, additional research is needed to understand the role of fathers and to identify effective ways for providers to support families in following these guidelines. Furthermore, the development of effective evidence-based interventions that are culturally and contextually relevant is needed.

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Conflicts of Interest

None declared.

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Abbreviations

APP: American Academy of Pediatrics
aRR: adjusted rate ratio
REDCap: Research Electronic Data Capture

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Using Wearable Video Cameras to Assess Screen Use Contexts in Preschool-Aged Children: Pilot Observational Study

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Abstract

Background: Wearable video cameras may offer a feasible approach to assess the contexts of screen use (eg, screen content and co-use) among preschool-aged children.

Objective: The objective of this study was to assess the contexts of screen use among preschool-aged children using wearable video cameras.

Methods: Children aged 2 to 5 years from Melbourne, Australia, wore a video camera for 1 day in the home environment during May 2023. One researcher manually coded video footage second by second; 15% was double coded for reliability. Coding included device type, screen activity, screen content classified using Common Sense Media ratings, streaming service, setting, social interaction, screen multitasking, and concurrent behaviors.

Results: A total of 37,944 seconds (10.5 hours) of video camera footage from 8 children were identified and coded as screen use, equating to 21.8% (37,944/174,290) of total camera wear time (range 0.3%-74.0%). Screen use was predominately characterized by program viewing (n=37,461, 98.7% seconds) on televisions (n=34,192, 90.1% seconds) in the lounge room (n=33,710, 88.8% seconds). Programs scored low for educational value (mean 1.7, SD 1.4 of 5 stars), and approximately one-third (3/9, 33.3%) of programs were classified as appropriate for an age older than that of the children in this sample. Screen multitasking was rare (n=46, 0.1% of seconds), and coviewing occurred in approximately one-third of all screen use (n=11,010, 29%).

Conclusions: Contexts considered beneficial for development (eg, educational and age-appropriate content) were infrequently observed. This suggests that interventions to equip parents with practical strategies to identify genuine educational content and recognize and avoid age-inappropriate content are warranted. However, our small sample size limits generalizability.

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KEYWORDS

early childhood; screen time; smartphone; television; tablet

Introduction

Young children are the fastest-growing users of screens [1], with 2025 estimates indicating that, by the age of 6 years, 62% of children own a tablet, and 10% own a smartphone [2]. The widespread availability of screen-based devices has fueled an ever-growing debate regarding their potential impact on preschool-aged children's health and development. As such, guidelines from the World Health Organization and several individual countries focus on setting time limits, recommending that children aged 2 to 5 years have no more than 1 hour of screen time per day [3-5]. There is emerging evidence suggesting that the context in which screen use occurs may alter associations with health and developmental outcomes. For example, an umbrella review of 102 meta-analyses (youth aged 0-18 years) indicated that coviewing (eg, with a parent) and educational screen content were associated with better literacy outcomes [6]. Additionally, results from a meta-analysis of 100 studies (children aged <6 years) indicated that age-inappropriate content was associated with worse psychosocial outcomes, whereas co-use was associated with better cognitive outcomes [7]. As such, in addition to time limits, pediatric societies of the United States, the United Kingdom, and Canada emphasize quality contexts, recommending that parents coview with their children, choose high-quality programming (eg, educational content), and avoid violent content [8-10].

Much of the evidence informing screen guidelines and recommendations is limited by methodological factors [11,12]. Evidence on preschool-aged children's screen use relies largely on parent-reported measures such as questionnaires and time use diaries, which are prone to bias (eg, social desirability and recall bias) [13]. Additionally, these measures typically focus on traditional media (ie, television and computer and video games) while overlooking newer devices (ie, tablets and smartphones) or aggregate total daily screen use [11,12,14]. Such methodology may fail to capture a comprehensive understanding of the nuanced contexts in which preschool-aged

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children engage with screens, such as content consumed, screen activity (eg, program viewing and communication), social interaction (ie, coviewing vs solo viewing), and concurrent behaviors (eg, eating and playing). Thus, measures capable of providing a nuanced understanding of the context of screen use among preschool-aged children are needed to better understand impacts on health and development and better inform guidelines. Wearable video cameras may provide a promising solution as they can continuously capture when, where, and how children interact with screens, providing rich contextual information on screen use.

To our knowledge, only 1 study has used wearable *video* cameras to examine screen use, albeit in an older age group [15]. That study recorded 1081 hours of video footage during the 2 hours before sleep among adolescents (N=83; aged 11-14 years) in New Zealand [15]. Results indicated that most participants used smartphones (n=72 participants; 87%) and televisions (n=70 participants; 84%) during the presleep period, but multiscreen use was also common (n=63 participants; 76%) [15]. The most common screen activities that adolescents engaged in before bed were program viewing (n=76 participants; 92%), browsing (n=68 participants; 82%), communication (n=65 participants; 78%), gaming (n=59 participants; 71%), and social media use (n=51 participants; 62%) [15].

Other studies have used wearable *photo* cameras to examine screen use among adolescents in New Zealand (N=108; aged 11-13 years; n=120,708 images) [16] and Australia (N=10; aged 13-17 years; n=71,396 images) [17]. Results from both studies indicated that television was the most used device (42% of screen time; 36% of images), followed by computers (32% of screen time; 32% of images), mobile devices (13% of screen time; 29% of images), and tablets (13% of screen time; 4% of images) [16,17]. The most common screen activity was program viewing (27% of screen time), followed by games (24% of screen time), social activities (eg, social media and SMS text messaging; 8% of screen time), and using the internet (including online shopping and watching videos on YouTube; 7% of screen time) [16]. Thomas et al [17] reported screen activity separately for each device and further classified screen use in terms of content, setting, social interaction, and concurrent behaviors. Televisions were used primarily for gaming (54% of images), whereas smartphones and tablets were mostly used for program viewing (50%-51% of images). Most screen content was classified as recreational (70% of images), was consumed in the living room (58%) or bedroom (30%), and involved limited co-use with adults (3%) or children (2%), and there were few instances of concurrent behaviors (eg, writing using a pen and paper or having a snack or meal; 13% of images) [17].

While those studies offer initial insights into the potential for wearable cameras to capture screen use contexts, several key evidence gaps remain. First, all prior investigations have focused exclusively on adolescents [15-17], which is unlikely to generalize to preschool-aged children. For example, survey data show that preschool-aged children's daily screen use is typically dominated by television viewing, with little engagement in gaming, social media, or video chatting [2]. In contrast, adolescents' screen use is typically more heavily dominated by social media, gaming, using the internet, and video chatting [18]. Second, most (2 out of 3) prior camera studies have considered a limited set of screen use contexts (ie, device type and screen activity) [15,16]. Other contextual factors such as social interaction and screen content are important to explore due to their potential impact on early childhood development [7]. Finally, with the exception of 1, prior studies have relied on wearable photo cameras rather than video-based devices [16,17]. Photo cameras typically capture images at fixed intervals (eg, every 10 seconds), which may result in missed instances of screen use. In contrast, wearable video cameras provide continuous recording, enabling a more comprehensive understanding of children's screen use contexts.

Extending wearable camera research to early childhood offers an opportunity to capture the nuanced environmental and social contexts of screen use, which are difficult to measure using traditional self-report approaches. To address these limitations, this study aimed to explore a broad range of screen use contexts among preschool-aged children using wearable video cameras. The screen use contexts considered included device type, screen activity, screen content, streaming service, setting, social interaction, coviewing partners, multiscreen activity, and concurrent behaviors.

Methods

Ethical Considerations

Ethics approval was obtained from the Deakin University Human Research Ethics Committee (HEAG-H 04_2023). Written informed parental consent and verbal child assent were obtained before data collection. Household members were asked to provide verbal permission. Data were collected during May 2023 and June 2023 and analyzed between April 2025 and June 2025. Data collected are stored on a restricted shared drive at Deakin University, are presented in aggregate form, and no video footage is published, to protect the identity of participants. Participants received an Aus $10 (US $7.08) supermarket voucher per child participating in the study as a token of appreciation for their time and participation.

Study Design

Data for this pilot observational study were drawn from a larger study that aimed to examine children's physical activity and sedentary behavior in home environments using a combination of wearable devices. Participants wore 3 movement sensors (activPAL [PAL Technologies Ltd], ActiGraph GT3X+, and ActiGraph GT9X Link) and a wearable video camera (Vimel ultrahigh-definition body camera; 1296p; 36 MP) during waking hours. While all devices contributed to the broader assessment of children's movement behaviors, this pilot study focused specifically on the screen use data captured via the wearable video cameras.

Participants and Recruitment

Participants included parents and caregivers (hereafter referred to as "parents") and their children aged 2 to 5 years from Melbourne, Victoria, Australia. To be eligible, parents needed to be able to read English and be aged >18 years. Recruitment took place through convenience and snowball sampling, with participants identified through the research team members' (KD,

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KDH, and SJJMV) known networks; institute-wide emails; and a public post on the institute Facebook page (October 30, 2024), which was also shared with the research team's networks. Potential participants were emailed a link to the online study recruitment page (via Qualtrics [Qualtrics International Inc]), where they could view and download an information sheet, undergo eligibility screening, and provide consent should they agree to take part in the study. During the consent process, parents were asked to report their children's date of birth; sex; and residential address, including postcode. Socioeconomic status was classified using the Australian Bureau of Statistics Index of Relative Socioeconomic Advantage and Disadvantage, which ranks postcodes in Australia according to neighborhood socioeconomic conditions from 1 (most disadvantaged) to 10 (most advantaged) [19].

Measures

Wearable Video Cameras

Parents were asked to attach a wearable video camera (Vimel ultrahigh-definition body camera; 1296p; 36 MP) to the front of their children's clothing using a clip and a quick-release lanyard for additional safety. The camera had a size of 75 × 57 × 30 mm and a battery life of approximately 8.5 hours, captured a 140-degree field of view, and was set up to record video only (no audio) for privacy reasons. The cameras were posted to parents along with detailed instructions on how to wear, charge, and turn off the camera (eg, when going to the bathroom or getting undressed). Children were asked to wear the camera exclusively in the home environment for a total of 8 to 10 hours, which could be spread over multiple days. Parents were given the opportunity to view (and delete if necessary) video footage before it was viewed by the research team. The research team removed any accidentally captured video data that were considered a breach of privacy (eg, diaper changes). Video data were date- and time-stamped and permanently deleted from the cameras following download and storage on a restricted share drive.

Image Coding

Video footage data for each participant were manually coded (second by second) by a research assistant using a 2-stage manual coding process in Microsoft Excel. First, all video data were coded to identify the activity undertaken (eg, screen based, reading, playing, eating, physical activity, and socializing). Second, video data that were initially coded as screen based were further classified using a comprehensive coding protocol adapted from similar studies [16,17] (Multimedia Appendix 1). Video footage data were coded for device type, screen activity, screen content, streaming service, setting, social interaction, coviewing partners, multiscreen activity, and concurrent behaviors. Screen content was classified using Common Sense Media's ratings for quality (ie, positive messaging, positive role models, violence and scariness [reverse scored], and educational value) and age-appropriateness [20]. Consistent with previous studies [21], each quality indicator was rated on a scale from 0 to 5, where 0 was "not present" or "not applicable," 3 indicated a fair amount of that content, and 5 indicated a lot of that content.

Footage that was "blocked" or had an obscured view was considered inconclusive for determining screen use behavior, especially if the camera angle was directed away from the screen or the footage was blackened due to obstruction. Blocked or obscured footage was partially coded. For example, if a device type was known to be in use but other screen information was blocked, the device type, but no other screen use information, was coded. A subset of the identified screen time video footage (15%) was double coded by the first author (AM).

Data Analyses

Analyses were conducted in Stata (version 18.0; StataCorp LLC). Camera wear time was calculated as the total number of minutes during which video footage was recorded. Descriptive statistics (means and proportions) were used to describe the sample and calculate time spent in each screen use context. Independent-sample 2-tailed *t* tests were performed to examine differences between mothers and fathers in terms of coviewing session duration and total coviewing duration. Interrater reliability for the double-coded footage was calculated using the κ statistic and interpreted as follows: κ=0.00 to 0.20 indicated slight agreement, κ=0.21 to 0.40 indicated fair agreement, κ=0.41 to 0.60 indicated moderate agreement, κ=0.61 to 0.80 indicated substantial agreement, and κ=0.81 to 1.00 indicated almost perfect agreement [22].

Results

Interrater Reliability

Coder agreement was high across most screen use contexts. Perfect reliability was achieved for device type, multiscreen activity, and setting (κ=1.00), whereas screen content (κ=0.95), streaming service (κ=0.94), social interaction (κ=0.87), screen activity (κ=0.84), and coviewing partners (κ=0.82) exhibited very strong agreement. In the initial coding round, the concurrent behavior categories of play and fidgeting were differentiated using time-based criteria, whereby shorter durations were coded as "fidgeting" and longer durations were coded as "playing." However, this interpretation was somewhat subjective, and the coding protocol was subsequently revised to distinguish between "object-based" and "non–object-based" play and fidgeting, which achieved substantial agreement (κ=0.64).

Sample Characteristics

A total of 11 parents of preschool-aged children consented to take part in the study; however, 2 (18.2%) of the participants refused to wear the video camera. The final sample comprised 9 children, who recorded a total of 174,290 seconds (48.4 hours) of video camera footage over the observation period. Mean wear time was 5.4 (SD 2.9; range 0.3-10.1) hours. A total of 37,944 seconds (10.5 hours) of video camera footage from 8 children were coded as screen use, equating to 21.8% (37,944/174,290) of total camera wear time (range 0.3%-74.0%). Children were, on average, aged 3.8 (SD 1.1; range 2-5) years, 2 were girls, and 6 were boys. The child who recorded no screen use in their 0.3 hours (n=1245 seconds) of recording was a girl aged 3 years. Children were predominantly from advantaged backgrounds, with most residing in areas classified within Index of Relative

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Socioeconomic Advantage and Disadvantage deciles 8 to 10; 1 child was from an area classified as decile 6.

Device Type, Screen Activity, Setting, and Social Interaction

Table 1 shows the duration of screen use by device type, screen activity, setting, and social interaction. Overall, screen use was quite homogeneous, with program viewing (37,461/37,944, 98.7% of seconds), televisions (34,192/37,944, 90.1% of seconds), and lounge room use (33,710/37,944, 88.8% of seconds) dominating screen activity, device type, and setting, respectively. Program viewing was the sole screen activity when using televisions (34,192/34,192, 100% of seconds) and tablets (2577/2593, 99.4% of seconds). In contrast, screen activity during smartphone use was more heterogeneous, including program viewing (692/1159, 59.7% of seconds), communication (345/1159, 29.8% of seconds), and browsing (122/1159, 10.5% of seconds). However, smartphone use accounted for only 3.1% (1159/37,944) of total screen use. Coviewing occurred in approximately one-third (11,010/37,944, 29% of seconds) of all screen use but differed by device type (television: 8053/34,192, 23.6% of seconds; smartphone: 567/1159, 48.9% of seconds; tablet: 2390/2593, 92.2% of seconds). Concurrent behaviors occurred during 38.6% (14,632/37,944) of screen use time, with eating snacks (5751/37,944, 15.2% of seconds) and non–object-based fidgeting (5847/37,944, 15.4% of seconds) being the most common, and these were relatively consistent across device types.

Table . Duration of screen use by device type, screen activity, setting, and social interaction.

	Smartphone (n=1159 seconds)	Television (n=34,192 seconds)	Tablet (n=2593 seconds)	Total (n=37,944)
Screen activity (seconds), n (%)				
Browsing	122 (10.5)	0 (0.0)	16 (0.6)	138 (0.4)
Communication	345 (29.8)	0 (0.0)	0 (0.0)	345 (0.9)
Program viewing[a]	692 (59.7)	34,192 (100.0)	2577 (99.4)	37,461 (98.7)
Setting (seconds), n (%)				
Child's bedroom	43 (3.7)	0 (0.0)	0 (0.0)	43 (0.1)
Kitchen	853 (73.6)	0 (0.0)	0 (0.0)	853 (2.2)
Lounge room	234 (20.2)	30,883 (90.3)	2593 (100.0)	33,710 (88.8)
Parents' bedroom	21 (1.8)	1125 (3.3)	0 (0.0)	1146 (3.0)
Playroom	8 (0.7)	2184 (6.4)	0 (0.0)	2192 (5.8)
Social interaction (seconds), n (%)				
Inconclusive	0 (0.0)	756 (2.2)	192 (7.4)	948 (2.5)
Coviewing	567 (48.9)	8053 (23.6)	2390 (92.2)	11,010 (29.0)
None	592 (51.1)	25,383 (74.2)	11 (0.4)	25,986 (68.5)
Concurrent behaviors (seconds), n (%)				
Eating meals	0 (0.0)	357 (1.0)	0 (0.0)	357 (0.9)
Eating snacks	293 (25.3)	5317 (15.6)	141 (5.4)	5751 (15.2)
Fidgeting—non–object-based	66 (5.7)	4686 (13.7)	1085 (41.8)	5847 (15.4)
Fidgeting—object-based	30 (2.6)	1627 (4.8)	109 (4.2)	1767 (4.7)
Playing—non–object-based	0 (0.0)	327 (1.0)	0 (0.0)	327 (0.9)
Playing—object-based	0 (0.0)	585 (1.7)	11 (0.4)	596 (1.6)
None	770 (66.4)	21,293 (62.3)	1247 (48.1)	23,312 (61.4)

[a]Program viewing predominately comprised watching programs and/or movies (35,028/37,461, 93.5% of seconds), but content selection (1034/37,461, 2.8% of seconds), waiting for autoplay (247/37,461, 0.7% of seconds), and loading screen content (27/37,461, 0.1% of seconds) were also categorized as program viewing.

Duration of Coviewing Sessions

A total of 44 coviewing sessions were captured. Among these 44 coviewing sessions, after excluding 3 (6.8%) involving both parents (to avoid double counting), 6 (13.6%) involving another child, and 2 (4.5%) where the coviewing partner could not be determined, there were 19 (43.2%) sessions involving fathers (with or without other family members) and 14 (31.8%) involving mothers (with or without other family members). Coviewing sessions involving fathers lasted, on average, 4.9 (SD 9.2; median 0.85, IQR 0.2-5.0; range 0.1-38.6) minutes, whereas sessions involving mothers lasted, on average, 1.1 (SD

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1.2; median 0.75, IQR 0.3-1.5; range 0.2-4.1) minutes; however, this difference was not statistically significant either before (t_{31}=–1.50; P=.14) or after (t_{30}=–1.55; P=.13) removing 1 outlier involving a coviewing session with a father lasting 38.6 minutes.

Coviewing Partners

Approximately one-third (11,010/37,944, 29%) of screen use involved coviewing. Table 2 shows the coviewing partners of preschool-aged children. Approximately two-thirds (7396/11,010, 67.2% of seconds) of coviewing instances involved at least one parent, mostly the father (5558/11,010, 50.5% of seconds) but occasionally both parents (882/11,010, 8% of seconds) or the mother (956/11,010, 8.7% of seconds). Coviewing with an older child was also common (3556/11,010, 32.3% of seconds). After excluding coviewing sessions involving both mothers and fathers to avoid double counting, fathers spent longer coviewing with their children (mean 1111.6, SD 923.07 seconds) compared with mothers (mean 159.33, SD 112.46 seconds), and this difference was statistically significant (t_9=–2.5; P=.03). However, after removing the outlier described above, this difference did not remain significant (coviewing involving fathers: mean 648.4, SD 680.42 seconds; coviewing involving mothers: mean 159.33, SD 112.46 seconds; t_9=–1.75; P=.11).

Table . Coviewing partners (by duration) of preschool-aged children (total duration=11,010 seconds).

Coviewing partner	Duration (seconds), n (%)
Unable to tell	58 (0.5)
Father	4807 (43.7)
Father and mother	882 (8.0)
Father and older child	6 (0.1)
Father and younger child	745 (6.8)
Mother	564 (5.1)
Mother and grandmother	46 (0.4)
Mother and older child	346 (3.4)
Older sibling	3556 (32.3)

Multiscreen Activity

There was very little multiscreen activity (46/37,944, 0.1% of all screen use), with a single recorded instance. This instance occurred for a brief duration (46 seconds) and involved watching sports on television while simultaneously watching a song video on a smartphone.

Streaming Services

Children viewed a range of content across various streaming services, including YouTube Kids (9/20, 45% of programs), Netflix (6/20, 30% of programs), SVT Barn (2/20, 10% of programs), Spotify (1/20, 5% of programs), ABC iview (1/20, 5% of programs), and Foxtel (1/20, 5% of programs). For 8.8% (3345/37,944) of seconds of video footage (6 occurrences involving 3 participants), the streaming service could not be determined due to the screen content being inconclusive.

Content Classifications

Content classifications were available for 45% (9/20) of the programs, representing 61.8% (23,441/37,944) of screen use footage. Programs scored approximately 3.0 out of 5 stars for positive messaging (mean score 3.0, SD 1.00; range 1-4 stars) and positive role models (mean score 3.1, SD 1.17; range 1-5 stars) and approximately 1 star for violence and scariness (mean 1.3, SD 1.22; range 0-3 stars) and educational value (mean 1.7, SD 1.41; range 0-4 stars). Approximately one-third (3/9, 33.3%) of programs were classified as appropriate for an older age than those of the children in this sample (ie, for the ages of ≥6, ≥8, or ≥10 years).

Content Classifications and Social Interaction

Table 3 shows the mean content classification scores for coviewing vs solo viewing. Mean content classification scores differed according to social interaction. Specifically, mean scores were lower for educational value and positive messaging and higher for violence and scariness and positive role models when programs were coviewed than when programs were solo viewed.

Table . Content classification and social interaction of preschool-aged children. Total viewing time was 7171 seconds for coviewing and 15,528 seconds for solo viewing.

Content classification	Coviewing (number of stars), mean (SD)	Solo viewing (number of stars), mean (SD)	*t* test (*df*)	*P* value
Educational value	1.3 (1.2)	2.7 (0.9)	–95.4 (22,697)	<.001
Violence and scariness	2.0 (1.2)	0.9 (0.6)	96.1 (22,697)	<.001
Positive messages	3.2 (0.8)	3.6 (0.5)	–48.6 (22,697)	<.001
Positive role models	3.6 (1.0)	3.22 (0.42)	–37.1 (22,697)	<.001

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Discussion

Principal Findings

This study appears to be the first, worldwide, to objectively assess preschool-aged children's free-living screen use contexts using wearable video cameras. Our analysis yielded 4 main findings. First, screen use contexts among preschool-aged children were relatively homogeneous. Second, screen content was generally classified as low in terms of educational value, and one-third of content (3/9, 33.3% programs) was considered age inappropriate. Third, coviewing occurred in approximately one-third of screen use (11,010/37,944, 29%). Fourth, wearable video cameras provided a feasible approach for assessing preschool-aged children's screen use contexts, albeit with some caveats. While a large amount of screen use data were captured (n=37,944 seconds), our findings should be considered alongside limitations associated with our small convenience sample (N=8).

This study showed that screen use contexts among preschool-aged children were relatively homogeneous. In our sample, almost all screen use involved program viewing of streamed or on-demand content on televisions in the lounge room. There was very little smartphone use or engagement in other screen activities such as communication or browsing. While the lack of variability in screen use may reflect our small, homogeneous sample, all from middle to high socioeconomic backgrounds, our focus on screen use in the home environment may have also influenced the results. Greater engagement with mobile devices and a wider range of screen activities might have been observed had we captured screen use outside of the home environment. For example, during interviews in a previous study, mothers (n=26) of preschool-aged children (aged 2-4 years) from the United Kingdom reported that they often allowed their children to use mobile devices outside of the home for a range of screen activities due to their multifunctionality, including playing games and taking and looking at photos, as well as program viewing [23]. Nonetheless, our finding that the television remains the primary source of screen use (34,192/37,944, 90.1%, of screen use in our sample) for preschool-aged children is consistent with results from previous studies [2,24,25] and suggests that older evidence from before the emergence of mobile devices is likely still relevant for this age group.

We found that the programs that preschool-aged children viewed were generally classified as having little educational content, and one-third of the programs (3/9, 33.3%) were classified as age inappropriate according to Common Sense Media ratings. Similarly, previous studies have shown that most content viewed by preschool-aged children is for entertainment rather than educational purposes [24,25]. It is possible that this finding reflects the nature of children's television programs, with a 2019 examination of 88 popular children's television shows in the United States indicating that, overall, shows aimed at children aged 2 to 5 years contained little educational content, scoring a mean of 2.44 out of 5 stars based on Common Sense Media classifications [21]. This is of concern given that substantial evidence demonstrates that high-quality educational television, such as Sesame Street, may benefit children's cognitive, literacy, and social outcomes [26-29] and age-inappropriate content can negatively impact psychosocial outcomes [7]. An alternative explanation for the low educational value of the screen content observed in this study may be that, although screen guidelines from pediatric societies emphasize high-quality programming [8-10], this messaging may not be reaching parents. Thus, interventions aiming to support healthier screen use behaviors in preschool-aged children might focus on equipping parents with practical strategies to identify genuine educational content and recognize and avoid content that may be age inappropriate. Efforts could also involve engaging with industry to formally and scientifically evaluate content before making educational claims [10].

Coviewing in our sample occurred in approximately one-third of screen use (11,010/37,944, 29%). In contrast, Thomas et al [17] reported that just 16% of screen use involved coviewing among adolescents, with <1% involving interactive coviewing (n=7 images involving a laptop computer). However, the authors did not describe how this was coded from the camera images, making it difficult to ascertain how comparable this finding is to our data. In our study, we could not distinguish between interactive coviewing (eg, where another person asks questions or explains content) and passive coviewing (eg, where another person is present but not interacting with the child). This distinction is important as research suggests that interactive rather than passive coviewing can enhance language and cognitive development (eg, attention and memory) [24,30,31]. While the inclusion of audio data alongside video footage could be used to assess the quality of interactions, this approach may present additional ethical and feasibility challenges given the sensitive nature of recording in home environments. Future work may consider the inclusion of ecological momentary assessment to capture interaction during coviewing.

Wearable *video* cameras offer a promising and feasible approach to assessing preschool-aged children's screen use in real-world contexts. Using these devices, we were able to objectively quantify a range of nuanced contextual information on preschool-aged children's screen use. While wearable cameras reduce recall bias and offer a richer, more detailed account of children's interactions with screens compared with self-report measures, several caveats must be considered. The success of this approach relies heavily on both parent consent and children's willingness to wear the device consistently. A total of 11 parents of preschool-aged children consented to take part in this study, and most children (9/11, 81.8%) were willing to wear the device (mean wear time 5.4 hours), indicating that our protocol was feasible. Additionally, establishing strong interrater reliability is essential to ensure the reliability and replicability of the results. Our coding protocol achieved a high level of interrater reliability, supporting the robustness of our findings. Lastly, the substantial volume of video data generated from wearable video cameras makes coding time and labor intensive, underscoring the need to account for these factors in the study planning phase. As such, while wearable video cameras offer valuable insights into preschool-aged children's screen use, their implementation requires careful ethical, practical, and methodological considerations.

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There are a number of study limitations that should be acknowledged. While a large amount of screen use data were captured (10.5 hours), the small convenience sample and relatively homogeneous demographic characteristics limit generalizability to the wider preschool population. As such, future studies using larger samples are needed to overcome this limitation. Moreover, video footage data captured screen use exclusively in the home environment. As screen use outside the home environment may yield different patterns, future wearable camera studies examining screen use contexts both inside and outside the home environment are warranted. A previous wearable camera study in adolescents recorded camera footage both inside and outside the home environment, including on public transport, public food outlets, and community venues, suggesting that this approach is feasible and acceptable [17].

Conclusions

Among a small sample, we showed that preschool-aged children's screen use is relatively homogeneous, predominately characterized by program viewing of streamed content on televisions in the lounge room. While there was some positive messaging and role models, the content viewed by children was generally considered of little educational value and at times age inappropriate. Coviewing occurred during approximately one-third of screen use and more often with fathers than mothers. We showed that wearable video cameras offer a feasible and acceptable approach to collect more accurate and detailed data on preschool-aged children's screen use contexts compared with traditional self-report measures. This study provides some useful insights for intervention development. However, being the first study of its kind in this population, further research on preschool-aged children's screen use contexts both inside and outside the home using wearable cameras in larger samples is warranted to confirm our findings.

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Data Availability

The datasets generated or analyzed during this study are not publicly available due to privacy reasons as it is not possible to fully deidentify video data due to the nature of the images captured.

Authors' Contributions

Conceptualization: AM, KDH
Formal analysis: AM
Funding acquisition: KDH
Methodology: KD, SJJMV
Project administration: KD, SJJMV
Supervision: KDH
Writing—original draft: AM
Writing—review and editing: KD, SJJMV, KDH

Conflicts of Interest

None declared.

Multimedia Appendix 1
Coding protocol.
[DOCX File, 21 KB - pediatrics_v9i1e85215_app1.docx]

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Responsive Feeding Practices Among Caregivers of Children Aged 6-35 Months in China: Descriptive Study Involving Survey and Video Observation Methods

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Abstract

Background: Responsive feeding is an integral component of nurturing care under the umbrella of early childhood development and has been recommended as an optimal feeding practice globally.

Objective: This study was conducted to explore responsive and nonresponsive feeding practices among caregivers of children aged 6 - 35 months in China. Factors influencing responsive/nonresponsive feeding practices were further explored.

Methods: This study used a combination of survey and video observation approaches and was conducted in Hebei Province from August to October 2020. A cross-sectional survey (n=409) was conducted to measure caregivers' responsive/nonresponsive feeding practices using a prevalidated scale (5-point Likert scale). The overall and individual dimension scores were calculated. Multiple linear regression was performed to explore the demographic factors associated with responsive/nonresponsive feeding practices. Video observation was conducted among 42 caregiver-child pairs to record the dining episodes of main meals for a day at participants' homes. Videos taken were coded, and the feeding practices were extracted. The occurrence of each feeding practice was calculated. The results from the 2 methods were confirmatory and complementary to each other.

Results: Caregivers adopted responsive feeding more frequently than nonresponsive feeding, with a median overall responsive feeding score of 3.52 (IQR 3.36-3.76) in the survey and a higher occurrence in video observation (responsive vs nonresponsive feeding: 75.6% - 97.6% vs 0%-46.3%). No significant differences in feeding practices were found across breakfast, lunch, and dinner (all P>.05). Nonparental caregivers (β=0.13, 95% CI 0.05-0.21) and those with a household monthly income of >5000 RMB (>US $721; β=0.07, 95% CI 0.01-0.14) had a higher score for overall responsive feeding, while unemployed caregivers (β=−0.07, 95% CI −0.13 to −0.01) had a lower score.

Conclusions: Caregivers appear to be more likely to use responsive feeding practices than nonresponsive feeding practices. Interventions to promote responsive feeding should target parental, unemployed, and low-income caregivers. The findings of this study might serve as a reference for the comprehensive assessment of responsive feeding practices.

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KEYWORDS

responsive feeding; survey; video observation; infant and toddler; factors

Introduction

Nurturing care is an essential element in the promotion of early childhood development [1]. In 2018, the World Health Organization (WHO) and other international organizations jointly proposed 5 core elements of nurturing care [2]. One of the elements is responsive parenting, which requires caregivers to discern children's needs from their movements, sounds, expressions, and oral requests in daily life, and to provide timely and appropriate responses [3]. Responsive feeding refers to the positive interaction between caregivers and infants during the feeding process, where caregivers provide timely and appropriate responses to signals of hunger and satiety in infants and young children [3]. Responsive feeding has been

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incorporated into the infant and young child feeding guidelines by the WHO [4]. On the contrary, nonresponsive feeding should be avoided. As described by our research team, responsive feeding practices include the practices of responsiveness to cues, modeling, active communication and interaction, and creating a good meal environment, while nonresponsive feeding practices include controlling, pressure to eat, the use of food as a reward, and emotional feeding [5,6].

Previous studies about responsive/nonresponsive feeding have mainly been conducted in North America, Europe, and Australia [7,8]. A study in the United States demonstrated that the average frequencies of responsive feeding practices (eg, modeling and reasoning) at breakfast, lunch, and dinner were 9.2, 9.7, and 15.4 times, respectively, while the frequencies of nonresponsive feeding practices (eg, coercive-controlling prompts) at the same points were 2.9, 3.0, and 5.8 times, respectively [7]. A study in Australia revealed that the scores for nonresponsive feeding among caregivers in Australia were relatively low, with a mean score of 1.86 (SD 0.99) for the use of food as a reward and 1.99 (SD 0.64) for emotional feeding among caregivers of 2-year-old children [8]. Moreover, some studies have investigated responsive/nonresponsive feeding in China, with the majority (16/20) conducted in southern China. Chinese studies examined the practices of pressure to eat, the use of food as a reward, and active communication and interaction, while there is a paucity of reports on controlling, responsiveness to cues, modeling, and creating a good meal environment [9].

Responsive/nonresponsive feeding practices are typically assessed by survey or observation methods, each with distinct advantages and limitations. The survey method, which has been adopted by most studies [10], allows for large-scale data collection. However, existing tools used by surveys are unable to cover all dimensions of feeding practices [11]. In the Chinese context, certain practices (eg, controlling and responsiveness to cues) are still underreported [9]. Most observation studies used videos to record the process of feeding [12]. Home is the natural environment where children dine. Thus, taking videos to record the feeding episodes at home is feasible and can reflect real-life feeding practices. However, the observation method is only suitable for studies with a small sample size due to its high cost and respondent burden. Combining survey and observation methods in a single study can obtain rich information and explore the topic in-depth [13-15]. The survey provides quantitative breadth, while the observation yields qualitative depth, and they together offer a holistic understanding of feeding practices. For example, a study in Ethiopia found that when children refused to eat, the coping strategies reported by caregivers in questionnaires included increasing food variety and pressure to eat, and additional strategies were observed in videos, including changing caregivers, communicating with the children, and threatening [13]. In this study, a combination of survey and video observation methods was necessary to gain a comprehensive understanding of responsive/nonresponsive feeding practices and to address the gaps in the Chinese literature.

This study had 3 primary aims. First, we sought to provide a quantitative profile of responsive and nonresponsive feeding practices among caregivers of children aged 6 - 35 months in China. Every dimension of responsive/nonresponsive feeding was examined. Second, we conducted video observation among a small sample, in order to gain an in-depth understanding of feeding interactions. The video observation allowed us to capture subtle, unreported behaviors and contextual details that surveys might miss, thereby complementing the survey data by providing richness and depth. Third, using the survey data, we aimed to identify key demographic factors (eg, caregiver's employment status, education level, family income, etc) associated with these feeding practices to inform future interventions. Consequently, this study would contribute to the literature by (1) providing novel and in-depth data on the responsive/nonresponsive feeding practices of Chinese caregivers; (2) demonstrating the value of a mixed methods approach, using a survey method for breadth and an observation method for depth to achieve a more holistic assessment of feeding practices; and (3) identifying potential targets for responsive feeding interventions in China.

Methods

Design

This study adopted a combined approach, involving a questionnaire survey conducted among a relatively large sample and a video observation study conducted among a relatively small sample. The survey was reported according to the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines, and the video observation was reported in adherence to the COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist.

Ethical Considerations

Approval to conduct this study was obtained from the Ethics Committee of Peking University (IRB00001052-20047; approval date: August 1, 2020). This study has been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. All caregivers signed a written informed consent form before any assessment. Adhering to privacy and confidentiality guidelines, all identifiable participant details, including names, hospital numbers, and recognizable features in images, were anonymized or omitted. Participants of the survey received a small toy valued at 5 RMB (US $0.72), while participants of the video observation received 100 RMB (US $14).

Survey

Study Design

A cross-sectional survey was conducted from August to October 2020 in Shijiazhuang City, Hebei Province, China. Methods for participant selection, recruitment, data collection, and the key instrument have been detailed in our previous publication [5,6].

Participants

Family members who took the primary responsibility of child caregiving were our potential participants. Caregivers were included if they (1) were permanent residents of the study area; (2) had a certain level of literacy; and (3) had a child at full-term delivery, of normal birth weight, and aged 180 days to 3 years (excluding the full age of 3 years). Caregivers were excluded if they had a child with diseases that affect eating (eg, cold,

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fever, diarrhea, and food allergies), congenital diseases, infectious diseases, genetic metabolic diseases, deformities, mental diseases (eg, depression), or other serious illnesses (eg, cancer, severe liver or kidney diseases, and AIDS). All included participants signed a written informed consent form before any assessment.

Recruitment and Data Collection

This study was advertised through posters at Loudi Township Hospital of Luancheng District. A convenience sampling method was used to recruit caregivers who visited the hospital for routine health check-ups and vaccinations. Eligible caregivers signed an informed consent form after being informed of the purpose and process of the study. Participants were then required to complete a questionnaire via a face-to-face interview with the researcher, which took approximately 20 minutes. They were given a small toy valued at 5 RMB (US $0.72) as an incentive to participate in this study. Researchers checked each completed questionnaire. Participants who provided missing or illogical answers were further contacted for adjustment. Data entry was finally performed, with 10% double entry for quality assurance.

Questionnaire

A cross-sectional questionnaire was developed to collect participants' general demographic characteristics and their responsive/nonresponsive feeding practices. Caregivers' responsive and nonresponsive feeding practices were measured by a scale, which was based on previous validated scales [16-18] and then further modified by our research team. Details on the construction and validation of this responsive/nonresponsive feeding scale have been provided in our previous publication involving the same study population [5]. In brief, the full Parents' Feeding Practices Scale for Infant and Young Child (PFPSIYC) was adopted to assess 5 feeding dimensions (including controlling, pressure to eat, the use of food as a reward, emotional feeding, and modeling). The PFPSIYC has been used to assess Chinese caregivers of children aged 6 - 23 months, with acceptable reliability and good validity [16]. Some items from the Infant Feeding Style Questionnaire (IFSQ) were used to evaluate caregivers' responses to dietary cues. The IFSQ has been used among caregivers in the United States, with good reliability [17]. Some items were adopted from the Young Child Feeding Questionnaire (YCFQ) to evaluate active communication and interaction between caregivers. The YCFQ has been applied to caregivers of children aged 6 - 18 months in China, with acceptable reliability [18].

To ensure the instrument's suitability for the context of this study, a pilot study was conducted among 132 caregivers in Hebei Province. This pilot study confirmed the feasibility of the survey procedures and the comprehensibility of the items. The pilot study showed acceptable internal consistency (Cronbach α=0.810) and structural validity (cumulative variance explained=61.6%) of the feeding scale. Following the pilot study, the survey was administered to the population of this study. The structural validity of the scale was good among the current sample, and the structure of each dimension was comparable to the original scales, with eigenvalue >1 for 7 factors (cumulative percentage of variance: 60.388%). The internal reliability was acceptable (Cronbach α: total, 0.765; controlling, 0.740; the use of food as a reward, 0.629; emotional feeding, 0.727; responsiveness to cues, 0.778; active communication and interaction, 0.771; modeling, 0.497; and pressure to eat, 0.441).

In this study, caregivers' frequency of each feeding practice in the previous 1 month was assessed using a 5-point Likert scale (1=never, 2=rarely, 3=sometimes, 4=often, and 5=always). The score for each feeding dimension was obtained by calculating the mean score of the items within the dimension. To calculate the overall score of responsive feeding, the scorings for nonresponsive feeding practices were first reversed, followed by taking the mean value of all responsive and nonresponsive feeding items. A higher overall score indicated a greater tendency to adopt responsive feeding practices.

Data Analysis

Participants' demographic characteristics and the scores of caregivers' responsive/nonresponsive feeding practices were described. Frequencies and percentages have been presented for categorical variables. Continuous variables in this study did not meet normal distribution according to a normality test, and thus, they have been presented using medians and quartiles. Mann-Whitney *U* and Kruskal-Wallis tests were used to examine the univariate association between caregivers' responsive/nonresponsive feeding practices and participants' demographic characteristics. Finally, multiple linear regression was used to determine the independent effects of participants' demographic characteristics on caregivers' responsive/nonresponsive feeding practices. Variables with $P<.10$ in the univariate analysis were entered into the regression model. A variance inflation factor of <5 was used to indicate a low degree of multicollinearity of the independent variables. Statistical analyses were performed using SPSS 22.0 (IBM Corp). A P value of <.05 was considered statistically significant.

Video Observation

Study Design and Participants

A video observation study was conducted from August to October 2020 in Luannan County, Tangshan City, Hebei Province, China. Eligible participants were infants and toddlers, and their primary caregivers. The inclusion criteria were the same as those for the survey, and caregivers were required to agree to participate in this observation study. Referring to previous video observation studies on feeding practices [14,19-21] and considering the time, financial, and human resources of this study, 42 caregiver-child pairs were recruited for this study, including 21 pairs each for children aged 6 - 23 months and those aged 24 - 35 months.

Recruitment and Data Collection

Convenience sampling was used to recruit participants. Researchers were led by village committee staff for household visits. Eligible caregivers were informed of the purpose and procedure of the study. Caregivers who agreed to take part in this study signed a written informed consent form and filled in a brief questionnaire on demographic information. The researchers made appointments with the caregivers for the time

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and place to carry out video recording. The caregivers were required to prepare meals and feed their children in a daily routine manner. On the day of the video recording, the researchers (who played the role of a videographer) dressed in a normal style so as not to arouse the curiosity or anxiety of the children. The researchers recorded the children's dining occasions of breakfast, lunch, and dinner, according to the instructions of the operation manual (see Multimedia Appendix 1 for details). For younger infants, 2 - 3 complementary meals were recorded. The total duration of the videos was about 1.5 hours for each caregiver-child pair. After completing each feeding episode, the researchers performed a quality check (eg, whether the picture was clear and whether the sound was recognizable). If the quality was not up to standard, the corresponding meal was recorded again on a later date until the quality of the video was assured. Upon the completion of all recordings, each caregiver received 100 RMB (US $14) as an incentive. All videos were saved to a password-protected removable hard drive and kept confidential by the researchers.

Pilot Study

Three households (one each for children aged <12 months, 12-23 months, and 24 - 35 months) were selected to record children's dining episodes within a day. The pilot study discovered that a meal lasted 5 - 30 minutes, and both caregivers and children could easily get used to the recording. The number of feeding episodes recorded (2 - 3 times per day) was acceptable to both the participants and researchers. Based on the pilot study, the researchers revised and finalized the operation manual for video recording (Multimedia Appendix 1).

Video Coding and Quality Control

Based on the literature, responsive (responsiveness to cues, active communication and interaction, modeling, and creating a good meal environment) and nonresponsive (controlling, the use of food as a reward, emotional feeding, and pressure to eat) feeding practices included 4 dimensions each [3,5,11]. All videos were viewed, and the practices of responsive and nonresponsive feeding were recorded and summarized into a codebook (Multimedia Appendix 2). Notably, the practice of emotional feeding could not be observed in the videos taken, and thus, this was not coded. Next, the number of times each practice appeared was recorded according to the codebook. Taking responsiveness to cues as an example, a caregiver was considered to have this practice as long as any of the corresponding behaviors were shown. A consecutive practice with an interval of <5 seconds was counted as 1, while the same practice with an interval of ≥5 seconds was counted as 2. Coding was performed using the Behavioral Observation Research Interactive Software (BORIS) [22], which automatically summarized the number and duration of each practice in each coded video. Regarding the practice of creating a good meal environment, the researcher scored the overall feeding environment for each feeding episode according to the predefined criteria listed in the codebook. When a criterion was met, a score of 1 was obtained. A higher accumulated score indicated that the caregiver was more likely to create a good meal environment. The scores of creating a good meal environment were recorded in Excel software (Microsoft Corp). All videos were coded by 1 researcher (MA), with 20% of the videos randomly selected for double-coding by another trained coder [23]. The intraclass correlation coefficients (ICCs) between the 2 coders for each feeding practice ranged from 0.587 to 0.885 (P<.05), indicating an acceptable level of reliability [24]. Finally, the coding results were processed by counting the number of times the feeding practices occurred at each dining occasion (breakfast/lunch/dinner). The score for creating a good meal environment was also calculated for each dining occasion. The duration of each feeding practice was not analyzed in this study owing to its low ICC values.

Quality control was performed for coding. First, the coders received intensive training on the content of the codebook, the coding process, and the use of coding software before any coding. Second, 20% of double-coding was performed to ensure the reliability of the coding results. Third, each coder signed a data confidentiality agreement before getting access to any data. Video coding was performed on a password-protected computer that was disconnected from the internet during coding. The coding results were kept confidential by the researchers.

Data Analysis

First, participants' demographic characteristics were described, and the chi-square test was used to analyze the difference in demographics between observation and survey participants. Second, the responsive/nonresponsive feeding practices extracted from coding were described, supplementing the results from the survey. Then, for each dining occasion (breakfast/lunch/dinner), the occurrence and observed number of responsive/nonresponsive feeding episodes were presented. The occurrence (%) was calculated as follows: (the number of videos in which responsive/nonresponsive feeding appeared for each occasion/the total number of videos for each occasion) × 100. Since the observed number did not meet a normal distribution, it was described by median (IQR). Statistical analyses were carried out using SPSS 22.0 software, and a P value of <.05 was used to indicate statistical significance.

Results

General Characteristics of the Participants

Among the 444 participants recruited, 16 did not complete the questionnaire; 2 provided ineligible informed consent; 1 provided a duplicate questionnaire; and 16 had a preterm child, had a child with an abnormal birth weight, or had a child of inappropriate age. Finally, a total of 409 participants were included in the survey. Most caregivers were parents (310/409, 75.8%; including 301 mothers), had a high school education or below (282/409, 68.9%), were unemployed (217/409, 53.1%), and had a normal weight status (207/409, 51.7%). The majority of children were aged 24 - 35 months (217/409, 53.1%), were male (214/409, 52.3%), were not the first child in the family (211/409, 51.6%), had a normal weight status (372/409, 93.0%), lived in an extended family (310/409, 75.8%), and had parents with a monthly household income of >5000 RMB (>US $721; 247/409, 60.4%) (Table 1).

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Table . General characteristics of the caregivers and children.

Characteristic	Survey (N=409), n (%)	Video observation (N=42), n (%)	Chi-square (*df*)	*P* value
Caregivers' characteristics				
Relationship with the child			2.098 (1)	.15
Parent	310 (75.8)	36 (85.7)		
Nonparent	99 (24.2)	6 (14.3)		
Education level			6.749 (1)	.009[a]
High school or below	282 (68.9)	37 (88.1)		
College or above	127 (31.1)	5 (11.9)		
Employment status			2.415 (1)	.12
Employed	192 (46.9)	25 (59.5)		
Unemployed	217 (53.1)	17 (40.5)		
Weight status			0.419 (2)	.81
Underweight	18 (4.5)	1 (2.4)		
Normal weight	207 (51.7)	22 (52.4)		
Overweight or obese	175 (43.8)	19 (45.2)		
Children's characteristics				
Age (months)			0.143 (1)	.71
6-23	192 (46.9)	21 (50.0)		
24-35	217 (53.1)	21 (50.0)		
Gender			3.152 (1)	.08
Male	214 (52.3)	28 (66.7)		
Female	195 (47.7)	14 (33.3)		
Child order			11.167 (1)	.001[a]
First	198 (48.4)	9 (21.4)		
Second or higher	211 (51.6)	33 (78.6)		
Infant weight status (based on BMI *z* score)			1.478 (2)	.48
Wasting or severe wasting	14 (3.5)	1 (2.4)		
Normal	372 (93.0)	38 (90.5)		
Overweight or obese	14 (3.5)	3 (7.1)		
Family structure			8.722 (1)	.003[a]
Nuclear family	99 (24.2)	19 (45.2)		
Extended family	310 (75.8)	23 (54.8)		
Monthly household income (RMB[b])			0.502 (1)	.48
≤5000	162 (39.6)	19 (45.2)		
>5000	247 (60.4)	23 (54.8)		

[a]*P*<.05, chi-square test.

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[b]A currency exchange rate of 1 RMB=US $0.14 is applicable.

A total of 42 caregiver-child pairs were included in the video observation, including 21 pairs each of children aged 6 - 23 months and those aged 24 - 35 months. In general, the characteristics of the participants in the video observation and survey were similar (Table 1).

Responsive and Nonresponsive Feeding Practices

The survey measured 7 dimensions of feeding practices. The scores for responsive feeding practices were generally higher than those for nonresponsive feeding practices. The median scores for responsiveness to cues, modeling, and active communication and interaction were 4.00, 3.67, and 3.88, respectively. The median scores for controlling, pressure to eat, the use of food as a reward, and emotional feeding were 3.33, 2.33, 3.00, and 2.67, respectively. The overall responsive feeding score was 3.52 (Table 2).

Table . Scores of responsive and nonresponsive feeding practices in the survey (N=409).

Behavior	Quartile		
	P_{25}[a]	P_{50}[b]	P_{75}[c]
Nonresponsive feeding practices			
Controlling	2.67	3.33	4.00
Pressure to eat	1.67	2.33	3.00
Use of food as a reward	2.00	3.00	3.50
Emotional feeding	2.00	2.67	3.00
Responsive feeding practices			
Responsiveness to cues	3.67	4.00	4.33
Modeling	3.00	3.67	4.00
Active communication and interaction	3.50	3.88	4.25
Overall score of responsive feeding	3.36	3.52	3.76

[a]P_{25}: 25th percentile.

[b]P_{50}: median.

[c]P_{75}: 75th percentile.

Video observation additionally assessed the dimension of “creating a good meal environment” that could not be examined by the survey. Except for caregivers’ emotional feeding, all dimensions could be observed by the videos (Table 3). A total of 105 videos were recorded, including 27 videos for breakfast, 37 for lunch, and 41 for dinner. In general, the occurrences of responsive feeding practices (75.6% - 97.6%) were higher than those of nonresponsive feeding practices (0% - 46.3%) at main meals. There was little variation in the occurrence of each practice during breakfast, lunch, and dinner. In addition, among nonresponsive feeding, controlling and pressure to eat were more likely to occur than the use of food as a reward. The practice of the use of food as a reward appeared at breakfast and dinner but not at lunch (Table 3). Notably, the practice of the use of food as a reward is very likely to occur during snacking, which was not recorded in this study. Therefore, the occurrence of the use of food as a reward reported here is likely to be underestimated. In terms of the observed number of practices at each dining occasion, the observed number of responsive feeding practices (2-11) was higher than that of nonresponsive feeding practices (0). The score for creating a good meal environment was high at 4 points. For each feeding practice, the observed number and scores at breakfast, lunch, and dinner were similar (Table 4).

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Table . Occurrence of responsive and nonresponsive feeding practices at main meals in the video observation.

Behavior[a]	Occurrence, n (%)		
	Breakfast (n=27[b])	Lunch (n=37[b])	Dinner (n=41[b])
Nonresponsive feeding practices			
Controlling	11 (41)	17 (46)	19 (46)
Pressure to eat	12 (44)	14 (38)	17 (42)
Use of food as a reward	3 (11)	0 (0)	2 (5)
Responsive feeding practices			
Responsiveness to cues	24 (89)	34 (92)	38 (93)
Modeling	24 (89)	31 (84)	31 (76)
Active communication and interaction	26 (96)	35 (95)	40 (98)

[a]The responsive feeding practice of creating a good meal environment was evaluated according to the score and not occurrence. The nonresponsive feeding practice of emotional feeding could not be observed by video in this study.

[b]Number of videos.

Table . Observations of responsive and nonresponsive feeding practices in the videos.

Behavior	Observations, median (IQR)		
	Breakfast (n=27[a])	Lunch (n=37[a])	Dinner (n=41[a])
Nonresponsive feeding practices[b]			
Controlling	0 (0-3)	0 (0-2)	0 (0-2)
Pressure to eat	0 (0-1)	0 (0-2)	0 (0-2)
Use of food as a reward	0 (0-0)	0 (0-0)	0 (0-0)
Responsive feeding practices			
Responsiveness to cues	7 (4-11)	5 (3-13)	6 (3-12)
Modeling	2 (1-4)	2 (1-6)	3 (1-6)
Active communication and interaction	11 (6-17)	10 (5-18)	11 (6-17)
Creating a good meal environment[c]	4 (3-4)	4 (3-4)	4 (3-4)

[a]Number of videos.

[b]The nonresponsive feeding practice of emotional feeding could not be observed by video in this study.

[c]The responsive feeding practice of creating a good meal environment was evaluated by the score and not the number of observations in the videos.

Observations from the videos provided rich and contextual narratives that illustrated responsive/nonresponsive feeding practices. For instance, the practice of "using food as a reward" frequently involved ultraprocessed foods such as sugary drinks and spicy strips. In 1 episode, a mother promised to provide her child with spicy strips for the purpose of encouraging the child's consumption of the main meal. She said: "OK…spicy strips… If you finish this meal, I will give you spicy strips." Moreover, the practice of "pressure to eat" was observed in the following three dimensions: (1) continue feeding despite the child's refusal (eg, turning the head away and crying), (2) use distractions (eg, toys and mobile phones) to coax the child into eating, and (3) insist on eating even after satiety cues (eg, verbally expressing fullness and pushing the bowl away). Video descriptions of "responsiveness to cues" have been presented in our previous publication [6].

Factors Influencing Responsive and Nonresponsive Feeding Practices

The results from univariate analyses that explored factors influencing responsive/nonresponsive feeding practices are shown in Multimedia Appendix 3. After controlling for potential confounders, the results from multivariate analyses are shown in Table 5. For the overall responsive feeding score, caregivers who were nonparents (β=0.13, 95% CI 0.05-0.21) and had a monthly household income of >5000 RMB (>US $721; β=0.07, 95% CI 0.01-0.14) had a higher overall score, while the score was lower among unemployed caregivers (β=−0.07, 95% CI −0.13 to −0.01). For nonresponsive feeding practices, caregivers whose children were not the first child (β=−0.20, 95% CI −0.39 to −0.02) and whose children were aged 24 - 35 months (β=−0.20, 95% CI −0.38 to −0.02) had a lower score. The score for pressure to eat was higher among unemployed caregivers

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(β=0.27, 95% CI 0.11-0.42). The score for the use of food as a reward was lower for caregivers who were nonparents (β=−0.45, 95% CI −0.69 to −0.22). The score for emotional feeding was higher among caregivers whose children were not the first child (β=0.18, 95% CI 0.03-0.34). In terms of responsive feeding practices, the score for responsiveness to cues was higher among caregivers who were nonparents (β=0.43, 95% CI 0.25-0.60), while the score was lower among unemployed caregivers (β=−0.19, 95% CI −0.33 to −0.05). The score for modeling was higher among caregivers whose weight status was underweight (β=0.44, 95% CI 0.07-0.80), and the score was lower among caregivers whose children were aged 24 - 35 months (β=0.22, 95% CI 0.07-0.37). Caregivers whose children were not the first child (β=−0.17, 95% CI −0.29 to −0.54) had a lower score for active communication and interaction.

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Table . Multivariate analysis of factors influencing responsive and nonresponsive feeding behaviors assessed in the survey (N=409).

Variable	Nonresponsive feeding practices, β[a] (95% CI)				Responsive feeding practices, β (95% CI)			Overall score of responsive feeding, β (95% CI)
	Controlling	Pressure to eat	Use of food as a reward	Emotional feeding	Responsiveness to cues	Modeling	Active communication and interaction	
Caregivers' characteristics								
Relationship with the child: nonparents (vs parents)	—[b]	−0.19 (−0.38 to 0.01)	−0.45 (−0.69 to −0.22)[c]	—	0.43 (0.25 to 0.60)[c]	—	—	0.13 (0.05 to 0.21)[c]
Education level: college or above (vs high school or below)	—	0.16 (−0.02 to 0.34)	0.05 (−0.17 to 0.27)	—	0.03 (−0.13 to 0.19)	—	—	−0.02 (−0.10 to 0.05)
Employment status: unemployed (vs employed)	—	0.27 (0.11 to 0.42)[c]	—	—	−0.19 (−0.33 to −0.05)[c]	—	—	−0.07 (−0.13 to −0.01)[c]
Weight status: underweight (vs normal weight)	—	—	—	—	—	0.44 (0.07 to 0.80)[c]	—	—
Weight status: overweight or obese (vs normal weight)	—	—	—	—	—	0.01 (−0.14 to 0.16)	—	—
Children's characteristics								
Age: 24-35 months (vs 6-23 months)	−0.20 (−0.38 to −0.02)[c]	—	—	—	0.11 (−0.04 to 0.25)	0.22 (0.07 to 0.37)[c]	—	—
Gender: female (vs male)	—	—	0.16 (−0.03 to 0.34)	—	—	—	—	—
Child order: second or higher (vs first)	−0.20 (−0.39 to −0.02)[c]	—	—	0.18 (0.03 to 0.34)[c]	—	—	−0.17 (−0.29 to −0.54)[c]	−0.06 (−0.12 to 0.01)
Family structure: extended family (vs nuclear family)	—	—	—	—	—	—	−0.06 (−0.20 to 0.08)	—
Monthly household income[d]: >5000 RMB (vs ≤5000 RMB)	—	—	—	—	—	—	—	0.07 (0.01 to 0.14)[c]

[a]β: unstandardized regression coefficient.

[b]The variable had a *P* value of >.10 in the univariate analysis (see Multimedia Appendix 3), and it was thus not included in the multivariate analysis.

[c]*P*<.05, multiple linear regression.

[d]A currency exchange rate of 1 RMB=US $0.14 is applicable.

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Discussion

Summary of the Study Findings

This study used a combination of survey and video observation methods to obtain a comprehensive understanding of the current status of caregivers' responsive and nonresponsive feeding practices among children aged 6 - 35 months and performed multivariate analyses of the survey data to explore factors influencing responsive and nonresponsive feeding practices. Both survey and video observation methods found that the frequencies of responsive feeding practices were higher than those of nonresponsive feeding practices. Video observation revealed that there was little variation in the occurrence/score of each feeding practice in main meals (ie, breakfast, lunch, and dinner). The survey demonstrated that caregivers' relationships with their children, employment status, and weight status; children's age and order; and the monthly household income were factors influencing responsive/nonresponsive feeding practices.

Caregivers' Responsive and Nonresponsive Feeding Practices

Both survey and video observation methods in this study found that caregivers adopted responsive feeding practices more frequently than nonresponsive feeding practices. In our survey, the scores for nonresponsive feeding practices were at a moderate to low level, similar to findings reported in other Chinese studies [16,25]. For example, a study in Hong Kong revealed that the scores for the use of food as a reward and emotional feeding were 2.68 (SD 0.66) and 2.31 (SD 0.70) points, respectively [26]. However, the score for pressure to eat among caregivers of children aged 3 - 18 months in Spain was 3.46 (SD 0.82) points [27], which is higher than that in our study. The scores for responsive feeding practices in our study were moderately high and were consistent with the findings of other national and international studies. For instance, a study in the United States revealed that the score for responsiveness to cues among children aged 3 - 18 months was 4.49 (SD 0.04) points [28]. The median scores for behaviors related to active communication and interaction among caregivers whose children were aged 18 months in Shanghai were between 4 and 5 points, indicating a relatively high level [18].

The video observation confirmed the results of the survey. In daily meals, caregivers adopted responsive feeding practices more frequently than nonresponsive feeding practices. Caregivers likely prepared a variety of nutritious foods for their children. Responsive feeding practices, such as modeling, are effective strategies for promoting children's intake of these healthy foods [6]. Furthermore, video observation found that the number of responsive feeding observations was similar among breakfast, lunch, and dinner. Similarly, a video observation study among children aged 12 - 36 months in the United States indicated that caregivers' feeding practices during each main meal had a certain degree of stability. Observation of a single main meal might be an alternative approach to examine responsive feeding in future studies, if resources are limited.

Factors Influencing Caregivers' Responsive and Nonresponsive Feeding Practices

Previous studies on feeding practices were mainly conducted among mothers. Our study adds to the literature by examining responsive and nonresponsive feeding practices among both parents and nonparents. In this study, the scores of overall responsive feeding and the practice of responsiveness to cues among nonparents (99% grandparents) were higher than those among parents. However, the score of the use of food as a reward among nonparents was lower than that among parents. This might be because grandparents were patient and responsible when feeding their grandchildren and had sufficient time to adopt responsive feeding strategies [29,30]. From our video observation, grandparents waited for a while after each feed and did not provide the next feed until the child swallowed the food (data not shown). Moreover, grandparents had previous experience in feeding children. Finally, with the broad use of the internet and smartphones, grandparents were knowledgeable in using appropriate feeding strategies. Our results imply that education on optimal feeding practices should be given to parents. For instance, local maternal and child health centers might deliver responsive feeding guidance (eg, recognizing children's satiety cues and optimizing mealtime interactions) to parents during children's routine health check-ups and vaccination visits. On the contrary, some studies failed to report differences in pressure to eat and the use of food as a reward between grandparents and parents, and some studies found that grandparents were more inclined to adopt the pressure to eat practice than parents [29,31]. Children in these studies were older than our study participants [31], which might explain the variation in results between our study and previous studies.

In this study, compared with employed caregivers, unemployed caregivers scored lower in overall responsive feeding and responsiveness to cues but scored higher in pressure to eat. Moreover, the score of overall responsive feeding was lower among caregivers whose monthly household income was ≤5000 RMB (≤US $721). Caregivers with a lower socioeconomic status likely paid less attention to responsive feeding practices. Likewise, a qualitative study in Thailand among factory worker parents of preschool children demonstrated that family income was one of the most influential factors on children's food choice, as parents prioritized their budget on food over nutritional quality due to economic constraints [32]. Therefore, interventions to enhance responsive feeding in China should attempt to target low-income groups. For example, community health centers might consider offering feeding workshops aligned with intergenerational care norms free of charge for low-income groups. Free personalized consultation could also be provided by community health care workers.

In this study, caregivers of children aged 24 - 35 months had a lower score for controlling and a higher score for modeling, in comparison with caregivers of children aged 6 - 23 months. It is likely that older children could express their dietary signals well, making it easier for caregivers to respond more appropriately. With an increase in their independence, children are more likely to eat on their own [33]. Caregivers' use of the modeling strategy could help the development of children's healthy eating habits. Therefore, specific education on feeding

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practices should be delivered to caregivers by considering the age of their children. Caregivers of younger children (less than 24 months of age) urgently need responsive feeding education.

Caregivers whose children were not the first child in the family were more likely to use emotional feeding but less likely to use active communication and interaction, and controlling strategies, in comparison with caregivers whose children were the first child. Based on the theory of family systems, the dilution of resources (time, energy, etc) for raising multiple children may affect caregivers' feeding practices [34]. With an increase in the number of children in the family, caregivers' time and energy allocated to each child decrease. Therefore, the frequency of caregiver-child interaction and verbal communication during feeding decreases [34]. Caregivers' practice of controlling children's eating also decreases. Caregivers are more likely to become impatient and use emotional feeding. However, a cross-sectional study in Thailand reported that the first child was more likely to receive inappropriate complementary feeding [35]. The Thai study focused on children's dietary intake and diversity, while our study focused on the behaviors of the caregiver-child interaction. Differences in research focus might account for the variations in findings between the studies.

Compared with caregivers having a normal weight status, underweight caregivers in this study adopted more modeling behaviors. The reason may be that underweight caregivers are more concerned about insufficient dietary intake or being underweight in childhood, and thus, they play the role of an eating model for their children and ensure that their children have a good nutritional status.

Notably, there was no difference in responsive/nonresponsive feeding practices when considering the child's gender. It appears that Chinese traditional patriarchal attitudes did not influence caregivers' feeding practices among our study participants. Additionally, caregivers' education, children's weight status, and the family structure were not associated with caregivers' responsive/nonresponsive feeding practices in this study.

Strengths and Limitations

This study adopted a combined approach involving survey and video observation methods to investigate responsive/nonresponsive feeding practices among caregivers of children aged 6 - 35 months. This approach provided an objective and comprehensive assessment of responsive/nonresponsive feeding practices. Findings from the survey and observation assessments were confirmatory and complementary to each other. The questionnaire had good reliability and validity and could comprehensively measure all dimensions of responsive and nonresponsive feeding practices. Video observation could objectively capture the actual feeding environment and caregiver-child interaction and assess the practice of "creating a good meal environment," which could not be measured by questionnaires. Moreover, this study used multivariate analysis to explore the factors influencing responsive and nonresponsive feeding practices. The findings of this study would be useful in the development of interventions and strategies to promote responsive feeding and in the identification of targeted populations for interventions.

The limitations of this study should be acknowledged. First, this study was conducted in some areas of Hebei Province. The results from this study might not be representative of caregivers living in other areas. Moreover, the caregivers in our survey sample had a higher education level but a lower employment rate than the general population [36]. National data indicate that the population in Hebei Province is at the top level and its economic output (reflected by gross domestic product) is at the middle level in China [36]. The health literacy of residents in Hebei Province [37] was similar to that at the national level (27.78%), according to 2022 surveillance data [38], implying that our findings might represent the Chinese population to some extent. Second, the use of food as a reward is more likely to occur in snacking occasions than during main meals. However, our video observation only recorded feeding episodes during main meals. Thus, the occurrence of the use of food as a reward reported in our video observation might be lower than the actual status. Third, owing to the COVID-19 epidemic, video observation could not be carried out at the planned location (Shijiazhuang city, where the survey was conducted). After careful discussion by the research team, Tangshan city was selected as an alternative location. The 2 cities are located in the same province, with a distance of 420 kilometers, ensuring the homogeneity of the samples to some extent. Fourth, the Hawthorne effect may have existed in the video recording process owing to the presence of the camera or videographer. Nevertheless, a number of efforts were taken to minimize the Hawthorne effect. For instance, we conducted the recording in a familiar environment (ie, home); we explicitly instructed caregivers to behave as usual prior to each recording; and the videographer dressed normally, remained silent, stayed hidden in a corner, and avoided participating in any feeding practices during the recording.

Conclusion

With a combined approach involving survey and video observation methods, this study revealed that the frequency of responsive feeding practices was higher than that of nonresponsive feeding practices among Chinese caregivers whose children were aged 6 - 35 months. The combined approach might serve as a methodological reference for research on feeding practices. Moreover, the survey demonstrated that parental, unemployed, and low-income caregivers were less likely to use responsive feeding strategies. Health care providers should consider this finding and target such groups for feeding education and intervention.

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Authors' Contributions

QZ, MA, and DL conceived and designed the study. MA, NW, XR, XL, and JH collected the data. DL and YW drafted the manuscript. MA and DL analyzed the data. QZ supervised data collection and analysis, and drafting of the manuscript. All authors have read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Operation manual for video recording.
[DOCX File, 17 KB - pediatrics_v9i1e78028_app1.docx]

Multimedia Appendix 2
Codebook of responsive and nonresponsive feeding practices.
[DOCX File, 23 KB - pediatrics_v9i1e78028_app2.docx]

Multimedia Appendix 3
Scores of responsive and nonresponsive feeding practices categorized by different demographic characteristics in the survey.
[DOCX File, 27 KB - pediatrics_v9i1e78028_app3.docx]

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Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Research
ICC: intraclass correlation coefficient
IFSQ: Infant Feeding Style Questionnaire
PFPSIYC: Parents' Feeding Practices Scale for Infant and Young Child
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology
WHO: World Health Organization
YCFQ: Young Child Feeding Questionnaire

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Parent Anxiety and Response to a Telehealth Intervention for Hypoglycemia Fear: Secondary Analysis of a Randomized Trial

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Abstract

Background: Parents of young children with type 1 diabetes (T1D) frequently report fear of hypoglycemia (FH), which can impact their diabetes management. REDCHiP (Reducing Emotional Distress for Childhood Hypoglycemia in Parents) is a telehealth-delivered cognitive behavioral intervention shown to reduce FH, but less is known about which parents benefit most.

Objective: This secondary analysis examined whether pretreatment parent anxiety moderated REDCHiP's effects and explored responder patterns by intervention arm and pretreatment anxiety.

Methods: This was a secondary analysis of a large, randomized clinical trial comparing REDCHiP to an attention control condition (ATTN). We assessed outcomes before treatment (time 1) and 3 months after treatment (time 3). Our primary outcome was parental FH at time 3, adjusted for time 1 FH. The original trial used validated measures of parent FH and general anxiety. We evaluated parent anxiety at time 1 as both a categorical variable (clinically elevated or not) and a continuous variable (centered). We defined responders as parents achieving a reduction of ≥0.5 SDs in FH from time 1 to time 3. An analysis of covariance tested the treatment arm by anxiety interaction, with sensitivity analyses modeling anxiety continuously.

Results: There was no significant treatment arm by anxiety interaction when modeling parent anxiety as either a categorical or continuous variable (P>.05). However, exploratory analyses found that the adjusted mean time 3 FH was numerically lower among REDCHiP parents than ATTN parents with clinically elevated anxiety. Among parents with elevated anxiety, 78.6% (22/28) of REDCHiP parents met our responder criterion compared with 47.4% (9/19) of ATTN parents. Among parents with elevated anxiety, the adjusted odds of meeting the responder criterion were higher for REDCHiP than ATTN parents (odds ratio 6.35, 95% CI 1.47 - 29.00).

Conclusions: While time 1 parent anxiety did not significantly moderate treatment response, exploratory analyses suggested a potentially meaningful pattern among parents with clinically elevated anxiety. As telehealth-delivered behavioral interventions expand in pediatric type 1 diabetes care, secondary analyses of participant characteristics may help guide targeted implementation and enhance treatment benefit.

Trial Registration: ClinicalTrials.gov NCT03914547; https://clinicaltrials.gov/study/NCT03914547

(JMIR Pediatr Parent 2026;9:e95475) doi:10.2196/95475

KEYWORDS

pediatrics; type 1 diabetes; hypoglycemia fear; parenting; anxiety

Introduction

Parents of young children with type 1 diabetes (T1D) commonly report fear of hypoglycemia (FH) [1,2], which may adversely influence their treatment decisions and consequently young children's glycemic control [2]. To address this concern, we designed REDCHiP (Reducing Emotional Distress for Childhood Hypoglycemia in Parents), a telehealth-based intervention to reduce parent FH [3]. Telehealth-delivered treatments may be more scalable for families managing T1D because they can reduce barriers associated with traditional in-person treatments, including transportation demands, time and scheduling constraints, and childcare responsibilities [4-7]. However, as the availability of telehealth interventions continues to expand [4,7], it is essential to identify which families are

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most likely to benefit so that we can implement programs efficiently and target the families with the greatest need.

Parent anxiety is an established correlate of FH [8-10], and higher anxiety may amplify the constant vigilance, worry, and avoidance behavior that characterizes FH. Because REDCHiP teaches parents cognitive and behavioral strategies for managing FH worry and reducing their reliance on potentially harmful hypoglycemia avoidance behaviors [3], it is possible that parents' pretreatment anxiety symptoms could influence their engagement with or responsiveness to treatment.

We recently completed a large 2-arm randomized clinical trial comparing REDCHiP to a study-specific attention control condition (ATTN) [11]. In the main trial, parents in both treatment arms experienced a significant reduction in FH [12]. Here, we present secondary analyses exploring pretreatment parent characteristics that may have been associated with parent treatment response. Specifically, we examined whether parents' pretreatment anxiety moderated reductions in parent FH. We also explored response patterns among participants by treatment group and their pretreatment anxiety level.

Methods

Ethical Considerations

We conducted the primary multisite clinical trial under a single institutional review board (IRB) agreement, with Children's Mercy Hospital-Kansas City as the IRB of record. Before enrolling parents, we obtained IRB approval on all study procedures, including the use of electronic documentation of parent informed consent and permission. The primary trial was registered at ClinicalTrials.gov (NCT03914547).

Study Design

We previously described the primary trial's inclusion and exclusion criteria, study procedures, and trial outcomes [11,12]. We randomized families following enrollment. We delivered the REDCHiP and ATTN treatments entirely via video telehealth following guidelines for best practices in digital behavioral health [13]. Both treatment arms had 10 sessions delivered nearly weekly over 12 weeks. We assessed parent outcomes at before treatment (time 1), immediately after treatment (time 2) and 3 months after treatment (time 3). To be consistent with the primary analyses from the REDCHiP trial, these secondary analyses also focused on outcomes at time 3 to examine maintenance of treatment effects.

Measures

Overview

All participating parents completed the same questionnaires online [11,12]. At time 1, we used a trial-specific questionnaire to capture family demographics, including parent and child age, sex, and race and ethnicity. We also asked parents to describe their relationship to the child, marital status, and education level, as well as provide information on their child's T1D, including date of diagnosis, treatment regimen, and history of severe hypoglycemia.

Hypoglycemia Fear

Parents completed the validated Hypoglycemia Fear Survey–Parents of Young Children (HFS-PYC) [2]. This questionnaire measures parents' FH based on the frequency of hypoglycemia-related worries and avoidance behaviors. Items used a 5-point Likert scale (1=never to 5=very often), with higher scores indicating greater FH. To simplify score interpretation, the primary trial transformed HFS-PYC scores to fit a 0 to 100 scale [12]; we applied the same rescoring method to the current analyses. To calculate a responder variable, we defined treatment response as parents who achieved a reduction of ≥0.5 SD from time 1 to time 3 using the time 1 HFS-PYC SD from the full sample [14]. We used this distribution-based approach because a minimal clinically important difference has not yet been established for the HFS-PYC [15].

General Anxiety

Parents completed the PROMIS-A (Patient-Reported Outcomes Measurement Information System Anxiety Short Form). This is a validated 7-item questionnaire assessing physical and cognitive symptoms of general anxiety over the past 7 days. Items used a 5-point Likert scale reflecting the frequency or intensity of symptoms. We selected parent anxiety as a candidate moderator based on theory and empirical findings linking elevated anxiety to greater FH [8-10]. We examined parent anxiety at time 1 as both a continuous variable, to capture the full range of symptom severity, and as a categorical variable based on normative guidelines to identify parents with or without clinically elevated anxiety (PROMIS-A T-scores ≥60) [16].

Statistical Analysis

Our primary model was an analysis of covariance examining time 3 parent FH. The model included treatment arm, time 1 anxiety (elevated versus not elevated), and the treatment arm by anxiety interaction as fixed factors and time 1 parent FH as a covariate. We also conducted a sensitivity analysis that modeled parent PROMIS-A T-scores as a continuous, centered variable, and retested the treatment arm by anxiety interaction. Finally, we explored responder rates by time 1 anxiety (elevated versus not elevated) by treatment arm. Among parents with elevated anxiety, we used logistic regression to explore whether responder rates differed by treatment arm after adjusting for time 1 parent FH. We conducted all analyses using SPSS (version 27; IBM Corp).

Results

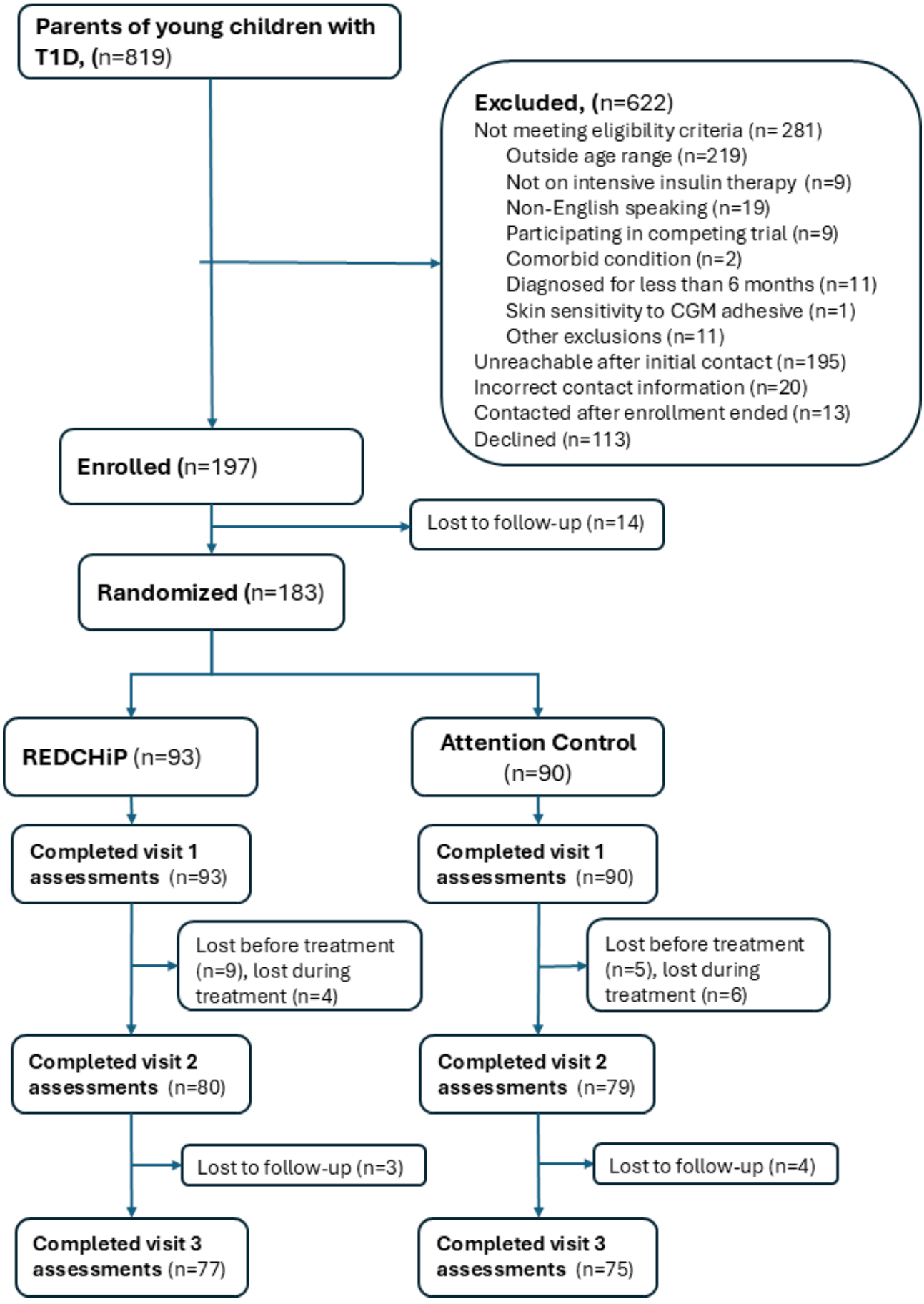
Of the 183 families randomized, 152 (83%) completed time 3, including 77 and 75 families randomized to REDCHiP and ATTN, respectively (Figure 1). Thirty-one families were lost to follow-up during the primary trial. There were no significant differences in time 1 demographics, child clinical characteristics, or parent-reported FH and general anxiety among those who completed the trial versus those who withdrew (Multimedia Appendix 1).

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Figure 1. CONSORT (Consolidated Standards of Reporting Trials) flowchart. REDCHiP: Reducing Emotional Distress for Childhood Hypoglycemia in Parents; T1D: type 1 diabetes.

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Figure 1. CONSORT Flow Chart



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Table 1 summarizes family demographics at time 1. There were no significant time 1 differences in family demographics or child T1D characteristics based on treatment arm. Likewise, there were no significant differences in time 1 parent FH or time 1 parent general anxiety. There was a significant group difference in time 3 parent FH. Specifically, parents randomized to REDCHiP reported lower time 3 FH than parents randomized to ATTN. At time 1, parents with elevated anxiety reported significantly higher FH (mean 64.1, SD 11.6) than parents without elevated anxiety (mean 53.3, SD 13.6; $P<.001$).

Table . Sample characteristics and outcome measures by treatment arm[a].

	Overall (n=183)	REDCHiP[b] (n=93)	ATTN[c] (n=90)	*P* value
Demographics				
Child age at time 1 (y), mean (SD)	4.4 (1.2)	4.5 (1.2)	4.3 (1.2)	.12
Child sex, male, n (%)	100 (54.6)	51 (54.8)	49 (54.4)	.54
Parent age at time 1 (y), mean (SD)[d]	36.3 (5.9)	36.7 (5.3)	35.9 (6.6)	.26
Clinical characteristics				
Time since diagnosis at time 1 (y), mean (SD)[e]	1.7 (1.1)	1.5 (1.0)	1.8 (1.3)	.11
Continuous glucose monitoring use, n (%)	151 (82.5)	78 (83.9)	73 (81.1)	.36
Automated insulin delivery use, n (%)	93 (50.8)	45 (48.4)	48 (53.3)	.25
HFS-PYC[f] total score at time 1, mean (SD)	56.4 (14.0)	55.4 (13.6)	57.4 (14.4)	.32
HFS-PYC total score at time 3, mean (SD)[g]	49.2 (11.0)	46.9 (9.5)	51.3 (12.1)	.009
Parent PROMIS-A[h] total score at time 1, mean (SD)	54.6 (9.8)	54.8 (10.0)	54.4 (9.5)	.77
Parents with clinically elevated anxiety at time 1, n (%)	54 (29.5)	31 (33.3)	23 (25.6)	.17

[a]Full description of time 1 sample characteristics is reported elsewhere [12]; the variables reported here are relevant to the current secondary analyses.

[b]REDCHiP: Reducing Emotional Distress for Childhood Hypoglycemia in Parents.

[c]ATTN: attention control condition.

[d]Data were available for 177 participants overall (REDCHiP: n=90; ATTN: n=87).

[e]Data were available for 182 participants overall (REDCHiP: n=93; ATTN: n=89).

[f]HFS-PYC: Hypoglycemia Fear Survey–Parents of Young Children.

[g]Data were available for 152 participants overall (REDCHiP: n=77; ATTN: n=75).

[h]PROMIS-A: Patient-Reported Outcomes Measurement Information System Anxiety Short Form.

In our primary model, the treatment arm by anxiety interaction was not statistically significant ($F_{1,146}=2.40$; $P=.12$; partial $\eta^2=0.016$; Table 2). The main effect of REDCHiP was significant ($F_{1,146}=6.58$; $P=.01$; partial $\eta^2=0.043$), suggesting lower adjusted time 3 HFS-PYC scores among parents in the REDCHiP arm. Additionally, adjusted means showed larger absolute differences between REDCHiP and ATTN parents with clinically elevated anxiety (45.8, SD 1.75 vs 52.6, SD 2.12 for REDCHiP and ATTN, respectively) versus parents without elevated anxiety (48.6, SD 1.33 vs 50.3, SD 1.19 for REDCHiP and ATTN, respectively), though these subgroup patterns should be interpreted cautiously in light of the nonsignificant moderation effects.

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Table . Analysis of covariance models examining time 1 anxiety and time 3 parent fear of hypoglycemia[a].

Predictor	*F* test (*df*)	*P* value	Partial η^2
Anxiety measured categorically			
Treatment arm	6.58 (1, 146)	.01	0.043
Elevated anxiety	0.013 (1, 146)	.91	0.001
Treatment arm×elevated anxiety	2.40 (1, 146)	.12	0.016
Time 1 HFS-PYC[b]	58.29 (1, 146)	<.001	0.285
Anxiety measured continuously			
Treatment arm	4.72 (1, 146)	.03	0.031
PROMIS-A[c] (centered)	0.004 (1, 146)	.95	0.001
Treatment arm×PROMIS-A	1.48 (1, 146)	.22	0.010
Time 1 HFS-PYC	51.70 (1, 146)	<.001	0.261

[a]Both models included time 1 HFS-PYC as a covariate and 151 participants with complete data.

[b]HFS-PYC: Hypoglycemia Fear Survey–Parents of Young Children.

[c]PROMIS-A: Patient-Reported Outcomes Measurement Information System Anxiety Short Form.

In a follow-up model with time 1 parent anxiety measured as a continuous variable, the treatment arm by anxiety interaction was also not significant ($F_{1,146}$=1.48; *P*=.22; partial η^2=0.010). However, the main effect of REDCHiP remained significant ($F_{1,146}$=4.72; *P*=.03; partial η^2=0.031; Table 2).

Within the REDCHiP arm, 78.6% (22/28) of parents with clinically elevated time 1 anxiety met our responder criterion for reduced time 3 parent FH. In comparison, 47.4% (9/19) of parents with elevated time 1 anxiety in the ATTN arm met our responder criterion (Table 3). In an exploratory logistic regression among parents with clinically elevated time 1 anxiety and adjusting for time 1 FH, REDCHiP parents had greater odds of meeting responder criteria than ATTN parents (odds ratio [OR] 6.35, 95% CI 1.47-29.00; *P*=.01). For context, responders in both treatment groups reported higher time 1 FH than nonresponders (*P*<.001), suggesting that greater time 1 FH may have provided more opportunity for improvement. Among REDCHiP parents, responders also reported higher time 1 anxiety than nonresponders (*P*=.004).

Table . Fear of hypoglycemia responder rates at time 3 by treatment arm and time 1 parent anxiety.

Time 1 anxiety	REDCHiP[a] parents		ATTN[b] parents	
	Responders, n (%)	Nonresponders, n (%)[c]	Responders, n (%)	Nonresponders, n (%)
Elevated	22 (78.6)	6 (21.4)	9 (47.4)	10 (52.6)
Not elevated	17 (34.7)	32 (65.3)	28 (50)	28 (50)

[a]REDCHiP: Reducing Emotional Distress for Childhood Hypoglycemia in Parents.

[b]ATTN: attention control condition.

[c] Percentages are calculated within each treatment arm and anxiety subgroup. Subgroup sample sizes were n=28 (REDCHiP) and n=19 (ATTN) for elevated anxiety, and n=49 (REDCHiP) and n=56 (ATTN) for nonelevated anxiety.

Discussion

In this secondary analysis of REDCHiP, we found that parents' time 1 anxiety did not significantly moderate treatment response when modeled as either a categorical (*P*=.12) or continuous (*P*=.22) variable. However, exploratory results revealed a potentially meaningful pattern among parents with clinically elevated anxiety. Specifically, we found that adjusted time 3 FH scores were numerically lower in REDCHiP than in ATTN, and 78.6% (22/28) of REDCHiP parents with elevated anxiety met the responder criterion compared with 47.4% (9/19) of ATTN parents with elevated anxiety. Moreover, results of an exploratory logistic regression restricted to parents with elevated anxiety and adjusting for time 1 FH suggested that REDCHiP parents had 6-fold greater odds of meeting the responder criterion than ATTN parents.

We designed REDCHiP to address parents' challenges with worry, hypervigilance, and avoidance related to childhood hypoglycemia [3,11]. While the current analyses did not support a significant moderating role for parent anxiety, the adjusted mean and responder findings suggest that it still may be worth considering parents' time 1 anxiety symptoms when examining response to cognitive behavioral interventions for FH. One possible reason is that, although REDCHiP specifically targets FH, the cognitive and behavioral skills it teaches may generalize to broader, nondiabetes-specific worries and anxiety. As a result, it is possible that parents with elevated anxiety may derive benefits from REDCHiP that extend beyond FH. However, this

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interpretation remains speculative. We will need larger trials with adequate power to evaluate moderator effects to determine whether these observations reflect meaningful differences in treatment response.

The results also complement the primary trial outcomes, which showed that parents across both treatment arms experienced overall reductions in FH [12]. Whereas the primary trial focused on whether REDCHiP reduced FH, these secondary analyses examined variability in treatment response and provided additional context for interpreting response patterns among trial participants.

Strengths of this study include the use of validated questionnaires and sensitivity analyses examining anxiety as both a categorical and continuous variable. As a limitation, we acknowledge that any reported subgroup differences among parents with clinically elevated time 1 anxiety should be regarded as exploratory because neither treatment arm by anxiety interaction was statistically significant. We acknowledge a risk of bias because we used complete cases rather than an intention-to-treat approach. However, post hoc comparisons of trial completers versus noncompleters on time 1 demographic and clinical characteristics yielded no significant differences. Our responder analyses were also post hoc, exploratory, and for the logistic regression, were restricted to a small subgroup of our sample; they should be interpreted cautiously and considered hypothesis generating. Relatedly, we acknowledge that for both treatment arms, responders reported higher time 1 FH than nonresponders, suggesting that time 1 FH severity and greater opportunity for improvement may have contributed to responder classification and should be considered when interpreting the clinical significance of these findings. Although our sample reflects the demographic characteristics of families typically seen in pediatric T1D care centers in the United States [17], the findings may not generalize to families from other clinical settings. Replication in future samples powered specifically for moderation and recruiting families from more diverse clinical samples will be important.

In conclusion, time 1 parent anxiety did not significantly moderate treatment response. However, in exploratory analyses, we found that REDCHiP parents with clinically elevated anxiety demonstrated lower adjusted FH scores and higher responder rates than comparable ATTN parents. While these exploratory results should be interpreted cautiously, they point to a clinically interesting pattern that warrants investigation in future studies. Additionally, as digital and telehealth-delivered behavioral health interventions continue to expand within pediatric diabetes care, this study highlights a need for further research examining the patient or family member characteristics associated with treatment response and how to use this information to match families to interventions that may improve reach, efficiency, and impact.

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Generative AI Use

The authors used Microsoft 365 Copilot to assist with proofreading and editing the manuscript and the response to reviewer comments. The authors reviewed all suggested revisions and take full responsibility for the final content.

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Data Availability

Data supporting the findings of the larger trial are not publicly available due to participant privacy and institutional restrictions. Deidentified data may be made available upon reasonable request to the corresponding author, contingent on appropriate data use agreements and ethical approvals.

Authors' Contributions

SRP wrote the first draft and reviewed and edited the manuscript. AM, NK, JR, and KD contributed to the discussion and reviewed and edited the manuscript.

Conflicts of Interest

SRP reports receiving grants from the National Institutes of Health, receiving an honorarium from the American Diabetes Association, and serving on a clinical advisory board for Glooko, Inc. AM, NK, JR, and KD report no conflicts of interest.

Multimedia Appendix 1
Sample characteristics based on trial completers versus non-completers.
[DOCX File, 15 KB - pediatrics_v9i1e95475_app1.docx]

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Abbreviations

ATTN: attention control condition
FH: fear of hypoglycemia
HFS-PYC: Hypoglycemia Fear Survey–Parents of Young Children
IRB: institutional review board
OR: odds ratio
PROMIS-A: Patient-Reported Outcomes Measurement Information System Anxiety Short Form
REDCHiP: Reducing Emotional Distress for Childhood Hypoglycemia in Parents
T1D: type 1 diabetes

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Family Experiences of the Strong Families Program in Thailand: Prospective Mixed Methods Cohort Study

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Abstract

Background: The Strong Families (SF) Program, developed by the United Nations Office on Drugs and Crime, is an evidence-informed family skills intervention designed to support caregivers and children in low-resourced, high-stress circumstances. Following a pilot phase, we revised the program materials according to the expert trainers' suggestions to best reflect the needs of the target population.

Objective: This study aimed to evaluate the feasibility, effectiveness, and cultural adaptability of the second phase of the SF Program expansion in northern Thailand.

Methods: This prospective mixed methods pretest-posttest feasibility cohort study involved 68 families (caregivers and children as 1:1) from Chiang Mai, Lamphun, and Chiang Rai—3 provinces in northern Thailand. The applied intervention consisted of a 3-week program with both separate and joint sessions for caregivers and children. Quantitative data were collected using the Parent and Family Adjustment Scales, Strengths and Difficulties Questionnaire, and Child and Youth Resilience Measure–Revised–Person Most Knowledgeable About the Child. Data were analyzed using linear mixed-effects regression. Qualitative data were gathered through semistructured interviews with 19 families and analyzed using content analysis to identify key themes.

Results: Quantitative analysis using linear mixed-effects regression revealed significant improvements in coercive parenting (β=−0.10; *P*=.003), child conduct problems (β=−0.04; *P*=.002), and peer relationship problems (β=−0.04; *P*=.048) for parents and in emotional (β=–0.05; *P*=.01) and conduct (β=−0.04; *P*=.02) behavior for children. However, scores for positive encouragement (β=0.05; *P*=.009) and parent-child relationship (β=0.28; *P*<.001) significantly declined, a discrepancy that may be due to response shift bias, in which participants adopt stricter self-evaluation standards after the intervention. Qualitative findings showed 5 themes that highlighted improved family atmosphere, better emotional regulation, and successful translation of knowledge into practice to better develop protective factors for young people. Participants viewed the program as feasible and culturally appropriate but recommended extending the duration and increasing paternal involvement for more significant, sustainable outcomes.

Conclusions: The SF Program is a culturally adaptable and effective intervention for improving family dynamics in low-resource settings.

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KEYWORDS

parenting skills; positive parenting; family health; program evaluation; mixed methods

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Introduction

Families worldwide face a range of adversities that undermine their capacity to provide safe and nurturing environments for children. These challenges include unemployment, schooling barriers, and limited access to goods and services in rural and underserved areas [1], as well as migration, displacement, residence in refugee camps, and exposure to conflict or postconflict situations [2]. Such circumstances place significant strain on caregivers and compromise their ability to engage in responsive, supportive parenting. Children's earliest and most formative interactions occur within the family, well before they reach school age, and those whose caregivers lack nurturing abilities, parenting skills, or the capacity to manage stressors such as poor health or financial hardship are at heightened risk of maladjustment across cognitive, emotional, and behavioral domains [3,4]. Strengthening family skills and competencies is therefore essential not only to support caregivers but also to foster the safe, stable, and nurturing relationships that promote children's healthy development and the well-being of both caregivers and children [5].

The United Nations Office on Drugs and Crime (UNODC) has implemented evidence-based family skills prevention programs in low- and middle-income countries worldwide since 2010 [6]. In 2017, the Strong Families (SF) Program was developed [7]. The program is designed for families in underserved settings, offering an evidence-informed prevention response that builds family skills to benefit the health and safe development of children. This program can be easily adapted to serve families in different contexts facing adverse circumstances. SF helps caregivers and children manage daily stressors and difficulties, aiming to strengthen family structures and functions to prevent drug use, violence, and other negative social consequences in their children. It is a universal program within this selective subgroup of families and is best suited for families with children aged between 8 and 15 years [7].

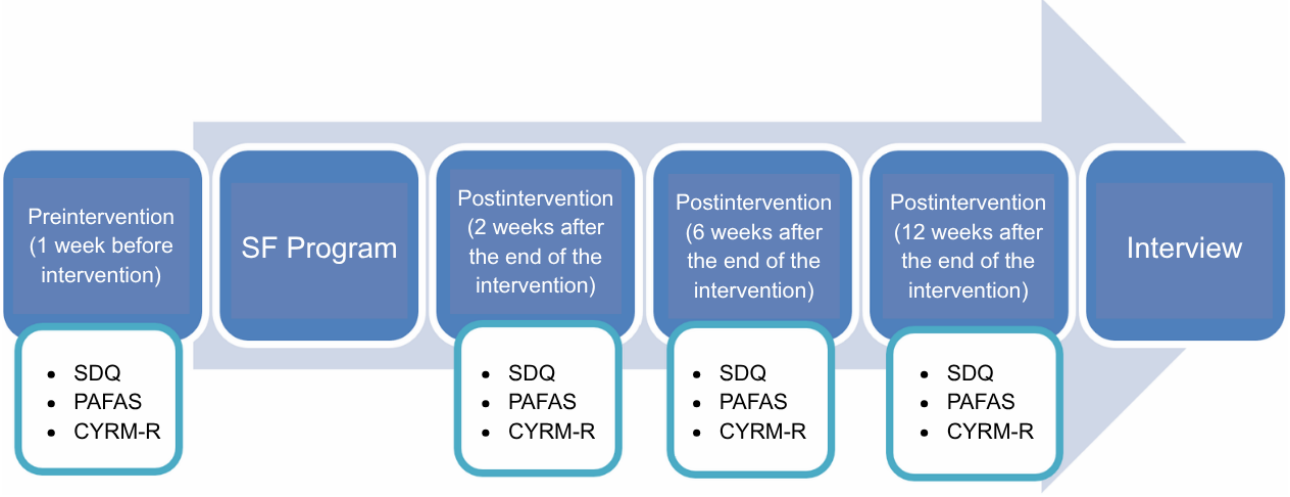
More than 30 countries have implemented the SF Program and found it effective in improving family relationships and parenting skills. SF was initially created and tested in Afghanistan and has since been implemented in Central America, Central and West Asia, and East and West Africa. An early 2024 pilot study of SF in Thailand was evaluated and refined based on the results of a previous project [8]. SF was found to be feasible to implement in Thailand during this first phase. The program strengthened family relationships and improved mutual understanding among family members. However, several challenges were identified, including language barriers, cultural mismatches in the materials, and difficulty handling challenging situations arising during program facilitation. In phase 2 (late 2024), several materials were adapted for the target population. Revisions included using simpler Thai words, Asian faces, and pictures that were easy to understand in the Thai cultural context. Training sessions for trainers, including skills to offer brief interventions, advice, and strategies for handling difficult situations during program implementation, were incorporated into program preparation. Therefore, the objective of this study was to evaluate the program's feasibility, effectiveness, and adaptability for further expansion in the country.

Methods

Study Design

This study used a mixed methods, pretest-posttest feasibility design with a prospective cohort of participants enrolled in the SF Program. Phase 2 ran a follow-up data collection at 4 time points (before the intervention and at 2, 6, and 12 weeks after the end of the intervention). The pretest was completed prior to the first week, and the posttest was completed within 12 weeks of the final programming date for estimating the long-term outcomes. Additional qualitative interviews were conducted between August 2025 and September 2025, approximately 12 weeks following the last session. Figure 1 illustrates the study timeline.

Figure 1. Study timeline. CYRM-R: Child and Youth Resilience Measure–Revised; PAFAS: Parent and Family Adjustment Scales; SDQ: Strengths and Difficulties Questionnaire; SF: Strong Families.



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The SF Program

This program was conducted between June 2025 and July 2025 in the Chiang Mai, Chiang Rai, and Lamphun provinces in northern Thailand, encompassing 8 study locations in total. Training for the Trainers of the SF Program was a 3-day workshop for trainers who would conduct SF in their local geographic areas. The workshop was led by master trainers certified by UNODC. The SF Program consisted of 3 sessions held on 3 consecutive weekends engaging caregivers and children. The first session was exclusively for caregivers, whereas children participated in parallel and joint activities in the second and third sessions, respectively. The topics for caregivers were (1) understanding strengths and stressors, (2) using love and limits, and (3) teaching children what is right. The topics for children were (1) learning about stress and (2) following rules and appreciating parents. The topics for joint sessions were (1) learning about each other and (2) supporting values and dreams. To ensure implementation fidelity, UNODC-certified master trainers attended and provided feedback for the Thai trainers at community sites during the first session of the SF Program.

Participants

The target population for this study consisted of the families (specifically, the caregivers and their children) who participated in the SF Program phase 2. We used a convenience sampling strategy recruiting 68 volunteer families (caregiver-child dyads) from 8 study locations across the 3 provinces. Families with children aged 8 to 15 years were included, aligning with the program's target demographic.

Sample Size Calculation

Quantitative Study

Using data from the first SF Program in Afghanistan [7], the total difficulty scale before and after completing the program was reported as 17.77 (SD 5.67) scores and 10.62 (SD 4.98) scores, respectively. The sample size calculation was based on a 1-group repeated-measure ANOVA [9,10] using the *wp.rmanova* package in R (R Foundation for Statistical Computing), a moderate effect size (f=0.25), a correlation of 0.5, power of 80%, and an α of .05. The required sample size was at least 45 participants to detect the effectiveness of the SF Program.

Qualitative Study

This project in Thailand included a sample size of 19 families (caregiver-child dyads), approximately 2 to 3 families per site across 8 locations in the 3 provinces. Volunteer families from each site were included. In the previous project with SF Program trainers, data saturation was achieved with interview data from 10 participants [8].

Ethical Considerations

This study was conducted following review and approval from the Institutional Ethics Committee of the Faculty of Medicine, Chiang Mai University, Chiang Mai, Thailand (ethics approval number 143/2025). All participants provided written informed consent prior to study commencement in accordance with the 1964 Declaration of Helsinki.

Data Measurement and Collection

Quantitative Study

Quantitative data were collected using the following validated instruments. The Parent and Family Adjustment Scales (PAFAS; 30 items) assessed caregivers' perceptions of their parenting practices, family functioning, and personal adjustment. The Strengths and Difficulties Questionnaire (SDQ; 25 items) assessed caregivers' perceptions of their children's emotional symptoms, conduct problems, hyperactivity, peer problems, and prosocial behavior. The Child and Youth Resilience Measure–Revised–Person Most Knowledgeable About the Child (CYRM-R-PMK; 17 items) assessed both caregivers' perceptions of their children's resilience and coping and children's self-reported resilience.

Qualitative Study

Qualitative data were gathered prospectively after the intervention through semistructured interviews guided by the reach, effectiveness, adoption, implementation, and maintenance framework [11,12]. Interviews with volunteer families were conducted individually, one family at a time. All participants were informed of the research study and provided consent with permission for audio recording. Each interview lasted approximately 40 minutes and was conducted on the same site as the workshops by research assistants who were not involved in the SF Program, supervised by NB and WJ.

Data Analysis

Quantitative Study

Descriptive statistics were used to summarize participant characteristics. The scoring key for the PAFAS indicates that higher scores reflect lower levels of parenting skills and family adjustment [13]. For the SDQ, higher scores indicate greater problems in emotional regulation, conduct, restlessness, and peer relationships; however, higher scores in the social relationships domain (prosocial behavior subscale) indicate greater strengths [14]. For the CYRM-R-PMK, higher scores reflect higher levels of child and youth resilience [15]. To examine the change in family functions in each domain of the CYRM-R-PMK, PAFAS, and SDQ over time (a week), a linear mixed-effects regression model was applied. The scores were treated as a continuous dependent variable. Time (week) was analyzed as a fixed effect. Child age, child sex, parent age, and parent sex were adjusted as potential confounders [16,17]. To account for within-subject correlation due to repeated measurements, a random intercept was specified for each participant. Model parameters were estimated using restricted maximum likelihood. Regression coefficients with corresponding 95% CIs were reported. All analyses were performed using Stata (version 17; StataCorp), and statistical significance was set at P<.05.

Qualitative Study

The qualitative interview data were analyzed using content analysis to evaluate the overall program. The datasets were uploaded into NVivo (version 12; Lumivero). Each transcript was read multiple times to aid familiarization and check the accuracy of each transcript. Two independent researchers (NB

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and WJ) led the analysis. Then, preliminary results were discussed with all authors. The inductive coding was developed from patterns in the text data and adapted iteratively during analysis. The identified codes were compared, and the similarities and differences were discussed until a consensus on the emergent themes and subthemes was reached.

Results

Overview

A total of 68 families attended the SF Program across the Chiang Mai, Lamphun, and Chiang Rai provinces in 2025. Most caregivers (59/68, 86.8%) were female, with a mean age of 47.4 (SD 13.8) years. In total, 51.5% (35/68) of the children were male, and their mean age was 10.8 (SD 1.6) years.

Table 1 shows the scoring and changes in all assessment tools. Regarding the PAFAS, the results showed a significant improvement in coercive parenting (β=–0.10; *P*=.003) as the decrease in scores reflected a reduction in maladaptive behaviors. However, the analysis indicates a significant increase in scores for positive encouragement (β=0.05; *P*=.009) and parent-child relationship (β=0.28; *P*<.001); based on the inverted scoring key, these suggest a decline in positive parenting skills and relationship quality during the study period. In terms of child difficulties (evaluated using the SDQ), parents reported significant improvements, evidenced by decreases in conduct problems (β=−0.04; *P*=.002) and peer relationship problems (β=−0.04; *P*=.048). However, social relationships (a strength-based domain) showed a decrease in scores (β=−0.05), suggesting a reduction in strengths, although this was not statistically significant (*P*=.09). Similarly, children self-reported significant improvements in emotional (β=−0.05; *P*=.01) and conduct (β=−0.04; *P*=.02) behaviors. No substantial changes were observed in child resilience (CYRM-R-PMK) from either the parent or child perspectives.

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Table . Scoring and changes in all assessment tools.

Measurements	Pretraining time point, mean (SD)	2 weeks after training, mean (SD)	6 weeks after training, mean (SD)	12 weeks after training, mean (SD)	β coefficient (95% CI)[a]	*P* value
Parents						
PAFAS[b]						
Parenting skills						
Parental consistency (0-15)	6.16 (1.96)	6.12 (2.31)	5.68 (2.76)	6.00 (2.39)	−0.02 (–0.07 to 0.03)	.48
Coercive parenting (0-15)	5.88 (3.13)	5.12 (2.83)	4.87 (2.99)	4.53 (2.83)	−0.10 (–0.16 to 0.03)	.003
Positive encouragement (0-9)	2.12 (1.93)	2.23 (2.04)	2.07 (1.74)	2.79 (1.38)	0.05 (0.01 to 0.09)	.009
Parent-child relationship (0-15)	1.74 (1.97)	2.43 (2.70)	1.79 (2.40)	5.37 (1.79)	0.28 (0.23 to 0.33)	<.001
Family adjustment						
Parental adjustment (0-15)	6.03 (2.09)	5.71 (2.38)	5.25 (2.48)	6.46 (2.24)	0.04 (–0.02 to 0.09)	.16
Family relationships (0-12)	2.76 (2.10)	2.40 (1.93)	2.21 (1.98)	3.31 (1.48)	0.05 (0.01 to 0.09)	.02
Parental teamwork (0-9)	2.37 (2.10)	2.37 (2.10)	1.50 (1.77)	2.16 (1.91)	−0.03 (–0.06 to 0.01)	.14
SDQ[c]						
Emotional behavior (0-10)	2.99 (1.87)	2.51 (1.80)	3.22 (2.14)	2.28 (2.03)	−0.04 (–0.08 to 0.01)	.09
Conduct behavior (0-10)	1.81 (1.43)	1.47 (1.37)	1.53 (1.59)	1.21 (1.30)	−0.04 (–0.07 to –0.01)	.002
Restless behavior (0-10)	3.53 (2.28)	3.04 (2.25)	3.06 (2.27)	2.93 (2.27)	−0.04 (–0.08 to 0.01)	.07
Peer relationship (0-10)	3.03 (1.41)	2.62 (1.60)	2.71 (1.81)	2.47 (1.38)	−0.04 (–0.07 to –0.01)	.048
Social relationship (0-10)	7.56 (1.83)	6.62 (2.38)	6.26 (2.79)	6.79 (2.32)	−0.05 (–0.10 to 0.01)	.09
CYRM-R-PMK[d]						
Child and youth resilience (17-85)	73.71 (7.11)	67.43 (18.40)	64.62 (23.12)	69.01 (16.70)	−0.06 (–0.19 to 0.07)	.37
Children						
SDQ						
Emotional behavior (0-10)	3.96 (2.17)	3.54 (1.86)	3.22 (2.14)	3.28 (2.10)	−0.05 (–0.09 to –0.01)	.01
Conduct behavior (0-10)	2.53 (1.71)	2.49 (1.63)	2.22 (1.66)	2.12 (1.49)	−0.04 (–0.07 to 0.01)	.02
Restless behavior (0-10)	3.93 (1.96)	3.96 (2.23)	3.15 (2.23)	3.66 (2.53)	−0.03 (–0.07 to 0.01)	.11
Peer relationship (0-10)	3.40 (1.71)	2.96 (1.62)	3.03 (1.77)	3.07 (1.68)	−0.02 (–0.05 to 0.02)	.33
Social relationship (0-10)	7.00 (1.65)	6.16 (1.80)	6.46 (2.03)	6.66 (2.01)	−0.01 (–0.05 to 0.04)	.82
CYRM-R-PMK						

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Measurements	Pretraining time point, mean (SD)	2 weeks after training, mean (SD)	6 weeks after training, mean (SD)	12 weeks after training, mean (SD)	β coefficient (95% CI)[a]	*P* value
Child and youth resilience (17-85)	68.29 (7.12)	64.69 (11.66)	63.85 (16.26)	66.38 (11.41)	0.01 (–0.13 to 0.15)	.92

[a]Score change per week from the pretraining time point to 12 weeks after training.

[b]PAFAS: Parent and Family Adjustment Scales.

[c]SDQ: Strengths and Difficulties Questionnaire.

[d]CYRM-R-PMK: Child and Youth Resilience Measure–Revised–Person Most Knowledgeable About the Child.

The qualitative study included a total of 19 families, or caregiver-child dyads. The participating caregivers were predominantly female (17/19, 89.5%), comprising 82.4% (14/17) mothers, 11.8% (2/17) grandmothers, and 5.9% (1/17) aunts, whereas the 10.5% (2/19) male participants included 1 father and 1 foundation staff member (caregiver for a child in the foundation). The ages of these caregivers ranged from 28 to 59 years, representing early working age to middle adulthood. Regarding the children, 52.6% (10/19) were female, and 47.4% (9/19) were male, with ages ranging from 7 to 14 years. This age group corresponded primarily to the late primary and early secondary school levels, critical developmental stages (early adolescence and middle childhood) for behavior and responsibility. From the qualitative analysis, 5 themes emerged (Textbox 1).

Textbox 1. Themes of qualitative results.

- Theme 1: motivation of program engagement
- Theme 2: perceptions of learning utility
- Theme 3: goodness manifesting across household members
- Theme 4: key facilitators of success
- Theme 5: recommendations for optimization

Theme 1: Motivation of Program Engagement

The main motivation for enrolling in the program was the desire to improve parenting skills. Caregivers indicated that they wanted to learn the correct ways to teach and manage their children's behavior and understand their children better. Some caregivers also sought to resolve relationship issues at home, motivated by a desire to reduce family stress or strengthen the bond between mother and children. Other motivations for caregivers and children to participate in the program were varied, including persuasion from community and school leaders; most participants were referred by village heads, schoolteachers, or religious leaders (churches and temples). Finally, some children expressed interest in enrolling so that they could participate in the children's activities, either as a way for the latter to enjoy time with their parents or as a response to an invitation from friends:

> *I want to know what "Strong Family" means in terms of strength. I want to know how to raise children properly.* [Caregiver; family 7]
>
> *I think if we go, we will know how we can talk to children, or how can we be patient with them?* [Caregiver; family 6]
>
> *I want to improve my communication skills with my children to reduce the gap.* [Caregiver; family 1]
>
> *Mr. Boom from Tambon Administrative Organization invited me to join, so I applied.* [Caregiver; family 16]
>
> *My mom invited me to come and learn together.* [Child; family 14]

Theme 2: Perceptions of Learning Utility

Family members reported acquiring new skills and practices, including stress management techniques such as breathing exercises and somatic coping techniques (ie, tapping various points on the body) to help control anger and reduce stress. Caregivers also reported learning positive communication skills, including encouragement to use reason instead of emotions, speaking in a softer tone of voice, and actively listening to children's needs. Caregivers shared that they learned about their children's stress levels through activities such as the "stress ladder" or "thermometer," gaining insights into children's perspectives that adults might not have previously known. They also reported learning how to show affection and establish discipline appropriately without using violence, including techniques for hugging, praising, and setting rules in the home:

> *Knowing how to manage our own emotions. Knowing how to persuade children to be interested in our instructions.* [Caregiver; family 11]
>
> *I didn't listen to my child's reasoning very much. After attending the training, I was able to review and listen to my child's reasons more.* [Caregiver; family 6]
>
> *I learned about the activities. I'm guessing what level of expectation they [children] have, so they can use it to adjust.* [Caregiver; family 7]

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I learn to express my stress. Then, rethink the situation or do something that helps relieve my stress. [Child; family 10]

Many things, for example, calming the mind and improving mood, such as the arm raise and lower pose, which makes the mind feel better. [Child; family 14]

Theme 3: Goodness Manifesting Across Household Members

Caregivers shared insights that they became more mindful and patient and reduced scolding, yelling, and use of violence (hitting children). Instead, they started reasoning more. Children became more responsible, enacting behaviors such as helping with household chores (washing dishes, doing laundry, and ironing), studying diligently, and doing homework independently without being told. Additionally, some children showed a decrease in aggressive behavior, such as stopping or reducing bullying at school. At the family level, it was found that the atmosphere at home improved; members became closer, talked more openly, and showed more affection toward each other such as hugging or kissing cheeks. Positive changes extended to other family members even though the spouses or other parents did not attend the training. When the parent who attended the program changed their behavior, the nonattending parent was found to drink less alcohol or act less violently and be more helpful with household chores. The younger siblings who did not attend the program often followed the positive behavior of the older sibling who did participate:

My child is easier to talk to, more confident making eye contact, and more willing to share problems. Because we don't yell or scold like before, but talk things out with reason. [Caregiver; family 16]

My child barely hugged me. But now, before he leaves, he comes to hug and kiss me. [Caregiver; family 6]

I have tried to think that our child is just like us. So, my anger has subsided. [Caregiver; family 11]

I took what I learned from the activity and told my husband. He started speaking better, so our arguments decreased. [Caregiver; family 3]

I study much harder now than I used to. I've become much more responsible.... Dad drinks less alcohol, and my younger sibling helps out more. [Child; family 14]

I do not tease on my friend anymore. [Child; family 3]

Theme 4: Key Facilitators of Success

Caregivers commented that the SF Program was a creative and fun activity and a family learning activity through shared experiences. Hearing problems from other families helped parents see their own strengths and weaknesses, not feel alone in solving problems, and know that they had clear and effective tools to improve the functioning of their family:

It helps parents learn the right way to teach their children, not just by forcing them, but by teaching them to learn through hands-on experience. [Caregiver; family 18]

If the family is strong-minded, bad external influences cannot affect our family. [Caregiver; family 11]

There was a fun game activity with my mom. [Child; family 16]

Theme 5: Recommendations for Optimization

To improve the experience of being enrolled in the SF Program and the family outcomes, caregivers stated that they would like to see activities organized regularly or continuously (eg, once a year) to prevent knowledge from fading. Participating caregivers suggested that the target group should be expanded to include more family members, such as other relatives, guardians, or siblings. Regarding the venue and time, participants shared that the activities were too short and some lacked depth. Some families suggested holding the SF Program sessions on Saturdays (as opposed to Sundays) to avoid religious obligations, and they also wanted a larger venue. They would like to see more content and training on etiquette for children, the language in the curriculum simplified, and families with specific problems selected as the target group to achieve the most noticeable changes:

I wish there were training for husbands or fathers too.... If the family training program could be done together, it would be even better. [Caregiver; family 14]

I want the program to get along with the older children who have to take care of their younger siblings.... We can help each other a lot. [Caregiver; family 5]

I want to do more activities with my mom. [Child; family 10]

Discussion

Principal Findings

This study represents the evaluation of the UNODC SF Program in Thailand. Findings suggest that while the program was highly acceptable and qualitatively perceived as beneficial, the quantitative outcomes present a complex picture of family dynamics during the transition phase of behavior change. The pattern of findings observed in this study is consistent with family systems and developmental prevention theories, which emphasize the reciprocal and dynamic nature of caregiver-child interactions. Improvements in coercive parenting alongside reductions in child conduct problems suggest that even brief changes in caregiver behavior can rapidly influence child outcomes through feedback processes within the family unit. Family skills interventions that focus on caregiver stress regulation, emotional awareness, and nonviolent discipline have been shown to interrupt maladaptive interaction cycles and promote healthier relational patterns, particularly in contexts of chronic socioeconomic stress. In this way, the SF Program operates by modifying discrete behaviors and also by strengthening relational processes that support child development and family resilience within broader ecological systems [4,18,19]. Regarding parenting and family adjustment

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(PAFAS), the results showed a significant improvement in coercive parenting. However, a decline in positive parenting skills and relationship quality during the study period was observed. In terms of child difficulties (SDQ), parents reported significant improvements. However, social relationships showed a non–statistically significant reduction in strength. Similarly, children self-reported significant improvements in emotional and conduct behaviors. No significant changes were observed in child resilience (CYRM-R-PMK) from either the parent or child perspective.

These findings are consistent with the program's logic model, which emphasizes stress management and nonviolent discipline. The qualitative data strongly corroborate this as caregivers reported becoming more mindful, reducing yelling, and using reasoning instead of violence in interactions with their children. Similarly, children self-reported significant improvements in emotional and conduct behaviors, suggesting that even a short 3-week intervention can interrupt the cycle of negative interaction within the family. Additionally, our study on the early implementation of the SF Program in Thailand, which assessed feedback from the trainers of SF, also illustrated this consistent outcome of improving family function [8]. Previous literature illustrates that positive parent-child relationships, especially early and middle childhood, are associated with a favorable impact on children's behavior, avoid early-onset conduct issues, and act as a buffer against negative childhood experiences, which reduces toxic stress and improves health [20,21].

The Divergence Between Quantitative and Qualitative Findings on Relationships

An intriguing finding in our study was the discordance between the quantitative scores for parent-child relationship and positive encouragement and the qualitative narratives. While the quantitative analysis indicated a significant increase in scores, interpreted as a decline in skills based on the instrument's inverted scoring, the qualitative themes painted a contrasting picture. In the interviews, families reported improved atmospheres, increased affection (eg, hugging), and better communication. The discordance may be attributed to response shift bias [22]. Participants likely recalibrated their internal standards of positive parenting after the intervention, leading to stricter self-evaluation at the posttest compared to the pretest time point. This may also be viewed through the stages of competence development [23]. Participants moving from unconscious incompetence to conscious incompetence tend to judge their past and current behaviors more critically, resulting in lower postintervention scores despite actual skill acquisition [23]. The significant reduction in child conduct problems (SDQ) contrasted with the nonsignificant changes in resilience scores (CYRM-R-PMK). This suggests a distinction between acute behavioral symptoms, which respond rapidly to changed parenting strategies, and resilience, which is a complex, enduring trait requiring a longer duration or sustained intervention to manifest significant change [24]. Furthermore, qualitative insights revealed that caregivers reported uncertainty about their children's expectations, suggesting a period of relational recalibration and heightened sensitivity rather than deterioration. These findings underscore the necessity of the mixed methods approach adopted in this study as it captured the nuanced developmental processes that quantitative tools alone might overlook [25].

Rather than reflecting program failure, the observed response shift in self-reported parenting measures may represent a meaningful indicator of learning and engagement. Response shift occurs when participants recalibrate their internal standards or conceptual understanding following exposure to an intervention, resulting in more critical self-assessment at the posttest time point despite genuine behavioral improvement [22]. In parenting interventions, increased awareness of positive parenting norms may lead caregivers to judge their behaviors more stringently over time. This process aligns with stages of competence development, in which individuals move from unconscious to conscious incompetence before achieving mastery [23]. Qualitative reports of increased patience, reflective communication, and emotional regulation suggest that caregivers were actively internalizing program content, underscoring the value of mixed methods designs for capturing developmental processes that may not be fully reflected in standardized self-report measures alone [25].

The nonsignificant resilience findings also contrast with rapid gains reported in conflict-affected settings that implemented and evaluated SF, such as Afghanistan and Iran [26,27]. This divergence likely reflects baseline severity; populations with high trauma exposure, such as those in prior SF implementations, often have lower baselines and greater room for improvement. In the nonconflict Thai cohort, where stressors were socioeconomic rather than acute, resilience building appears to be a gradual process requiring a longer intervention duration than 3 weeks to produce statistically detectable change.

Feasibility and Cultural Adaptability

Thai communities accepted SF in the 2024 pilot, with trainers reporting that the curriculum improved family relationships and mutual understanding. The pilot's qualitative comments revealed language obstacles. Facilitators also struggled to handle intensely tough, highly emotional familial situations that spontaneously developed during group sessions. The second phase allowed for the incorporation of brief interventions and strategies for handling difficult situations relevant to the local context, as suggested from our previous phase [8]. Thus, program materials were culturally localized before phase 2. The translated texts were heavily simplified into colloquial Thai; visual assets were replaced with culturally congruent imagery (eg, Asian faces and contextually appropriate domestic scenarios); and, most importantly, the Training for the Trainers curriculum was expanded to teach trainers how to offer targeted advice and de-escalate difficult participant interactions during live facilitation. From families' perspective, this study confirms that the SF Program is feasible and culturally adaptable for Thailand. Qualitative feedback highlighted that the program was viewed as creative and fun, and the shared experience with other families helped reduce isolation. The motivation to join varied from community persuasion to a genuine desire to resolve family conflicts, underscoring the importance of community leaders (eg, village heads and teachers) in the recruitment process for such public health interventions. The research shows

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that implementing SF was feasible and had a good impact on parenting skills and the mental health of families. Because the program includes sessions for both caregivers and children independently and together, SF can enhance positive characteristics and understanding of each other and help families develop new skills in coordination [27]. Families can benefit from a wide range of positive parenting activities, such as the development of good relationships, improved communication, and stress management [28].

In Myanmar, the UNODC executed a vital implementation of the SF Program in Kachin State. This open, multisite pilot feasibility and acceptability trial enrolled 100 families using a universal approach within the camps. The program demonstrated remarkable efficacy. There was an improvement across the SDQ regarding child mental health, as well as distinct enhancements in parenting practices and parent and family adjustment skills. Crucially, the data indicated that improvements were most pronounced among caregivers and children who presented with the greatest psychological and behavioral challenges at the baseline assessment, proving the intervention's high utility in acute humanitarian crises. The success of this trial directly advocated for the programmatic prioritization of family skills [29].

Barriers to Resilience and Future Directions

We observed no significant changes in child resilience (CYRM-R-PMK). Resilience is a complex, multidimensional construct that likely requires a longer duration to manifest than the immediate behavior changes observed in conduct or parenting styles. To increase resilience, the intervention needs to be continuous and comprehensive [30,31]. A 3-week intervention may plant the seeds for resilience, but measurable change may require longitudinal follow-up or sustained booster sessions, as suggested by participants who requested continuous activities to prevent knowledge from fading. Additionally, a recurring theme was the need for paternal involvement. Most participating caregivers were female (59/68, 86.8%), and participants explicitly expressed a wish for husbands or fathers to attend. The predominance of female caregivers in our study reflects traditional gender roles in rural Thai society, where child-rearing is often viewed as the maternal domain [32]. However, qualitative feedback explicitly calling for paternal involvement suggests a shifting awareness within families. Future iterations of the program should specifically target fathers through gender-sensitive recruitment strategies to maximize the systemic impact on family dynamics.

Evidence from parenting intervention research indicates that father-inclusive approaches are associated with greater and more sustained improvements in child behavior and family functioning, particularly when interventions jointly address discipline practices and emotional communication [33]. Future iterations of the SF Program may benefit from gender-sensitive recruitment strategies that actively engage fathers and other caregivers, thereby enhancing the systemic and equitable impact of family skills interventions.

Limitations

Several limitations should be noted. First, the sample size was relatively small (n=68 for quantitative assessment and n=19 for qualitative assessment) and restricted to specific provinces, limiting generalizability. Second, the absence of a control group prevents us from attributing changes solely to the SF intervention. Third, volunteer families may already possess higher motivation to improve family dynamics. The potential for response shift bias in self-reported measures suggests that future studies should include observational metrics or third-party reports to validate parenting changes. Fourth, there was a potential for recall bias in the interview session. However, we aimed to assess family behavior after the training session. Finally, the short follow-up period (12 weeks) may not capture the long-term sustainability of the skills acquired.

Conclusions

The SF Program in Thailand demonstrates strong feasibility and promising effectiveness in reducing coercive parenting, child conduct problems, and child emotional problems. While quantitative measures of relationship quality yielded mixed results, qualitative evidence strongly supports the program's value in fostering family bonding and emotional regulation. Scaling up this intervention with an emphasis on engaging fathers and providing long-term support could significantly benefit vulnerable families in the region.

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Conflicts of Interest

None declared.

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Abbreviations

CYRM-R-PMK: Child and Youth Resilience Measure–Revised–Person Most Knowledgeable About the Child
PAFAS: Parent and Family Adjustment Scales
SDQ: Strengths and Difficulties Questionnaire
SF: Strong Families
UNODC: United Nations Office on Drugs and Crime

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Online Lifestyle Support for Adolescents Undergoing Metabolic and Bariatric Surgery: Pilot Prospective Cohort Study

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Abstract

Background: Metabolic and bariatric surgery (MBS) is a safe and effective treatment for adolescents with severe obesity, yet no standardized lifestyle interventions exist to support sustained behavior change after MBS.

Objective: This pilot study assessed the feasibility and acceptability of TeenLyft, an online lifestyle support program for adolescents undergoing MBS, and explored preliminary clinical and safety outcomes to inform the design of a future randomized trial.

Methods: Adolescents aged 13 to 18 years were recruited from a tertiary care MBS center and enrolled in TeenLyft. The study was not powered or designed as a randomized controlled trial but rather as a pilot to guide future randomized controlled trial development. Feasibility domains included recruitment, retention, data completeness, intervention fidelity, and engagement, with predefined progression criteria of ≥80% enrollment, ≥70% retention, ≥70% data completeness, and ≥90% fidelity. Exploratory clinical and safety measures (weight, BMI, and cardiometabolic markers) were collected descriptively to confirm that participation was not associated with harm.

Results: Twenty-nine adolescents (mean age 15.9 years, SD 1.1; n=22, 75.9% female; n=13, 44.8% Hispanic; mean BMI 47.8, SD 7.3 kg/m^2) were enrolled, representing 145% of the recruitment target (n=20), with 72.4% retention at 6 months. All feasibility progression criteria were met. Descriptive trends showed expected post-MBS reductions in weight and BMI and improvements in blood pressure and hemoglobin A_{1c}, with no adverse cardiometabolic effects observed.

Conclusions: TeenLyft demonstrated high feasibility, acceptability, and safety as an adjunct to adolescent MBS care. Findings support progression to a fully powered randomized trial to evaluate long-term effectiveness and sustainability.

Trial Registration: ClinicalTrials.gov NCT05393570; https://clinicaltrials.gov/study/NCT05393570

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KEYWORDS

adolescents; metabolic and bariatric surgery; lifestyle intervention; weight loss; cardiometabolic

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Introduction

Severe obesity in childhood, defined as a BMI ≥120% of the 95th percentile for age and sex or an absolute BMI >35 kg/m^2, represents the most rapidly increasing form of pediatric obesity in the United States [1]. Among adolescents aged 13 to 19 years, the prevalence of class III obesity rose from 2.1% in 2019 to 2.7% in 2023, equivalent to nearly 1 million youth (*P* value for trend <.001) [2]. Reflecting its growing impact, the American Academy of Pediatrics (AAP) has described pediatric severe obesity as "an epidemic within an epidemic" [3]. This condition contributes to elevated risks for cardiometabolic, hepatic, and renal complications, as well as diminished sleep quality and mental health, ultimately lowering health-related quality of life [3-5]. In addition, obesity in adolescence strongly predicts adult obesity and is linked to increased rates of asthma, arthritis, metabolic dysfunction, psychological distress, and at least 13 forms of cancer, contributing to reduced life expectancy [6-10].

Although behavioral lifestyle programs are foundational to pediatric obesity treatment, evidence indicates that such programs alone rarely produce sustained or clinically meaningful weight loss in adolescents with severe obesity [11-14]. In contrast, metabolic and bariatric surgery (MBS) has been shown to be both effective and safe for this population [15-18]. The 2019 AAP clinical practice statement recommends a family-centered, nonstigmatizing approach to obesity treatment that includes behavioral and lifestyle interventions, pharmacotherapy beginning around age 12 years, and MBS as an option for adolescents with severe obesity from approximately age 13 years when clinically appropriate [3,19]. To promote equitable access, the AAP further emphasizes that health care providers should inform families about surgical options and provide comprehensive preoperative and postoperative support [19]. Consistent with this guidance, national data show a steady rise in MBS use among US adolescents [2,20]. The treatment landscape for adolescent obesity continues to evolve with the approval of glucagon-like peptide-1 receptor agonists for pediatric obesity treatment. Although these medications have expanded therapeutic options for adolescents with severe obesity, MBS remains the most effective intervention for achieving substantial and sustained weight loss among appropriately selected youth [15-18]. Accordingly, there remains an ongoing need for strategies that support long-term behavioral adherence following surgery.

Despite this progress, there remains a critical gap in standardized, age-appropriate lifestyle interventions designed to accompany and sustain the behavioral changes required for long-term success after MBS [21,22]. To address this gap, we developed TeenLyft, a tailored online lifestyle support program grounded in the principles of the Diabetes Prevention Program Group Lifestyle Balance (DPP-GLB) model [23-27]. Prior DPP-GLB implementations have demonstrated improvements in BMI and cardiometabolic markers in adult populations [28]. The adaptation process for TeenLyft incorporated adolescent and caregiver input to prioritize relevant content and delivery methods. Core curriculum topics included caloric balance, nutrition, physical activity, and strategies for overcoming setbacks. Formative research also identified key motivational factors (eg, health improvement and family encouragement) and barriers (eg, fear of complications and lack of peer support) that informed the intervention design [29].

The present study reported findings from the pilot evaluation of TeenLyft among adolescent MBS recipients. Specifically, this analysis examined feasibility domains including recruitment, retention, data completeness, intervention fidelity, and participant engagement, as well as exploratory safety indicators (eg, weight, BMI, and cardiometabolic markers) to ensure the program was not associated with harm. These pilot data were collected to inform the design, progression criteria, and outcome selection for a future randomized controlled trial (RCT).

Methods

Procedures

In 2021, we were awarded funding from the Eunice Kennedy Shriver (NCT05393570) to develop and evaluate a lifestyle support program tailored for adolescents undergoing MBS. The study used a mixed methods, proof-of-concept framework to guide intervention development and pilot testing [30]. Between January 2023 and March 2024, participants were recruited from a multidisciplinary adolescent MBS clinic offering integrated psychological and nutritional care. The TeenLyft intervention content was codeveloped with input from adolescents and caregivers, drawing on principles of the DPP-GLB curriculum.

In brief, TeenLyft was a 6-month behavioral lifestyle support intervention adapted from the DPP-GLB curriculum and tailored for adolescents undergoing MBS. Guided by social cognitive theory and formative work with adolescents and caregivers, TeenLyft addressed healthy eating, physical activity, stress and emotion management, motivation, and strategies for maintaining weight-related behavior change following surgery. Content was delivered through brief online video modules distributed through YouTube (Alphabet Inc) and Facebook (Meta Platforms). A total of 86 videos were developed, including preoperative and postoperative content, with videos averaging approximately 2 to 5 minutes in length. Additional details regarding intervention development and adaptation have been published previously [29].

Ethical Considerations

Human subjects approval was obtained prior to study initiation from the University of Texas Health Science Center at Houston Institutional Review Board (IRB; HSC-SPH-19 - 0406), with the University of Texas Southwestern Medical Center and the Children's Health System of Texas participating under IRB reliance agreements. Parental consent and adolescent assent were secured in accordance with ethical standards. Although consent materials were available in English and Spanish, all participants elected to complete the study in English. All study procedures were conducted in accordance with the ethical standards of the institutional review board and the Declaration of Helsinki.

Study Design

This investigation used a quasiexperimental, prospective cohort design without a control group or random assignment, consistent

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with the intent of a pilot feasibility study. The primary objective was to evaluate feasibility and acceptability outcomes including recruitment, retention, data completeness, intervention fidelity, and participant engagement to inform the design and implementation of a future fully powered RCT. Given this feasibility focus, no control group was included, and statistical analyses were descriptive in nature. Reporting followed the TREND (Transparent Reporting of Evaluations with Nonrandomized Designs) guidelines, which complement the CONSORT (Consolidated Standards of Reporting Trials) extension for pilot and feasibility trials by emphasizing transparent reporting of design, conduct, and feasibility outcomes for nonrandomized studies. Because this was a single-arm feasibility study without randomization or treatment allocation, participants, study staff, and outcome assessors were not blinded. Clinical outcome measures were obtained from routinely collected electronic health record data using standardized clinical procedures.

The study was guided by the RE-AIM (reach, effectiveness, adoption, implementation, and maintenance) framework. RE-AIM informed the selection of feasibility outcomes by focusing on participant reach (enrollment), implementation (intervention fidelity), and maintenance (retention and follow-up completion). Consistent with the goals of a pilot study, recruitment, retention, data completeness, intervention fidelity, and participant engagement were selected as primary feasibility indicators to inform progression to a future randomized trial. Exploratory clinical outcomes, including anthropometric and cardiometabolic measures, were collected to evaluate safety and identify candidate end points for future efficacy testing and are reported elsewhere [30].

Participants

Adolescents were recruited from the adolescent MBS program at Children's Health System of Texas. Eligibility criteria included (1) age 13 to 18 years, (2) meeting National Institutes of Health criteria for adolescent MBS [31], (3) ability to communicate in English or Spanish, and (4) access to study materials through the internet or a smartphone. Participants were required to complete the standard multidisciplinary clinical evaluation process for MBS, including psychological clearance. Exclusion criteria included adolescents who were not medically eligible for MBS, declined participation, or had diabetes requiring mealtime insulin. Eligibility criteria were intentionally broad to reflect real-world clinical practice and support evaluation of intervention feasibility and acceptability in a representative adolescent MBS population. All participants underwent laparoscopic sleeve gastrectomy. Roux-en-Y gastric bypass was not performed among adolescents treated within the study program during the enrollment period; therefore, no participants undergoing gastric bypass were available for inclusion.

Feasibility Measures

Feasibility outcomes were the primary end points of this pilot study. Enrollment counts (consented participants) were tracked against a target of 20 participants to assess recruitment success. Retention rates at 3- and 6-month follow-up visits were recorded to evaluate ongoing engagement. Data completeness for anthropometric and laboratory measures was used to assess the feasibility of data collection processes. Online platform analytics (YouTube and Facebook) quantified module views and average watch times during the 6-month intervention. Fidelity was monitored through delivery checklists ensuring adherence to planned content and format, and qualitative notes captured any technology-related barriers or participant burden.

Feasibility was defined a priori as achieving ≥80% of the recruitment target, ≥70% retention by 6 months, ≥70% data completeness, and ≥90% fidelity to planned intervention delivery. Outcome assessments were obtained at baseline (before MBS) and during routine clinical follow-up visits approximately 3 and 6 months following surgery. Anthropometric and cardiometabolic measures were extracted from the electronic health record as part of standard clinical care.

Exploratory Clinical and Safety Measures

Although not powered for hypothesis testing, exploratory outcomes were collected to ensure the intervention was not associated with harm and to guide end point selection for future trials. Measures included excess weight loss, BMI (raw, percentile, and *z* score), and cardiometabolic indicators (systolic and diastolic blood pressure, hemoglobin A_{1c} (HbA_{1c}), fasting glucose, and lipid profiles).

Covariates

Age, sex, race, ethnicity, and social determinants of health (SDOH) were treated as covariates. SDOH variables were derived from a standardized health system screener comprising 13 questions spanning key domains including health literacy, social support, food security, transportation access, financial stability, housing conditions, and tobacco exposure [31,32]. The screener aligns with the SDOH priority areas outlined in Healthy People 2030 [33]. Specifically, food and housing insecurity correspond to the economic stability domain; tobacco use, transportation, and access to utilities and the internet align with neighborhood and built environment; and social support and health literacy map to the social and community context and health care access and quality domains [34]. The instrument incorporates validated items, such as the hunger vital sign for food insecurity, adapted for pediatric and family use [35].

Statistical Analysis

Feasibility outcomes were summarized descriptively to assess recruitment, retention, data completeness, intervention fidelity, and participant engagement. These metrics were compared against prespecified progression criteria to determine whether the study design and procedures were suitable for a future RCT.

For exploratory purposes, descriptive analyses were used to summarize the study sample's baseline demographic, clinical, and SDOH characteristics. Continuous variables are presented as means and SDs, and categorical variables as frequencies and percentages. Changes in anthropometric and cardiometabolic indicators at 3 and 6 months after MBS were described using summary statistics and graphical trends to estimate potential effect sizes and to confirm the absence of adverse outcomes.

Although this pilot study was not powered for hypothesis testing, exploratory comparisons were conducted to examine patterns

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in excess weight loss by participant characteristics. These analyses included nonparametric methods (Wilcoxon signed-rank and Fisher exact tests) and random-effects models for repeated measures to explore within-participant changes over time. Results were interpreted descriptively to guide selection of candidate outcome measures for a future trial rather than to infer efficacy. All analyses were performed using SAS (version 9.4; SAS Institute).

Results

Participant Characteristics

Summary descriptive statistics are available in Table 1.

Table . Participant characteristics before metabolic and bariatric surgery (N=29).

Descriptive characteristics	Participants
Age (y), mean (SD)	15.9 (1.1)
Age (y), n (%)	
13 - 16	19 (65.5)
17 - 18	10 (34.5)
Sex, n (%)	
Female	22 (75.9)
Male	7 (24.1)
Race and ethnicity, n (%)	
Non-Hispanic White	4 (13.8)
Non-Hispanic Black	11 (37.9)
Hispanic	13 (44.8)
Other	1 (3.4)
Weight (kg), mean (SD)	135.0 (22.1)
BMI (kg/m^2), mean (SD; range)	47.8 (7.3; 36.9 - 62.4)
Social determinants of health (positive), n (%)	
Food insecurity	4 (13.8)
Health literacy challenges	5 (17.2)
Inadequate social support	16 (55.2)
Transportation insecurity	3 (10.3)
Financial insecurity	5 (17.2)
Housing insecurity	1 (3.4)

Feasibility Outcomes

A total of 29 adolescents enrolled in TeenLyft, exceeding the planned sample of 20 and achieving 145% of the recruitment target. Retention at 6 months was 72.4% (21/29), with these 21 participants completing all scheduled follow-up assessments, clinical appointments, and laboratory measures. Most attrition reflected missed follow-up visits or inability to complete scheduled assessments rather than adverse events or concerns related to the intervention. Data completeness exceeded the 70% threshold for anthropometric and biomarker collection. The intervention was delivered with 100% fidelity to planned content and schedule. Across both online platforms (YouTube and Facebook), 86 session modules were delivered, garnering 520 total views and an average watch time of 3.38 minutes per module, indicating consistent participant engagement. No major technology barriers or participant burden were reported. Informal feedback collected during clinical visits indicated that participants found the modules easy to navigate and relevant to their postoperative needs. All feasibility progression criteria were achieved (Table 2).

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Table . Feasibility outcomes and progression criteria for the TeenLyft pilot study.

Feasibility domain	Definition or metric	Prespecified target	Observed outcome	Target met?
Recruitment	Number and percent of participants enrolled compared to target (n=20 planned)	≥80% of target enrollment	29 enrolled (145% of target)	Yes
Retention	Participants completing 6-month follow-up assessments	≥70%	72.4% (21 of 29 enrolled participants); >100% (21 of planned 20 participants)	Yes
Data completeness	Participants with complete anthropometric and laboratory data through 6 months	≥70%	72.4% (21 of 29 enrolled participants); >100% (21 of planned 20 participants)	Yes
Intervention fidelity	Sessions delivered as planned (video content and schedule)	≥90%	100% delivered as planned	Yes
Participant engagement	Online module views and average watch time (YouTube and Facebook)	Descriptive only	520 total views; 3.38-min average watch time	N/A[a]
Acceptability	Informal feedback on ease of use and relevance	Qualitative assessment	Participants reported that the content was easy to navigate and relevant	Positive

[a]N/A: not applicable.

Exploratory Clinical and Safety Outcomes

Exploratory analyses of weight and cardiometabolic indicators were conducted to confirm that the intervention was not associated with harm and to estimate potential effect sizes for future studies. From baseline to 6 months after MBS, participants exhibited expected postoperative improvements, including decreases in mean weight from 136.1 (SD 28.0) kg to 95.7 (SD 15.9) kg and mean BMI from 48.3 (SD 8.3) kg/m² to 33.3 (SD 4.5) kg/m², as well as decreases in BMI percentile and *z* score. Systolic blood pressure and HbA_{1c} showed modest decreases, while diastolic blood pressure, fasting glucose, and lipid profiles remained stable (Table 3). These trends are consistent with anticipated post-MBS trajectories and suggest that participation in TeenLyft did not adversely affect expected surgical outcomes.

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Table . Anthropometric and cardiometabolic biomarker change from before metabolic and bariatric surgery (MBS) to 3 and 6 months after MBS (n=21).

Outcome	Before MBS, mean (SD)	3 months after MBS, mean (SD)	6 months after MBS, mean (SD)	*P* value
Anthropometric measures				
Weight (kg)	136.1 (28.0)	110.3 (15.7)	95.7 (15.9)	<.001[a]
BMI (kg/m^2)	48.3 (8.3)	38.4 (5.6)	33.3 (4.5)	<.001
BMI percentile	99.7 (0.7)	98.5 (1.5)	96.5 (2.8)	<.001[b]
BMI *z* score	3.7 (1.2)	2.4 (0.5)	1.9 (0.4)	<.001[a]
Cardiometabolic outcomes[c]				
Systolic blood pressure (mm Hg)	125.4 (14.3)	119.2 (11.8)	117.6 (13.6)	.04
Diastolic blood pressure (mm Hg)	71.4 (10.3)	69.1 (11.2)	66.4 (8.6)	.17
Glucose (mg/dL)	99.5 (35.4)	86.3 (5.5)	88.0 (7.6)	.31
Hemoglobin A_{1c} (%)	5.7 (1.2)	4.9 (0.1)	5.1 (0.3)	.049
Total cholesterol (mg/dL)	151.2 (29.6)	0[d]	146.8 (23.7)	.59
High-density lipoprotein cholesterol (mg/dL)	39.6 (7.1)	0	43.2 (9.0)	.10
Low-density lipoprotein cholesterol (mg/dL)	90.4 (25.7)	0	86.2 (24.5)	.57
Triglycerides (mg/dL)	106.8 (49.1)	0	87.4 (21.1)	.12

[a]Multiple comparison testing using Tukey approach showed statistically significant differences between before MBS and 3 months after MBS and before MBS and 6 months after MBS, but no statistical difference between 3 and 6 months after MBS.

[b]Tukey comparison showed statistically significant differences across all time points.

[c]Lipid profiles were only collected at 6 months after MBS.

[d]Three-month lipid results are not summarized because data were available for only one participant, precluding calculation of an SD.

Exploratory Patterns in Excess Weight Loss

Although the study was not powered for hypothesis testing, exploratory comparisons were conducted to describe patterns in excess weight loss (EWL) by participant characteristics. Adolescents achieving EWL >50% tended to be older and more likely to be female compared with those with EWL ≤50%. No clear differences were observed by presurgery BMI or SDOH variables (Table 4). These patterns are provided descriptively to guide refinement of subgroup analyses and sample size planning for a future randomized trial.

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Table . Comparison of excess weight loss (EWL) at 6 months among adolescents who participated in TeenLyft[a].

Variables	EWL >50% (n=9)	EWL ≤50% (n=12)	*P* value[b]
Age (y), mean (SD)	16.8 (0.7)	15.3 (1.1)	.008
Sex, n (%)			
Female	4 (44.4)	0 (0)	.006
Male	5 (55.6)	12 (100)	
Race and ethnicity, n (%)			.06
Hispanic or Latino	7 (77.8)	7 (58.3)	
Non-Hispanic Black	0 (0)	4 (33.3)	
Non-Hispanic White	2 (22.2)	0 (0)	
Other	0 (0)	1 (8.3)	
Presurgery BMI, mean (SD)	48.9 (7.6)	44.1 (5.3)	.19
Food insecurity, n (%)			.40
No	1 (33.3)	3 (100)	
Yes	2 (66.7)	0 (0)	

[a]This pilot study was not powered for hypothesis testing; all comparisons are descriptive and intended to inform outcome selection for future trials.
[b]Comparisons between groups (EWL >50% vs ≤50%) were evaluated using Wilcoxon signed-rank and Fisher exact tests, as appropriate.

Discussion

Principal Findings

This pilot study primarily evaluated the feasibility, acceptability, and safety of implementing TeenLyft, a virtual lifestyle support intervention, for adolescents undergoing MBS. The study demonstrated high recruitment, retention, and engagement, with all predefined feasibility progression criteria achieved. Recruitment feasibility was particularly strong, with enrollment exceeding the funded target (29 vs 20 participants), suggesting both high interest and successful clinic integration. This overenrollment further supports the feasibility of scaling up TeenLyft for a larger randomized trial. Participants reported the program to be accessible, relevant, and easy to use, and the intervention was delivered with full fidelity and no technological barriers. Collectively, these findings confirm that TeenLyft is a feasible and acceptable adjunct to standard adolescent MBS care and can be scaled for evaluation in a larger randomized trial.

Exploratory clinical and safety outcomes were collected to verify that participation in TeenLyft was not associated with adverse effects and to generate preliminary effect-size estimates for future research. As expected, participants experienced reductions in weight, BMI, and systolic blood pressure, along with modest improvements in HbA_{1c} over the first 6 months after surgery. Fasting glucose and lipid profiles remained stable. These trends align with previously reported outcomes for adolescent MBS cohorts [36-46], suggesting that the addition of TeenLyft did not negatively influence expected surgical results. Importantly, these findings support the safety of integrating structured behavioral support into postoperative care.

Although exploratory patterns suggested that older adolescents experienced greater EWL than younger participants and that male participants exhibited smaller reductions, the small sample size precludes firm conclusions. These patterns are consistent with prior literature indicating potential age- and sex-related differences in short-term postoperative outcomes [37-41]. Similarly, while SDOH were not strongly associated with weight outcomes, trends such as higher food insecurity among those with greater EWL highlight complex resilience factors that warrant exploration in future work [47-50].

Psychosocial outcomes were not included as formal quantitative end points in this pilot feasibility study, but psychosocial experiences have been examined within the broader TeenLyft research program [51]. Prior qualitative work identified the importance of motivation, social support, body image, weight stigma, and mental health throughout the adolescent MBS journey. Consistent with those findings, participants in the present study described perceived improvements in self-confidence, body image, motivation, and emotional well-being following surgery and participation in TeenLyft [51,52]. Future randomized trials should incorporate validated psychosocial measures to more comprehensively evaluate both benefits and potential unintended consequences of behavioral support interventions following adolescent MBS.

These feasibility findings reinforce the value of integrating digital, flexible support into adolescent MBS pathways. Online engagement through TeenLyft modules demonstrates that adolescents are willing to participate in brief, accessible, and self-directed educational content alongside clinical care. This approach may help maintain continuity of behavioral reinforcement between visits and facilitate equitable access to postoperative support, key priorities emphasized in the AAP's guidance on comprehensive obesity treatment [3,19].

Limitations and Future Directions

This study has several limitations. The small sample size, single-site design, and 6-month follow-up limit generalizability and preclude assessment of long-term outcomes. The relatively

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short follow-up period is particularly important given that obesity is a chronic disease requiring long-term management. While the first 6 months following MBS are characterized by rapid weight loss and high clinical engagement, longer-term outcomes may be influenced by changes in adherence, psychosocial factors, nutritional challenges, use of antiobesity medications, or the need for additional surgical or medical interventions. Future studies should evaluate whether behavioral support interventions such as TeenLyft contribute to sustained weight management and health outcomes beyond the early postoperative period. Additionally, the absence of a control group was intentional and appropriate for a feasibility study but prevents direct evaluation of comparative effectiveness. Nonetheless, observed weight and cardiometabolic outcomes were consistent with published benchmarks for MBS in adolescents [42-47], indicating that TeenLyft did not compromise expected clinical benefits. Future studies should include a larger, more diverse sample, extend follow-up duration, and incorporate quantitative engagement metrics to assess dose-response relationships between participation and outcomes. A randomized design comparing MBS alone versus MBS plus TeenLyft will be essential to determine the program's added value beyond feasibility and safety.

Conclusions

TeenLyft demonstrated high feasibility, acceptability, and safety as a virtual adjunct to adolescent MBS care. The program achieved or exceeded all predefined feasibility criteria and showed no evidence of harm to expected postoperative outcomes. These findings provide critical groundwork for a fully powered RCT to assess the effectiveness, cost, and long-term sustainability of integrating structured, technology-based lifestyle support into standard adolescent MBS care.

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Data Availability

Deidentified data from this study are not available in a public archive. Deidentified data from this study will be made available (as allowable according to institutional review board standards) upon reasonable request by emailing the corresponding author. Analytic code used to conduct the analyses presented in this study are not available in a public archive. They may be available upon reasonable request by emailing the corresponding author. Some materials used to conduct the study are available in a public archive: ClinicalTrials.gov (NCT05393570) [53].

Authors' Contributions

SEM was responsible for the conception and design of the study and was the executive coordinator of the project. SEM and MA were responsible for the first draft. FGQ was the lead metabolic and bariatric surgeon on the project. MSM, JMF, and RB led the data coordination components, including survey operation, coordination of quantitative and qualitative data acquisition, and logistics. MAA was responsible for oversight of all qualitative study components. JMF, RB, and SN performed qualitative procedures and analysis. SEB, AW, BRC, and FGQ provided clinical expertise and oversight of all aspects of the study. SEM and FDA led all statistical analyses and table and figure design. JMF and RB led all project coordination efforts. All authors contributed to participant recruitment, data acquisition, and quality control. All authors had full access to all study data, contributed to data interpretation, critically reviewed the first draft, approved the final version, and agreed to be accountable for the work.

Conflicts of Interest

FGQ is a consultant at Ethicon Industries. All other authors declare no conflicts of interest.

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Abbreviations

AAP: American Academy of Pediatrics
CONSORT: Consolidated Standards of Reporting Trials
DPP-GLB: Diabetes Prevention Program Group Lifestyle Balance
EWL: excess weight loss
HbA_{1c}: hemoglobin A_{1c}
MBS: metabolic and bariatric surgery
RCT: randomized controlled trial
RE-AIM: reach, effectiveness, adoption, implementation, and maintenance
SDOH: social determinants of health
TREND: Transparent Reporting of Evaluations with Nonrandomized Designs

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Family-Focused Digital Mental Health Care for Pediatric Oppositional Symptoms and Caregiver Outcomes: Retrospective Analysis

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Abstract

Background: Oppositional symptoms in youth are characterized by an angry or irritable mood and excessive defiance (eg, arguing), negatively impacting the mental well-being of children, adolescents, and their caregivers. Pediatric digital mental health interventions (DMHIs) that approach care from a whole-family perspective may effectively address mental health (MH) symptoms in both pediatric participants and their caregivers, though this has not been explored in the context of oppositional symptoms.

Objective: The purpose of this study was to assess oppositional symptoms in children and adolescents (aged 6 to 17 years) participating in care within the real-world conditions of a family-centered DMHI. We aimed to (1) examine baseline oppositional severity and its associations with child demographic and clinical characteristics (eg, co-occurring MH symptoms), and caregiver symptoms; (2) evaluate demographic, clinical, and engagement factors associated with oppositional symptoms during care with the DMHI; and (3) determine whether changes in oppositional symptoms during care are associated with improvements in caregivers' stress, burnout, and sleep.

Methods: Retrospective analyses included 3781 child-caregiver pairs who participated in coaching and therapy with Bend Health Inc, a family-centered, pediatric DMHI. Assessments at baseline and monthly during care measured pediatric and caregiver symptoms. Children and adolescents were grouped by oppositional severity at baseline: not significant, subclinical, and clinical. Pediatric characteristics, care type, and caregiver symptoms were compared between groups. Linear mixed-effects models assessed oppositional symptoms over months and then tested whether oppositional severity and rate of symptom improvement were associated with caregiver outcomes over time.

Results: Baseline oppositional symptoms were not significant for 51.55% (1949/3781), subclinical for 26.47% (1001/3781), and clinical for 21.98% (831/3781). More severe oppositional symptoms were associated with younger age (P<.001), nonfemale sex (P<.001), White race or ethnicity (P<.001), higher rates of MH diagnoses (all P<.001), and higher rates of co-occurring inattention, hyperactivity, depression, and sleep problems (all P<.001). Odds of elevated caregiver symptoms increased with more severe oppositional symptoms (all P<.001). At the end of care (final follow-up), oppositional symptoms improved for 73.93% (740/1001) with subclinical symptoms and 82.43% (685/831) with clinical symptoms. Symptom trajectories followed a logarithmic curve, with the greatest improvements in the first several months (P<.001). While more severe oppositional symptoms were associated with more severe caregiver stress, burnout, and sleep problems (all P<.001), monthly improvements in caregiver symptoms were significantly larger for those whose child improved more quickly (all P<.001).

Conclusions: Family-centered DMHIs may effectively address pediatric oppositional symptoms, as well as co-occurring impairments in caregiver well-being. These findings highlight the broader, system-level impact of scalable DMHIs (such as Bend) in addressing complex family MH needs. Future work should examine these effects in the long term and evaluate opposition-specific care pathways within DMHIs.

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KEYWORDS

oppositional defiant disorder; attention-deficit hyperactivity disorder; parental stress; pediatric mental health; therapy

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Introduction

Oppositional and defiant behaviors in children and adolescents are characterized by an angry and irritable mood, temper tantrums, frequent arguing, and vindictiveness [1]. Emerging as early as 4 years of age [2], oppositional symptoms may become persistent and severe enough to meet the criteria for oppositional defiant disorder (ODD) [3]. Estimates of the prevalence of ODD vary widely [1], with one meta-analysis of 25 studies citing a 3.3% global prevalence [4], and another study reporting a 1 in 10 lifetime prevalence in the United States [5]. These rates are even higher among clinical populations and youth in the justice system [6,7]. ODD is also a known precursor to more severe behavioral diagnoses, including conduct disorder (CD) and antisocial personality disorder [8-11], and is associated with early disciplinary issues [11], elevated risk for substance use, and higher prevalence of co-occurring mental health (MH) challenges [2,5,6,10-12]. Attention-deficit hyperactivity disorder (ADHD), a neurodevelopmental disorder characterized by disruptions in attention and executive function, is also closely linked to ODD, as these disorders share overlapping risk factors and approximately 60% of individuals with ADHD also have ODD [12].

While various environmental and genetic factors appear to be associated with ODD, maladaptive family dynamics are particularly predictive of the development of ODD [13,14]. Disruptions in the parent-child relationship, including inconsistent or reactive discipline, can inadvertently reinforce defiant behaviors, contributing to a cycle of escalating conflict and emotional strain within the family [13]. In a study of preadolescent boys (aged 8 to 13 years), negative reinforcement of oppositional and defiant behaviors was associated with a higher incidence of antisocial behavior over the following 2 years [14]. Caregivers are also negatively affected by this cycle, as persistent child behavior problems can erode caregivers' emotional regulation and capacity to implement effective strategies, further intensifying strain within the household. Caregivers of children with ODD often report high levels of stress [15-18], potentially related to their child's disciplinary issues, school difficulties, and, in some cases, involvement with the justice system [14,19]. They also experience elevated rates of sleep disturbances, anxiety, depression, and substance use [7,20-22]. Together, these patterns highlight the urgent need for accessible, family-centered interventions that can interrupt problematic dynamics and promote healthier outcomes for both children and their caregivers.

Parent management training and family-based interventions are considered effective ODD treatments for children, especially those aged 12 years and younger [1,23,24]. Children who have developed the skills to reflect on their emotions and behaviors (around 8 years of age) can have a more active role in treatment and, therefore, may also benefit from cognitive behavioral therapy (CBT) and social problem-solving skill training [24-27]. However, there is some evidence suggesting that oppositional symptoms are relatively resistant to treatment, especially those that do not involve caregiver interventions. Studies among youth have demonstrated stable or worsening symptoms over time, even as comorbid MH symptoms improve, especially in the absence of targeted intervention [7,28,29]. These challenges have led to growing interest in integrated approaches that combine accessible parent-focused training with child-directed behavioral care (eg, CBT), offering a more comprehensive, whole-family model that may be better suited to address both child symptoms and broader family dynamics.

Digital mental health interventions (DMHIs) address youth MH challenges by providing timely access to care, supporting individualized treatment plans, and integrating multiple types of care within one platform [30-33]. Studies have demonstrated the efficacy of DMHIs for many different symptom domains in children and adolescents, with most studies focusing on anxiety, depression, and stress [31,33-37]. While several coaching and therapy-based DMHIs treat child behavior problems, evaluations often overlook oppositional behaviors. Instead, many programs rely on broad checklists (eg, the pediatric symptom checklist) to measure general progress [37], or claims of symptom improvement are not peer-reviewed [38]. While one study of symptoms during coaching and therapy with a family-centered pediatric DMHI (Bend Health, Inc) used an opposition-specific measure, findings of improvement were limited by a relatively short treatment duration (<2 months) and small sample size (n=20) [28]. This study also did not address the role of co-occurring symptoms (eg, anxiety or depression) or program engagement in treatment outcomes. Further, while there is evidence that caregiver well-being improves during a child's participation with various pediatric DMHIs [21,22,39,40], and oppositional symptom reduction mediates improvements in caregiver well-being [41], the extent to which child and adolescent oppositional symptoms may associate with caregiver outcomes during care with a DMHI has not been addressed. There remains a need for a large-scale evaluation of paired youth-caregiver outcomes within the context of a real-world DMHI using a family-centered approach to address oppositional symptoms.

The purpose of this retrospective analysis was to assess oppositional symptoms in children and adolescents (aged 6 to 17 years) participating in care with a family-centered DMHI. We aimed to (1) examine baseline oppositional symptom severity and its associations with child demographic and clinical characteristics (eg, co-occurring MH symptoms), and caregiver symptoms; (2) evaluate demographic, clinical, and engagement factors associated with oppositional symptoms during care with the DMHI; and (3) determine whether changes in oppositional symptoms during care are associated with improvements in caregivers' stress, sleep, and burnout.

Methods

Study Design and Participants

This retrospective analysis included outcomes of pediatric members (aged 6 to 17 years) and their caregivers enrolled in coaching, therapy, or psychiatry programs with Bend Health Inc (Bend) between January 2023 and June 2025. The programs evaluated in this study were offered by Bend Health, Inc, through Bend Health Psychiatric Services and affiliated physician practices. Programs were delivered by MH providers in video-based sessions, and regular symptom assessments

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facilitated measurement-based care. Children were not eligible to enroll in Bend programs if they were in detox for alcohol or illicit drug use, or had any of the following: active command hallucinations or severe thought disorganization, moderate-to-severe intellectual disability, neurocognitive disorder with severe memory or functioning difficulties, severe eating disorders (including BMI <18), or severe autism spectrum disorder.

Members were eligible for study inclusion if they attended at least 3 sessions by July 1, 2025 (n=6632). Members were excluded from all analyses if they did not complete valid baseline and follow-up assessments for oppositional symptoms. Caregivers were excluded if they did not complete valid baseline assessments. The final analytic sample included 3781 members and 3780 caregivers (sample sizes for specific caregiver outcomes were as follows: n=3778 for stress, n=3779 for sleep, and n=3780 for burnout).

Ethical Considerations

Before participating in care with Bend, eligible caregivers agreed to terms and conditions, and they consented to the treatment of a minor (on behalf of their child aged <18 years), agreeing to the collection of electronic data for the purposes of measurement-based care and for future data analyses. Adolescents (aged 13 to 17 years) also consented on behalf of themselves. Study participants were not recruited or compensated because all analyses were retrospective. Study procedures were approved by the Biomedical Research Alliance of New York (Study 23-12-034-1374; approved June 5, 2023).

Treatment

Treatment with Bend has been described previously [28,34]. Caregivers enroll their child (aged 6 to 17 years) in care with Bend via the online web-based portal. During enrollment, caregivers provide information including insurance or employer coverage for services and demographic information for their child (date of birth, sex at birth, race and ethnicity, and gender identity). Then, they complete a series of MH screening questions followed by fully validated assessments to measure pediatric and caregiver MH symptoms (refer to the "Assessments" section). At the end of online enrollment, the caregiver schedules an intake session with a behavioral care manager (BCM), who is responsible for coordinating the member's care between internal and external providers.

During the video-based intake session, the BCM meets with the member and their caregiver to discuss care options with Bend (eg, coaching and therapy), desired services, and insurance or employer coverage for services. Bend addresses pediatric MH challenges using a collaborative care approach, by which care may involve the following Bend providers: behavioral health coach ("coach"), licensed therapist ("therapist"), or psychiatric provider (nurse practitioner or psychiatrist). Based on the information gathered before and during intake, BCMs assign one or more of these providers to each member's care team. All members are assigned a coach. Those who have more severe or complex MH symptoms are also assigned a therapist. Psychiatric providers are also assigned to a member's care team if medication management ("psychiatry") is indicated or included in the referral. Members and their caregivers regularly participate in video-based sessions with providers on their care team, with 30-minute coaching sessions typically scheduled twice monthly and 45-minute therapy sessions once monthly, as applicable. Psychiatry sessions are as needed. BCMs continue to coordinate care and monitor progress throughout participation with Bend.

Coaching and therapy sessions follow module-based care programs designed to address specific symptom domains—for example, ADHD, problematic behaviors, anxiety, and depression—using evidence-based methods delivered over approximately 12 weeks. Care programs are designed to be age-appropriate, with age-based variations between care plans for children (aged <13 years) and adolescents (aged 13 to 17 years). Care programs deliver caregiver interventions (eg, parent training) alongside member-targeted pediatric interventions. Caregiver-targeted interventions are a significant component of care for child programs (vs adolescent programs), as well as programs addressing symptoms known to be well-managed by parent involvement (eg, problematic behaviors). Between sessions, content from care programs is reinforced through an online learning resource center (including supplemental information and activities), and caregivers can communicate with their assigned care team using asynchronous messaging. To enable measurement-based care and monitor progress, members and caregivers complete follow-up MH assessments monthly.

Assessments

Child and adolescent opposition, ADHD (inattention and hyperactivity), anxiety, depression, and sleep problems are initially screened by a series of brief MH screener questions. When symptoms are flagged by responses to the screeners (screen-in), symptoms are measured using full validated assessments. Caregivers of children and adolescents (aged <18 years) respond to questions for opposition and ADHD (inattention and hyperactivity), given the higher validity of proxy report for these symptom assessments [42]. Caregivers of children (aged <13 years) respond to the anxiety, depression, and sleep questions on behalf of their child. To facilitate accurate reporting and incorporate multiple perspectives, caregivers are instructed to complete assessments with their child, consulting on current behaviors and feelings. Adolescents (aged 13 to 17 years) self-report their own anxiety, depression, and sleep problems.

Opposition is screened by the question "...how much (or how often) has your child/teen had problematic behaviors in relation to others?" and inattention and hyperactivity are screened by the single inattention question from the *DSM-5* (*Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*) cross-cutting measure [3]. The *DSM-5* cross-cutting measure also screens child anxiety (3 items) and depression (2 items), and sleep problems for children and adolescents (1 item) [3]. Responses to the opposition and *DSM-5* cross-cutting screeners are on a 5-item Likert-type scale from "Not at all" (score=0) to "Nearly every day" (score=4). Adolescent anxiety and depression are screened using the first 2 questions from the Generalized Anxiety Disorder 7-item (GAD-7) and Patient

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Health Questionnaire 9-item (adolescent version; PHQ-9A) [43,44]. These measures are known as the Generalized Anxiety Disorder 2-item (GAD-2) and Patient Health Questionnaire 2-item (PHQ-2), respectively, and have been widely validated as screeners [45,46]. GAD-2 and PHQ-2 responses are on a 4-item Likert-type scale from "Not at all" (score=0) to "Nearly every day" (score=3).

Full assessments are completed based on responses to the MH screeners (screen-in; refer to Multimedia Appendix 1 for details). Opposition and ADHD symptoms are assessed using the Swanson Nolan and Pelham-IV (SNAP-IV), which includes 26 items total to measure opposition (items 19 - 26), inattention (items 1 - 9), and hyperactivity (items 10 - 18) symptoms. Child anxiety (10 items) and depression (11 items), and child and adolescent sleep problems (8 items) are assessed using the corresponding Patient-Reported Outcomes Measurement Information System assessments [47-49], as recommended by the *DSM-5* for these age groups. Adolescent anxiety and depression are assessed using the remaining items from the GAD-7 and PHQ-9A [43,44], respectively. For the PHQ-9A, the final item regarding suicidal ideation is not presented due to the asynchronous delivery of the assessment [50]; thus, the measure is 8 items.

Caregivers self-report their own stress, burnout, and sleep. Caregiver stress is screened by 2 items from the 18-item Parental Stress Scale (PSS) [51], which measures distress related to caregiving responsibilities and the parent-child relationship. The PSS has been validated in clinical populations [52]. Caregivers complete the remaining 16 items of the PSS if stress is flagged by screeners [51]. For continuity between member-caregiver dyads, caregivers self-report the frequency of sleep problems in the past 2 weeks using the child and adolescent screening item [3]. Caregivers rate their subjective burnout using a validated single item with a 5-item Likert-type scale from "I enjoy my work. I have no symptoms of burnout" (score=1) to "I feel completely burned out..." (score=5) [53]. Details on all full assessments are in Multimedia Appendix 1.

Measures

Member characteristics, clinical information, care engagement, and member and caregiver MH assessments were obtained from Bend's electronic health records. The following member characteristics were used: age in years (at baseline assessment), sex (male, female, and nonbinary), gender (male, female, transgender, nonbinary, and other), and ethnicity (reported categories: White, Asian, Black or African descent, Hispanic or Latino, and Other). Diagnosed conditions were reported in the following categories: ADHD (any subtype), ODD or CD, anxiety disorders (eg, generalized anxiety disorder), and major depressive disorder or dysthymia. Assessment scores were aggregated per standard procedures for each validated assessment [42-44,47-49,53]. To facilitate clear reporting, severity categories (based on score) were reported as follows: not significant for screened out (ie, full assessment not taken) and low severities, subclinical for mild severity, and clinical for moderate and severe severities.

The baseline assessment was defined as the most recent completed within the 30 days before intake (preintake). If no preintake baseline was identified, the earliest assessment completed before the first session with a coach, therapist, or psychiatrist was retained as baseline. Assessments completed before baseline were excluded. All assessments after baseline were follow-up assessments. The timing of follow-up assessments was the date of completion relative to baseline, reported in 30-day months.

The first care program assigned was summarized as "externalizing" for the ADHD, executive functioning, and problematic behaviors care programs, and all other programs (eg, anxiety and resilience) were considered not externalizing. Total sessions were calculated as the aggregate sum of attended coaching, therapy, and psychiatry sessions within the study timeframe. Session counts were also calculated for each provider type. Sessions per month were calculated as total sessions divided by the duration in care (first to last session). For members with a duration in care of less than 1 month, the denominator of this calculation was set to 1 month to prevent artificial inflation of sessions per month values. Members were categorized as having therapy or psychiatry if they attended at least one session with the corresponding provider during the study period. Members were classified as having comorbid externalizing symptoms if they had clinical inattention or hyperactivity at baseline, and comorbid internalizing symptoms if they had clinical anxiety, depression, or sleep problems at baseline. Additional details on measures are in Multimedia Appendix 1.

Statistical Analysis

Data preparation and statistical analysis were conducted using R (version 4.4.1; R Core Team) [54]. An alpha level of .05 was used for all statistical tests. Members were assigned oppositional severity groups ("group") based on baseline severity: not significant, subclinical, or clinical. Group was coded numerically (ordered by severity) for analyses, as appropriate. Assessment scores were rescaled so that 0 represented the lowest possible score, as applicable. Data preparation methods are further detailed in Multimedia Appendix 1.

Child and Adolescent Baseline Symptoms and Characteristics

The following characteristics were described by the oppositional severity group: age (in years; mean, SE), and the percentages of females and gender-sex conforming members, percent representation by ethnicity category, percentages of each type of MH diagnosis, percentages with clinical baseline MH symptoms (inattention, hyperactivity, anxiety, depression, and sleep problems). Treatment with Bend was described by the percentage of members with an externalizing symptom care program as their first care program, and those in therapy or psychiatry. Continuous variables were compared between groups using a linear model and categorical variables were compared using Cochran-Armitage trend tests with 2 levels. For ethnicity, levels were collapsed to White versus non-White; all other variables retained their original levels.

Change in Oppositional Symptoms

Full-sample duration in care was described as median (IQR) months from first to last session, and median (IQR) months

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from baseline to follow-up assessments. Central trends (median [IQR]) for coaching, therapy, psychiatry, and total sessions attended were reported, with therapy and psychiatry sessions only reported for those in the corresponding type of care. Rates of oppositional symptom improvement (score decrease) and recovery (score <8) at each member's last follow-up were reported for subclinical and clinical oppositional severity groups.

Changes in oppositional symptoms over the 7 months after baseline (refer to Multimedia Appendix 1 for details) were assessed using linear mixed-effects models of score over months (from baseline assessment). To determine the most accurate functional form of time, linear (months), quadratic (months^2), and logarithmic (log [months+1]) models were evaluated. Each model included time, oppositional severity group, and their interaction as primary predictors, with a random effect of participant (member) on the intercept. Based on prior research for this program [35,55,56], we controlled for sex (female), age (in years), internalizing and externalizing symptoms, participation in an externalizing care program, therapy, psychiatry, and average sessions per month. All continuous predictors except time were mean-centered to reduce multicollinearity. Likelihood ratio tests (LRTs) identified the logarithmic model as the best fit. Adding a random effect of participant on the slope further improved model fit (P<.001) and was, therefore, retained. Finally, we evaluated potential moderators of symptom change by using LRTs to test interactions between time and each fixed effect. The final model included oppositional severity group, age (centered), externalizing care program, and psychiatry as interactions, and all other effects were retained as main effects.

Symptom change was evaluated at the full sample's typical treatment duration using both observed and model-estimated values to characterize treatment responsiveness and to confirm model accuracy. Model-estimated scores for baseline and follow-up at 3.73 months (median follow-up) were generated for each group. Observed values were calculated using scores from baseline and final follow-up assessments completed within 4 months. Model-estimated and observed values were used to calculate the percentage reduction in symptoms from baseline to follow-up. Comprehensive details regarding oppositional model selection and refinement, including LRT results, are provided in Multimedia Appendix 1.

To prepare for caregiver symptom modeling, each child's rate of improvement at the typical treatment duration was calculated as the estimated instantaneous slope at 3.73 months. Estimates were derived from member-specific fixed and random effects to isolate the rate of improvement from other covariates. The rate was subsequently inverted and mean-centered, such that higher values represent faster improvement.

Caregiver Symptoms and Change in Oppositional Symptoms

Caregiver symptoms were first described as the percentage reporting stress, burnout, and sleep problems for all members and by oppositional severity group, with between-group differences tested by the Cochran-Armitage test. The change in likelihood for elevated caregiver symptoms associated with each 1-point increase in baseline oppositional symptom severity was expressed as odds ratios (ORs) with 95% CIs and associated P values.

For caregivers with mild-to-severe stress (n=2129), burnout (n=1680), and sleep problems (n=1760) at baseline, symptom severity (score) over the first 7 months of follow-up was assessed by linear mixed-effects models with fixed effects of time, oppositional symptom severity group, child's rate of improvement (centered), and interactions of each effect with time. A random effect of participant (member) on the intercept accounted for individual differences. Months (log-transformed) were used as the time variable because logarithmic time was identified as the best-fit functional form for all caregiver models. Additionally, a random effect of participant (member) on the slope improved model fit and was retained in all models. To further describe associations between caregiver symptoms and child oppositional symptoms, modeled caregiver symptom trajectories were plotted by oppositional severity group and child treatment response (derived from rate of improvement), including slow responders (rate=–SD), typical responders (rate=0), and fast responders (rate =+SD).

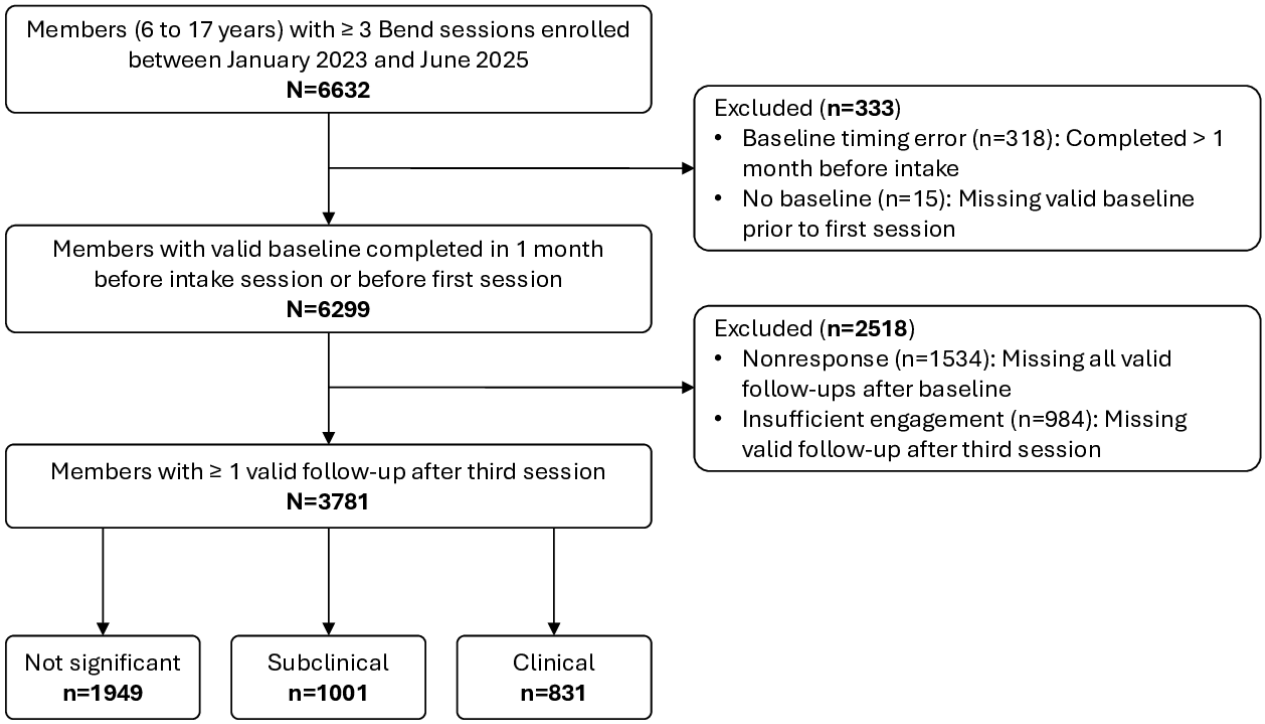
Results

Child and Adolescent Baseline Symptoms and Characteristics

Oppositional symptoms were evaluated in N=3781 children and adolescents (Figure 1). Given baseline symptoms, the oppositional severity group assignments were: 51.55% (1949/3781) not significant, 26.47% (1001/3781) subclinical, and 21.98% (831/3781) clinical (moderate: 13.96% [528/3781] and severe: 8.01% [303/3781]). Regarding characteristics (Table 1), children and adolescents with more severe symptoms tended to be younger (P<.001), were less likely to be female (P<.001), and more likely to be White (ethnicity: P<.001). They also had higher rates of ADHD, ODD, and anxiety disorder diagnosis, as well as elevated MH symptoms (except for anxiety; all P<.001). Externalizing symptom care programs and therapy were associated with more severe symptoms (all P<.001).

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Figure 1. Participant study flow chart, including oppositional severity group assignments based on baseline symptoms.



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Table . Characteristics reported for children in each oppositional severity group[a].

Characteristic	Not significant (1949/3781, 51.55%)	Subclinical (1001/3781, 26.47%)	Clinical (831/3781, 21.98%)	Between-group test; *t* test (*df*) or Z score	*P* value
Age (years), mean (SD)	11.77 (3.15)	10.78 (3.07)	10.39 (3.06)	–11.52 (3779)[b]	<.001[c]
Sex (female), n (%)	1089 (55.87)	461 (46.05)	363 (43.68)	6.48[d]	<.001[c]
Gender-sex conforming, n (%)	1877 (96.31)	979 (97.80)	805 (96.87)	1.21[d]	.23
Ethnicity, n (%)				3.50[d]	<.001[c]
White	969 (49.72)	519 (51.85)	475 (57.16)		
Asian	104 (5.34)	61 (6.09)	25 (3.01)		
Black or African descent	99 (5.08)	29 (2.90)	39 (4.69)		
Hispanic or Latino	108 (5.54)	42 (4.20)	36 (4.33)		
Other	669 (34.33)	350 (34.97)	256 (30.81)		
Diagnosed conditions, n (%)					
ADHD[e]	459 (23.55)	360 (35.96)	369 (44.40)	11.37[d]	<.001[c]
ODD[f] or CD[g]	3 (0.15)	33 (3.3)	81 (9.75)	13.14[d]	<.001[c]
Anxiety disorder	1003 (51.46)	458 (45.75)	309 (37.18)	6.90[d]	<.001[c]
MDD[h] or dysthymia	391 (20.06)	181 (18.08)	169 (20.34)	0.16[d]	.87
Clinical MH[i] symptoms, n (%)					
Inattention	285 (14.62)	307 (30.67)	416 (50.06)	19.61[d]	<.001[c]
Hyperactivity	89 (4.57)	143 (14.29)	250 (30.08)	18.39[d]	<.001[c]
Anxiety	781 (40.07)	390 (38.96)	348 (41.88)	0.67[d]	.51
Depression	581 (29.81)	323 (32.27)	344 (41.40)	5.67[d]	<.001[c]
Sleep problems	717 (36.79)	417 (41.66)	399 (48.01)	5.57[d]	<.001[c]
Externalizing symptom care program, n (%)	416 (21.34)	349 (34.87)	391 (47.05)	13.[d]89	<.001[c]
Therapy, n (%)	830 (42.59)	476 (47.5)	401 (48.26)	3.08[d]	.002[j]
Psychiatry, n (%)	996 (51.10)	540 (54.15)	450 (54.15)	1.67[d]	.10

[a]Between-group test (*t* test and Cochran-Armitage tests) results identify differences in characteristics between oppositional severity groups. Cochran-Armitage test results are reported for categorical variables, and *t* test results for age.

[b]*t* test value.

[c]*P*<.001.

[d]Z value.

[e]ADHD: attention-deficit hyperactivity disorder.

[f]ODD: oppositional defiant disorder.

[g]CD: conduct disorder.

[h]MDD: major depressive disorder.

[i]MH: mental health.

[j]*P*<.01.

Change in Oppositional Symptoms

In the first 7 months, the first and last sessions were a median of 2.63 (IQR 1.33 - 4.7) months apart, and final follow-up assessments were a median of 3.73 (IQR 2.33 - 5.87) months after baseline. Members attended a median of 7 (IQR 4 - 12) sessions, corresponding with an average of 3.00 (SD 0.82) sessions per month. Members attended 6 (IQR 3 - 9) coaching sessions. Members with therapy (45.15%, 1707/3781) had a median of 3 (IQR 2 - 4) therapy sessions, and members with

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psychiatry (52.53%, 1986/3781) had a median of 1 (IQR 1 - 1) psychiatry session. At the last follow-up, 73.93% (740/1001) of the subclinical oppositional severity group improved and 52.55% (526/1001) recovered, while 82.43% (685/831) of the clinical severity group improved and 23.83% (198/831) recovered.

Symptom trajectories fit a logarithmic model, characterized by rapid initial improvement during the first several months of care followed by a gradual decline in monthly improvements. Full results from the logarithmic model are reported in Table 2. In brief, oppositional symptoms improved over months (log-transformed; P<.001). Symptoms were more severe for members with greater baseline severity (P<.001), and those with comorbid externalizing symptoms (P<.001), comorbid internalizing symptoms (P=.03), an externalizing care program (P<.001), therapy (P<.001), and greater sessions per month (P=.01). Symptoms were less severe for older members (P=.004) and females (P=.006). While psychiatry was associated with less severe symptoms, the main effect did not reach statistical significance (P=.07). Rates of symptom improvement were significantly greater (faster improvement) for members with more severe baseline symptoms ($P_{interaction}$<.001). Specifically, those with clinical symptoms demonstrated rapid improvement over the first several months, whereas the subclinical group showed more gradual improvement. Scores for the not significant oppositional severity group remained largely stable (Figure 2). Rate of improvement was also significantly greater for older members ($P_{interaction}$<.001) and significantly smaller for members with psychiatry (P=.01). At the sample's typical final follow-up (3.73 months), the model-estimated aggregate symptom reduction was 27.73% for the subclinical oppositional severity group and 34.48% for the clinical oppositional severity group. These estimates were consistent with observed improvements across groups (Table 3).

Table . Results from the logarithmic model of oppositional symptom severity during care with the DMHI[a].

Effect	Estimate (SE)	*t* test (*df*)	*P* value
Main effects			
Intercept	9.55 (0.11)	85.89 (17039)	<.001[b]
Months (log-transformed)	−1.92 (0.07)	−26.83 (17039)	<.001[b]
Oppositional severity group	9.93 (0.09)	112.65 (17039)	<.001[b]
Age at baseline	−0.04 (0.02)	−2.89 (17039)	.004[c]
Sex (female)	−0.24 (0.09)	−2.76 (17039)	.006[c]
Comorbid externalizing symptoms	0.83 (0.10)	8.04 (17039)	<.001[b]
Comorbid internalizing symptoms	0.21 (0.09)	2.27 (17039)	.02[d]
Externalizing care program	0.45 (0.11)	4.04 (17039)	<.001[b]
Therapy	0.37 (0.09)	3.94 (17039)	<.001[b]
Psychiatry	−0.17 (0.10)	−1.82 (17039)	.07
Sessions per month	0.13 (0.06)	2.31 (17039)	.02[d]
Interactions with months (log-transformed)			
Oppositional severity group	−3.14 (0.08)	−38.78 (17039)	<.001[b]
Age at baseline	−0.06 (0.01)	−4.20 (17039)	<.001[b]
Externalizing care program	0.17 (0.10)	1.67 (17039)	.10
Psychiatry	0.22 (0.09)	2.54 (17039)	.01

[a]DMHI: digital mental health intervention.

[b]P<.001.

[c]P<.01.

[d]P<.05.

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Figure 2. Logarithmic trends for oppositional symptoms during care for oppositional severity groups.

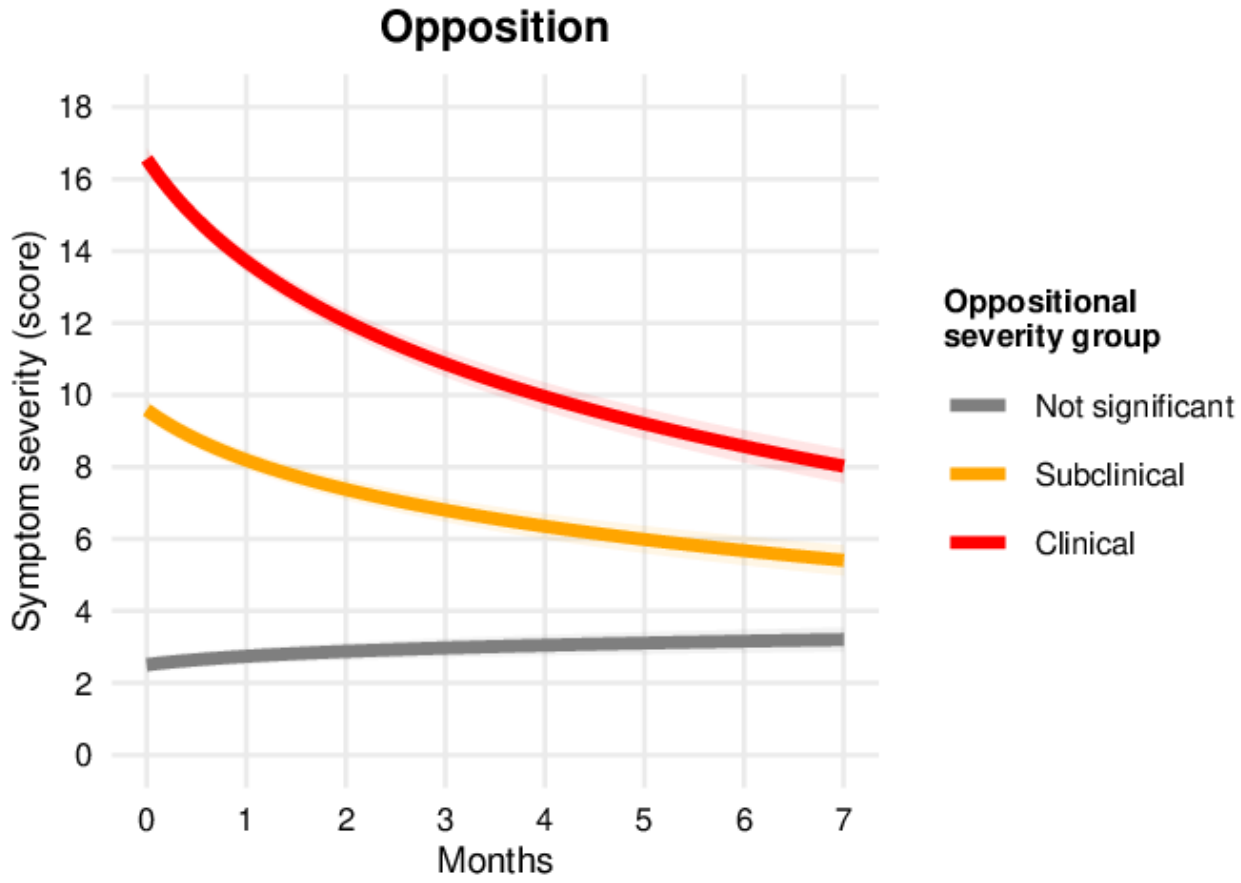


Table . Model-estimated and observed baseline and follow-up scores[a] at the median treatment duration, and the aggregate percent reduction from baseline to follow-up.

Oppositional severity group	Baseline score, mean (SD)	Follow-up score[a], mean (SD)	Percent reduction (%)
Not significant (n=1949)			
Model-estimated	2.75 (1.14)	3.45 (2.76)	−25.12
Observed	2.56 (2.65)	3.35 (3.66)	−30.84
Subclinical (n=1001)			
Model-estimated	10.14 (1.21)	7.33 (2.96)	27.73
Observed	10.41 (1.67)	7.83 (4.33)	24.77
Clinical (n=831)			
Model-estimated	17.39 (1.66)	11.39 (4.01)	34.48
Observed	17.82 (3.11)	12.34 (5.73)	30.76

[a]Model-estimated values are derived from a logarithmic mixed-effects model and calculated at the sample's median treatment duration (3.73 months). Observed values represent the last follow-up assessment completed within the first 4 months of care for each member.

Caregiver Symptoms and Change in Oppositional Symptoms

At baseline, 57.34% (2129/3713) of caregivers reported stress, 45.14% (1680/3722) reported burnout, and 47.35% (1760/3717) reported sleep problems; these rates differed across oppositional severity groups (all P<.001; Table 4). As hypothesized, greater oppositional symptom severity was associated with significantly greater odds of elevated caregiver stress (OR 1.11, 95% CI 1.10-1.12), burnout (OR 1.06, 95% CI 1.05-1.08), and sleep problems (OR 1.03, 95% CI 1.02-1.04); all P<.001. Stress was the most strongly associated with oppositional symptoms, with a 10-point change in oppositional symptom score (eg, an increase from subclinical to clinical symptoms) associated with an 184% increase in odds of caregiver stress.

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Table . Caregiver symptoms reported for each oppositional severity group[a].

Symptom	Not significant, n/N (%)	Subclinical, n/N (%)	Clinical, n/N (%)	Between-group test (Z score)	*P* value
Stress	844/1914 (44.10)	634/980 (64.69)	651/819 (79.49)	17.91	<.001
Burnout	720/1919 (37.52)	469/980 (47.86)	491/823 (59.66)	10.86	<.001
Sleep problems	832/1918 (43.38)	496/978 (50.72)	432/821 (52.62)	4.87	<.001

[a]Between-group test (Cochran-Armitage tests) results identify differences in caregiver symptoms between oppositional severity groups.

All logarithmic model estimates for caregiver symptoms over months are reported in Table 5. Caregiver stress, burnout, and sleep problems decreased over months (all P<.001), following logarithmic curves with rapid improvement in the first several months and then more gradual declines later in care. More severe caregiver symptoms were associated with more severe oppositional severity (all P<.001). Faster improvement in child symptoms (greater child rate of improvement) was associated with less severe stress (P<.001) and burnout (P=.04), though this main effect was not significant for sleep (P=not significant).

Regarding the magnitude of change in caregiver symptoms over time (Figure 3), more severe oppositional symptoms were associated with larger improvement in stress ($P_{interaction}$<.001) and burnout ($P_{interaction}$=.02), whereas this effect was not observed for sleep ($P_{interaction}$=not significant). Faster improvement in child symptoms was associated with larger improvements in all caregiver symptoms over time (all P<.001), as demonstrated by diverging child treatment response trajectories for slow, typical, and fast responders (Figure 4).

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Table . Results from logarithmic models of caregiver symptom severity during care with the DMHI[a].

Fixed effect	Estimate (SE)	*t* test (*df*)	*P* value
Stress			
Intercept	27.53 (0.19)	141.52 (9434)	<.001[b]
Months (log-transformed)	−2.88 (0.12)	−23.71 (9434)	<.001[b]
Oppositional severity group	5.13 (0.33)	15.60 (9434)	<.001[c]
Child's rate of improvement	−6.32 (0.72)	−8.83 (9434)	<.001[b]
Months (log-transformed) × oppositional severity group	−0.60±0.21	−2.89 (9434)	.004[c]
Months (log-transformed) × child's rate of improvement	−5.89 (0.45)	−13.21 (9434)	<.001[b]
Burnout			
Intercept	2.28 (0.02)	140.34 (7545)	<.001[b]
Months (log-transformed)	−0.44 (0.01)	−31.40 (7545)	<.001[b]
Oppositional severity group	0.11 (0.03)	4.09 (7545)	<.001[b]
Child's rate of improvement	−0.15 (0.06)	−2.49 (7545)	.01[d]
Months (log-transformed) × oppositional severity group	−0.05 (0.02)	−2.27 (7545)	.02[d]
Months (log-transformed) × child's rate of improvement	−0.40 (0.05)	−7.58 (7545)	<.001[b]
Sleep problems			
Intercept	2.76 (0.02)	127.03 (7921)	<.001[b]
Months (log-transformed)	−0.46 (0.02)	−26.02 (7921)	<.001[b]
Oppositional severity group	0.15 (0.04)	3.96 (7921)	<.001[b]
Child's rate of improvement	−0.07 (0.08)	−0.88 (7921)	.38
Months (log-transformed) × oppositional severity group	−0.01 (0.03)	−0.37 (7921)	.71
Months (log-transformed) × child's rate of improvement	−0.39 (0.07)	−5.84 (7921)	<.001[b]

[a]DMHI: digital mental health intervention.

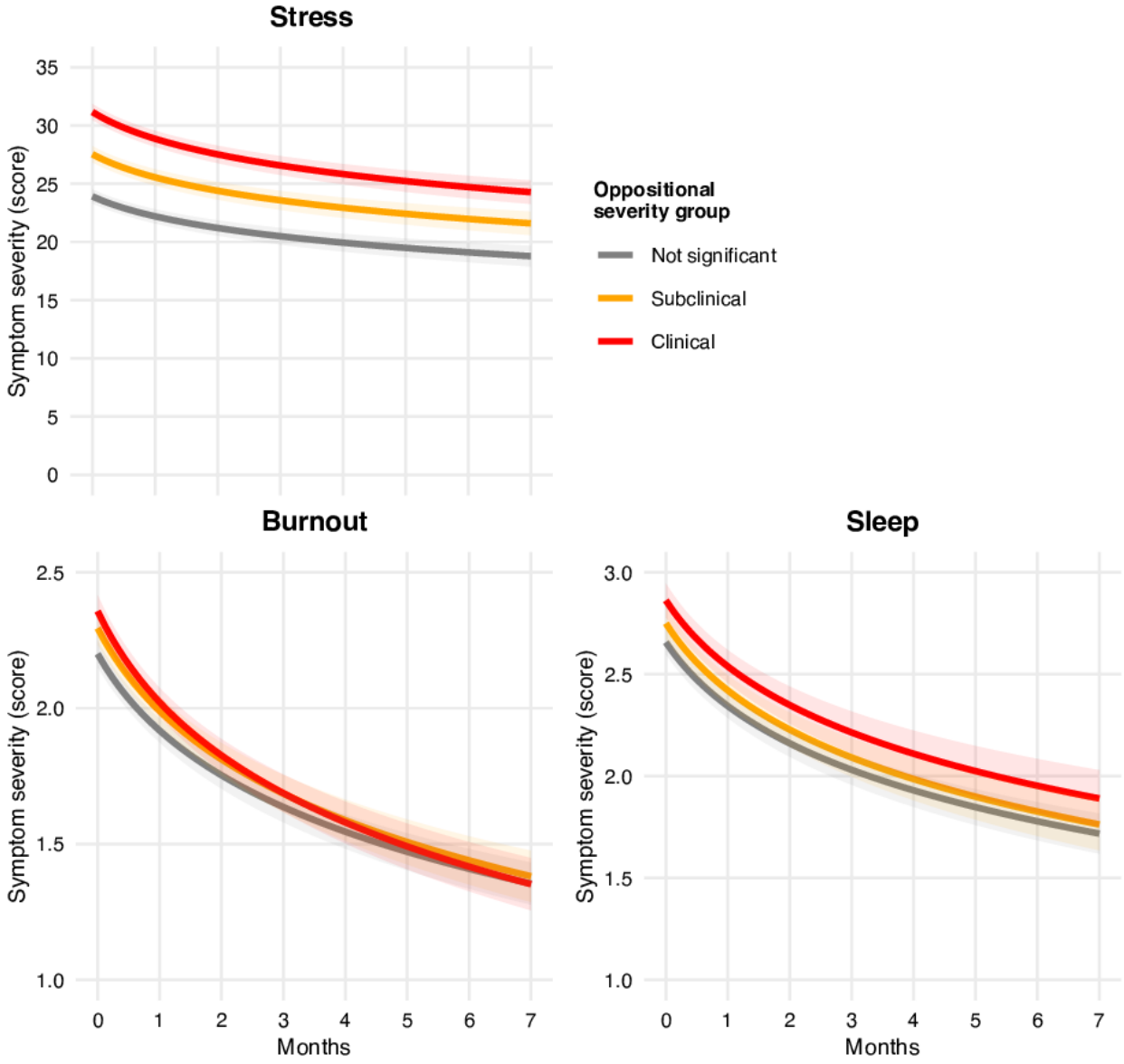
[b]*P*<.001.

[c]*P*<.01.

[d]*P*<.05.

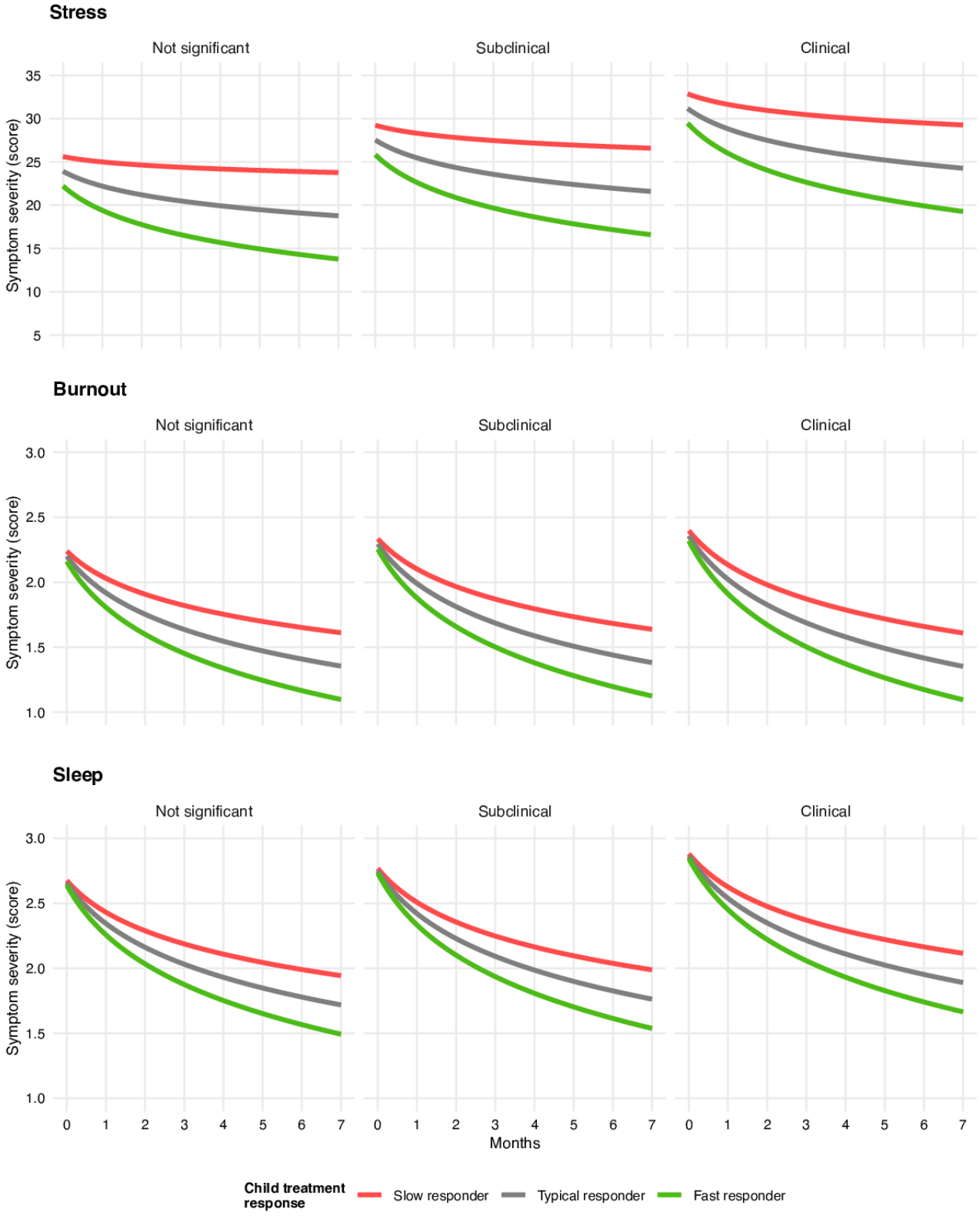
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Figure 3. Longitudinal trajectories for caregiver symptoms over months, reported for each oppositional severity group.



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Figure 4. Longitudinal trajectories for caregiver symptoms over months, reported by child treatment response for each oppositional severity group.



Discussion

Principal Findings

This study characterized child and adolescent (aged 6 to 17 years) oppositional symptoms and associated caregiver outcomes within the real-world setting of a family-centered DMHI. Oppositional symptoms were associated with age, sex, and comorbid MH diagnoses and symptoms. Oppositional symptoms improved during DMHI participation, and those with more severe symptoms at baseline improved more rapidly. Older children and adolescents tended to improve more quickly than younger children and adolescents, and participation in psychiatry was associated with slower improvement. While more severe oppositional symptoms were associated with caregiver sleep

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problems, stress, and burnout, caregivers of those with more severe oppositional symptoms reported larger improvements in their own symptoms, and caregiver improvements were more rapid for those whose child's rate of oppositional symptom improvement was greater (eg, fast responders).

This study described oppositional symptom presentation in children and adolescents receiving treatment from a DMHI and identified unique demographic factors associated with symptoms. Approximately 1 in 5 (22%) of children and adolescents had clinically elevated oppositional symptoms, yet only 10% of those with clinical symptoms had a formal diagnosis of ODD or CD. These findings are largely consistent with broader literature; while the global prevalence of ODD and CD is relatively low (<5%) [4], prevalence rates of 28% to 65% have been observed in clinical samples [6]. Boys had more severe symptoms than girls, consistent with higher ODD diagnostic rates among males [5,57,58]. Nonetheless, 45% of children and adolescents with oppositional symptoms were female. Considering that diagnostic tools and criteria are largely based on behaviors more common in males with ODD versus females (eg, physical vs relational aggression), these results demonstrate the need to monitor and address ODD in both males and females [59]. This study also found that oppositional symptoms were less severe for older children and adolescents, likely reflecting the gradual decrease in the severity of oppositional symptoms (especially defiant behaviors) from preadolescence and into adulthood [9,60]. Those with more severe oppositional symptoms were more likely to have additional MH challenges, with inattentive and hyperactivity symptoms, and ADHD and ODD diagnoses particularly prevalent among those with problematic behaviors. This finding is expected given the high rate of comorbidity between ADHD and ODD [12,58]. Notably, however, children and adolescents with oppositional symptoms varied in their individual and clinical characteristics (eg, age, sex, and co-occurring MH conditions). The DMHI evaluated here implements measurement-based care using a standardized screening protocol, potentially flagging relevant clinical symptoms in otherwise undiagnosed youth and circumventing demographic-based biases by applying the same criteria across all participants. Ultimately, findings demonstrate the value of standardized and routine screening (such as Bend) to evaluate and address oppositional behaviors in the context of pediatric DMHIs.

Though most children and adolescents did not receive care through a targeted oppositional behavior track, Bend successfully reduced oppositional symptoms in the majority (78%) of those with clinical and subclinical presentations. Symptom reductions were evident monthly, with the largest improvements in the first months of care. This finding aligns with the broader literature demonstrating that oppositional symptom improvement is associated with participation in a variety of evidence-based behavioral programs, particularly those emphasizing parenting and caregiver interventions [1,23,24,61]. With Bend, children and adolescents who started with more severe oppositional symptoms improved more quickly over the course of care, suggesting that treatment through DMHIs like Bend is effective even for participants with more serious behavior problems. Other commercial DMHIs have demonstrated improvements across a range of pediatric symptoms with coaching and therapy [37,38], and several studies have shown reduction of MH symptoms, including anxiety, depression, and ADHD, during participation with Bend [28,34,35,56]. While there is evidence that digital game-like interventions may also address ADHD and ODD in children and adolescents [62-64], this is the first rigorous study, to our knowledge, to report significant improvements in oppositional symptoms via family-centered coaching and therapy with a DMHI.

While engagement with Bend's DMHI was associated with substantial reductions in oppositional behaviors, there were differences in treatment responsiveness. First, older children and adolescents improved more quickly during care. Unlike younger children, older children and adolescents can take an active role in their treatment, potentially yielding greater gains from child-targeted interventions (eg, CBT and social problem-solving skill training) [24-27]. Additionally, because caregivers of older children are less likely to have elevated parental stress and burnout [22,40], they may be better equipped to support their child's treatment (eg, via implementation of caregiver-directed interventions) [65,66]. Children and adolescents with psychiatry, on the other hand, tended to improve less quickly than those without psychiatry. This finding suggests that children and adolescents in psychiatry were less responsive to coaching or therapy alone, such as those with more complex cases and comorbidities. Thus, it is likely that medication management in psychiatry was appropriately assigned to those requiring this higher level of care. Notably, children and adolescents with more severe symptoms had more frequent sessions during care, but sessions per month were not a significant predictor of the rate of improvement, suggesting that care intensity was scaled to meet higher clinical need. This finding contrasts with other studies reporting associations between engagement metrics and better MH outcomes, including management of behavior problems [67]. Taken together, it is likely that factors beyond engagement—including demographics, caregiver involvement, and type of care—have stronger associations with symptom progress. Overall, DMHIs that have an individually tailored and family-centered approach may be an effective solution for treating opposition, even for those with severe and complex symptom presentation.

Bend's family-centered approach provides simultaneous support to both pediatric members and their caregivers. Specifically, caregivers whose children were more responsive to care (eg, improved more quickly) also reported larger improvements in their own stress, burnout, and sleep. These findings are consistent with prior research highlighting the reciprocal relationship between child behavioral dysregulation and caregiver well-being, in which elevated externalizing symptoms in children and adolescents contribute to greater emotional strain, physiological stress, and impaired functioning in caregivers [14,15,17]. On the other hand, improvements in child behavior lessen caregiver burden and may have positive downstream effects on caregiver well-being [22,41,68]. While caregiver stress, burnout, and sleep problems improved over time in care, those supporting children with more severe

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behavior problems showed the largest gains. While other studies have demonstrated improvements in caregiver symptoms during pediatric DMHI treatment [21,22,39,40]—including a recent study showing co-occurring improvements in general pediatric symptoms and caregiver symptoms—this is the first to demonstrate the sensitivity of caregiver symptoms to their child's oppositional behaviors. Indeed, reductions in caregiver stress and sleep problems are associated with better long-term outcomes, including lower incidence of MH problems, improved cardiovascular health, lower morbidity, and improved cognitive function [69-71]. These results position DMHIs such as Bend to support scalable, system-level change in pediatric and family MH care. Future studies should examine the effectiveness of opposition-specific care programs, as well as long-term outcomes of children and adolescents with symptoms of ODD.

Strengths and Limitations

This study has several notable strengths. First, this study addresses significant research questions by combining pediatric and caregiver data, contributing greatly to the clinical and scientific knowledge base on the detection and treatment of ODD symptoms. Second, by conducting primary analyses on a large sample of member-caregiver pairs (N=3781) who meaningfully engaged with the DMHI in a real-world setting for at least 3 sessions, the findings presented are more reliable and generalizable than the previous study of oppositional symptoms with Bend [28]. Third, children and adolescents with subclinical and nonsignificant symptoms were included in analyses of change. Thus, findings highlight early intervention effects and the robustness of the DMHI and analytic strategy in detecting improvements among less symptomatic children. This is notable given that such individuals typically have smaller gains and are vulnerable to potential floor effects. Additionally, by measuring symptoms over care for those with nonsignificant symptoms at baseline, we demonstrate that few children and adolescents developed new oppositional symptoms during participation with the DMHI. Thus, we can be confident that our findings reflect substantive clinical change rather than a regression to the mean. Fourth, observed and model-estimated values for oppositional symptom improvement were comparable, demonstrating the generalizability and accuracy of the results reported here. The rigor of the study is further strengthened through the use of validated, psychometrically sound measures administered at repeated time points.

Regarding limitations of the study, its retrospective and observational design precludes causal inferences; observed improvements in caregiver outcomes may reflect co-occurring changes or shared contextual factors rather than direct effects of the DMHI. Indeed, we cannot determine the directionality of the relationship between pediatric and caregiver symptom changes. The findings presented here are specific to a single DMHI (Bend) and may not generalize to other digital platforms or traditional therapy. Further research should be conducted on different DMHI tools to pinpoint particularly effective interventions and determine whether findings are generalizable. This study represents a modest follow-up period of 7 months maximum, with a typical length of participation of four months. Prior research has shown mixed long-term outcomes for ODD symptoms, with some reporting diagnostic instability (particularly in younger children) [29,72,73] and others demonstrating sustained reductions in disruptive behaviors following intervention [74]. Future studies would benefit from an extended follow-up period to evaluate the long-term stability of symptom improvements. Regarding outcome measures, the SNAP-IV is a widely used tool for assessing ODD symptoms, but it is not intended for diagnostic purposes. While multiple screening tools exist, there is no consensus on best practice [24]. Nonetheless, the cut-off scores used in this study align with standardized guidelines [75]. Another limitation is the use of caregiver report for many pediatric symptoms. Caregiver report is broadly used to measure observable behaviors (including opposition and defiance), as well as symptoms in young children (eg, aged <13 years) [47]. However, outcomes may differ significantly by informant, particularly for internalizing symptoms and symptoms or behaviors that lack cross-situational consistency (eg, behaviors present at school and not at home) [76,77]. While caregivers in this study were encouraged to seek input from their child when reporting symptoms and behaviors, future studies should use a multi-informant framework. This approach would account for potential informant discrepancies and offer a more nuanced, comprehensive assessment of child functioning. Finally, though the models controlled for several variables, residual confounding from unmeasured factors may remain. For example, the study did not evaluate several critical child and caregiver characteristics—including pediatric health outcomes, caregiver MH history and demographics, and family socioeconomic circumstances—which are likely to influence outcomes [78-81]. These additional variables should be included in future research to better elucidate their impact on family-wide MH.

Conclusions

This study provides novel evidence that oppositional symptoms in children and adolescents can improve meaningfully during participation in a family-centered DMHI, even in the absence of targeted ODD treatment. Improvements were observed across clinical and subclinical severity levels and were more pronounced in younger children and adolescents and those with more severe baseline symptoms. While engagement varied by symptom severity, session frequency did not predict the rate of improvement, suggesting that the DMHI may have effectively tailored care intensity to individual needs. Notably, improvements in caregiver outcomes were closely linked to child oppositional symptoms at baseline and during care, with greater oppositional severity and larger improvements associated with larger reductions in stress, burnout, and sleep problems. These findings underscore the promise of family-centered DMHIs (such as Bend) in delivering scalable, flexible, and family-centered care that supports both pediatric MH and caregiver well-being. Future work should examine the long-term stability of these outcomes, explore potential mechanisms of change, and evaluate how caregiver-level factors influence treatment responsiveness within digital care models.

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Data Availability

The datasets generated or analyzed during this study are not publicly available, per Bend Health Inc's privacy policy, but are available from the corresponding author on reasonable request.

Authors' Contributions

All authors conceptualized and designed the study, and contributed to the methodology. DL-S conducted all statistical analyses. JH supervised the project. DL-S and KM drafted the manuscript, and all authors reviewed and approved the final version.

Conflicts of Interest

At the time of initial submission, DL-S, DM, and MR were employed by Bend Health, Inc (Bend), the developer of the digital intervention in this study, and JH was a paid consultant for Bend. KM is employed by JH at Fit Minded, Inc. Since the initial submission, Bend was acquired by Lyra Health. The authors' compensation and employment status are not affected by or dependent on the results of their research.

Multimedia Appendix 1
Supplemental methods, including additional information on assessments and measures, and detailed methods for data processing and statistical analyses.
[DOCX File, 2492 KB - pediatrics_v9i1e82039_app1.docx]

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Abbreviations

ADHD: attention-deficit hyperactivity disorder
BCM: behavioral care manager
CBT: cognitive behavioral therapy
CD: conduct disorder
DMHI: digital mental health intervention
***DSM-5*:** *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*
GAD-2: Generalized Anxiety Disorder 2-item
GAD-7: Generalized Anxiety Disorder 7-item
LTR: likelihood ratio test
MH: mental health
ODD: oppositional defiant disorder
OR: odds ratio
PHQ-2: Patient Health Questionnaire 2-item
PHQ-9A: Patient Health Questionnaire-9 adolescent version
PSS: Parental Stress Scale
SNAP-IV: Swanson Nolan and Pelham-IV

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An Innovative Approach to Enhanced Care Management for High-Need Pediatric Medicaid Members: Retrospective Cohort Study

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Abstract

Background: The California Advancing and Innovating Medi-Cal (CalAIM) initiative supports Enhanced Care Management (ECM) for high-need pediatric populations but published evidence of the impact of ECM in pediatric populations is lacking.

Objective: We evaluated a novel multidisciplinary care model (Pair Team) for delivering ECM services, focusing on implementation and early outcomes for children and adolescents enrolled in California's Medicaid program (Medi-Cal).

Methods: We conducted a retrospective, observational cohort study of Medi-Cal-enrolled children and adolescents who enrolled in Pair Team's program between July 2022 and November 2024. Program engagement, health care engagement, and depressive symptoms were assessed using program data, electronic health records, and prescription data.

Results: The main cohort included 1294 enrollees with 12 months of follow-up data (mean age 8.9 years, 50.3% (651/1294) female, 81.8% (1058/1294) experiencing homelessness). Members averaged 2.8 interactions per month with care team members over the first 3 months and 57.1% (851/1491) were still enrolled at 12 months. In the year prior to enrollment compared to the year postenrollment, the prevalence of an asthma diagnosis increased from 7.8% to 10.0% (P=.005), outpatient visits increased 7% (rate ratio, RR=1.07, P<.001), emergency department visits decreased 9% (RR=0.91, P=.002), and antibiotic prescriptions increased 41% (RR=1.41, P=.001). For those with depressive symptoms at enrollment, mean PHQ-9 score decreased from 15.4 (SD 4.7) to 10.2 (SD 6.8) after 3 months (P<.001).

Conclusions: An innovative ECM program successfully engaged with and retained high-need pediatric Medicaid patients. Program members had higher engagement with other health care in the year following enrollment, and depressive symptoms improved. These results highlight the potential for this model to improve outcomes for the highest-need pediatric Medicaid patients.

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KEYWORDS

ECM; complex needs; HRSN; Pair Team; CalAIM; Enhanced Care Management; health-related social needs; California Advancing and Innovating Medi-Cal

Introduction

Children and adolescents with complex medical and social needs, particularly those enrolled in Medicaid, face profound challenges accessing consistent, coordinated care [1]. These pediatric populations often experience fragmented health care, unmet behavioral needs, and health-related social needs such as housing instability, food insecurity, or caregiver challenges [2]. These barriers contribute to suboptimal primary and preventive care, high emergency department (ED) use, and adverse long-term outcomes [3,4]. Emerging evidence suggests that such barriers may also lead to underdiagnosis of common conditions; for example, a national analysis of Medicaid claims data found that in 17 states, asthma diagnosis rates among Medicaid-enrolled children were lower than self-reported prevalence estimates for the general pediatric population,

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highlighting potential missed or delayed diagnoses in this group [5].

In response to these challenges, among others for patients of all ages, California launched the California Advancing and Innovating Medi-Cal (CalAIM) initiative in 2022 for enrollees in California's Medicaid program, Medi-Cal. A cornerstone of CalAIM is the Enhanced Care Management (ECM) benefit, which provides intensive, whole-person care coordination for Medi-Cal beneficiaries with the most complex needs [6]. Eligibility criteria extends to children and adolescents, particularly those experiencing homelessness, serious mental illness (SMI), or at risk of avoidable hospital or ED utilization [7]. Uptake among children remains low; for example, only 4040 of an estimated 95,000 eligible children in California Children's Services (CCS) were enrolled in ECM as of 2024 [8]. Implementers also report persistent challenges with referrals, outreach, and limited infrastructure to support scalable care coordination [9]. Further, despite the inclusion of pediatric populations, limited data exist on ECM implementation and outcomes in children and adolescents.

Shortly after CalAIM launched, Pair Team, a California-based medical group and ECM provider, introduced a novel multidisciplinary care model to deliver ECM services at scale [10]. The Pair Model includes two features not required by California's ECM program, both designed to address limitations in prior programs for high-need, high-cost patients. It supplements limited primary care access with telemedicine-based nurse practitioners (NPs) who support chronic disease management and care transitions, and it partners with community-based organizations (CBOs), providing training, tools, and funding to help address patients' social needs like housing, food, and transportation. This model leverages care managers from local communities, along with behavioral health clinicians, NPs, and a tech-enabled platform to coordinate services. Early evaluations have shown promising outcomes among adult participants, including increased engagement with health care and improved mental health [11]. However, children and adolescents' distinct development stages and health care utilization patterns necessitate separate evaluation of ECM's impact in younger populations.

Accordingly, in this study, we evaluate the implementation and early outcomes of Pair Team's ECM program for children and adolescent members (<18 y) enrolled in Medi-Cal. We assess both program engagement metrics and changes in trends in health care engagement pre- and postenrollment, overall and among subgroups with asthma and depressive symptoms, with the goal of demonstrating that a multidisciplinary, scalable approach to ECM can successfully engage pediatric populations. Our findings add to the evidence base on community-based care management for pediatric Medicaid populations and offer practical insights into adapting ECM to better serve youth with complex needs.

Methods

Study Design and Population

In this retrospective, observational cohort study, we analyzed metrics on program engagement, patient engagement with health care, and behavioral health outcomes for children and adolescent patients who enrolled with Pair Team. In order to enroll with Pair Team's ECM program, patients had to be Medi-Cal members who fell within at least one Population of Focus defined by the State of California: experiencing homelessness, at risk for avoidable hospital or ED utilization (with at least three ED visits and/or two inpatient stays over 12 mo), having SMI or substance use disorder, transitioning from a youth correctional facility, enrolled in CCS or CCS Whole Child Model with additional needs beyond the CCS condition, involved in child welfare, or having intellectual or developmental disabilities [7]. Patients or their families or guardians were referred to Pair Team by local CBO partners, health system partners, or Medicaid managed care plans, and Pair Team community engagement specialists contacted them with the option to enroll in Pair Team.

To be included in the current analysis, program members must have enrolled in the Pair Team ECM program between July 1, 2022, and November 30, 2024, been under 18 years of age when they enrolled, and have been continuously enrolled in the program for at least 105 days from their enrollment date. The 105-day threshold was chosen as a proxy for a 3-month timeframe because Pair care team members flag members for disenrollment if they have not responded to outreach in the first 90 days of enrollment and then make final attempts to engage before disenrolling the patient. For analyses that included data from one-year prior to and one-year postenrollment, only program members who enrolled prior to March 15, 2024, were included, to allow for at least one year of postenrollment data to be available from a Health Information Exchange (HIE) on the date of data extraction, accounting for a 6-week buffer period.

Subgroups of members with asthma at enrollment and those with depressive symptoms were also constructed, as these are among the most prevalent chronic conditions in pediatric populations, and disproportionately so for Medicaid enrollees [12-14]. Patients who had at least one provider diagnosis of asthma (an *ICD-10* code of J45.xx) and at least one prescription for a short-acting beta 2-agonist (SABA) "rescue" medication sent to a pharmacy in the year prior to enrollment were classified as having asthma at enrollment [15,16]. Depressive symptoms were defined as having a PHQ-9 (Patient Health Questionnaire-9) score >9 at enrollment, and only those at least 12 years old were included.

Program Description

The Pair Model takes an integrated approach to providing care to patients with complex medical and social needs. After patients are referred to the program, they begin with completing a comprehensive health and social needs assessment. They are then assigned to a care team, consisting of three bilingual Lead Care Managers (LCMs), an NP, a registered nurse (RN), and a Behavioral Health Care Manager (BHCM). Similar to

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community health workers, the LCMs help foster deep trust-based relationships with the patients, schedule and manage appointments, coordinate with the rest of the care team and help navigate patients through the medical and social care system. The RNs provide patient education and triage urgent health needs. The BHCMs provide behavioral health interventions and referrals as needed. NPs play a notable and differentiating role in the Pair program by supplementing the limited availability of primary care in the community; this is not a standard component of ECM. They offer virtual visits, coordinate closely with patients' primary care providers, and provide follow-up after ED visits, hospital discharges, and for chronic disease management. The majority of interactions between patients and the care team are with LCMs, as the program is designed to focus on addressing social needs while scaling the impact of NPs, RNs, and BHCMs over a broad population.

Another distinguishing feature of the Pair Model is its partnership with CBOs, including homeless services organizations, shelters, and food banks, who join Pair Team's value-based network. They are provided with operational training and key tools to streamline care coordination and receive funding for services provided to patients. This partnership can help quickly address social needs of patients (such as housing, transportation needs, food and financial insecurity, etc). This level of partnership is not a standard component of ECM.

Additionally, the Pair Model utilizes a custom case management platform (Arc) that allows for in-depth care planning and automation of clinical operations, is connected to HIEs and Admission, Discharge, Transfer (ADT) feeds that provide access to outside health records and alerts when patients are in the ED or hospital, and supports seamless interactions between the care team and patients via text, phone, and email.

Additional information on the Pair Model has been previously reported [11].

Measures

Self-reported demographics and participant characteristics were collected at program enrollment in Pair Team's proprietary case management platform. Population of Focus characterizations were specific to the pediatric member rather than the parent or guardian. Program retention rates at 3, 6, and 12 months were calculated as the percent of those who had enrolled at least 3/6/12 months prior to data extraction who were continuously enrolled 3/6/12 months postenrollment.

Program engagement was measured by the number of interactions the member or their parent/guardian had with the Pair care team, including in-person, text, phone call, and email interactions. These are logged by care team members in the custom case management platform when they conclude an interaction. Only parent/guardian interactions related to their child were attributed to the pediatric member's engagement.

Health care visit data, including outpatient, ED, and inpatient visits, were extracted for one-year prior to and one-year postenrollment from an HIE that partners with the two largest national EHR networks: CommonWell Health Alliance and Carequality. Combined, these networks include over 75,000 provider sites and over 270 million patients across the country, including significant coverage in California. Provider sites include acute care centers, ambulatory care centers, hospitals, lab systems, pharmacies, and postacute care centers. Visits were classified as outpatient, ED, or inpatient according to the class coding of the original Consolidated-Clinical Document Architecture record. These visits did not include interactions with Pair NPs.

Medication prescription data for one-year prior to and one-year postenrollment were extracted from an HIE that partners with Surescripts. The Surescripts network covers 99% of US pharmacies and over 324 million patients across the US. Prescription rates were calculated based on the number of records of medications dispensed to a patient with unique combinations of dispense date, National Drug Code, and fill type (first fill or refill). Rates of antibiotic prescriptions were analyzed for the overall population; asthma medications including SABA rescue medications, oral steroids, and long-term controllers were analyzed for the asthma subgroup; and for the subgroup with depressive symptoms, tricyclic antidepressants, selective serotonin reuptake inhibitors, serotonin-norepinephrine reuptake inhibitors, norepinephrine-dopamine reuptake inhibitors, tetracyclic antidepressants, atypical antipsychotics, and mood stabilizers were analyzed.

Depressive symptoms were measured by the PHQ-9 [17], which was collected for all patients over 12 years old at program enrollment, and attempts to collect follow-up scores were made monthly for all members with a score >9 at enrollment. Analysis of change in PHQ-9 scores at 3 months was conducted for those in the depressive symptoms subgroup who had a follow-up PHQ-9 score in the window of 75 - 135 days postenrollment. When there were multiple scores reported in that window, the one closest to 90 days post-enrollment was used for analysis.

Statistical Analysis

We present descriptive statistics to describe the demographics of the study sample, as well as program retention and engagement rates. For binary outcomes (eg, the presence or absence of a diagnosis), we used McNemar's test to compare pre- and postperiod diagnosis rates within individuals.

To assess changes in visit rates and medication use, we calculated the rate ratio (RR) and corresponding 95% confidence interval (CI) using the Wald method. This method evaluates whether the rate of events (eg, provider visits or number of medications dispensed) per unit time differs significantly between two time periods, accounting for the count nature and distributional assumptions of the data, assuming that the natural logarithm of the RR is approximately normally distributed. The standard error (SE) of the log-transformed RR was calculated as the square root of the sum of the reciprocals of the event counts in each group. The 95% CI was then computed as the exponential of the log rate ratio ±1.96 times the SE.

Changes in depression severity were assessed using two complementary statistical approaches applied to PHQ-9 scores collected from the same individuals at two time points. First, to evaluate changes in the mean PHQ-9 score, we used a paired t-test. Second, to assess changes in the distribution of PHQ-9

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scores without assuming normality, we applied the Wilcoxon Signed-Rank test.

All tests were two-sided, and significance was defined at the .05 level. Analyses were conducted using Python, Snowflake SQL, and Microsoft Excel.

Ethical Considerations

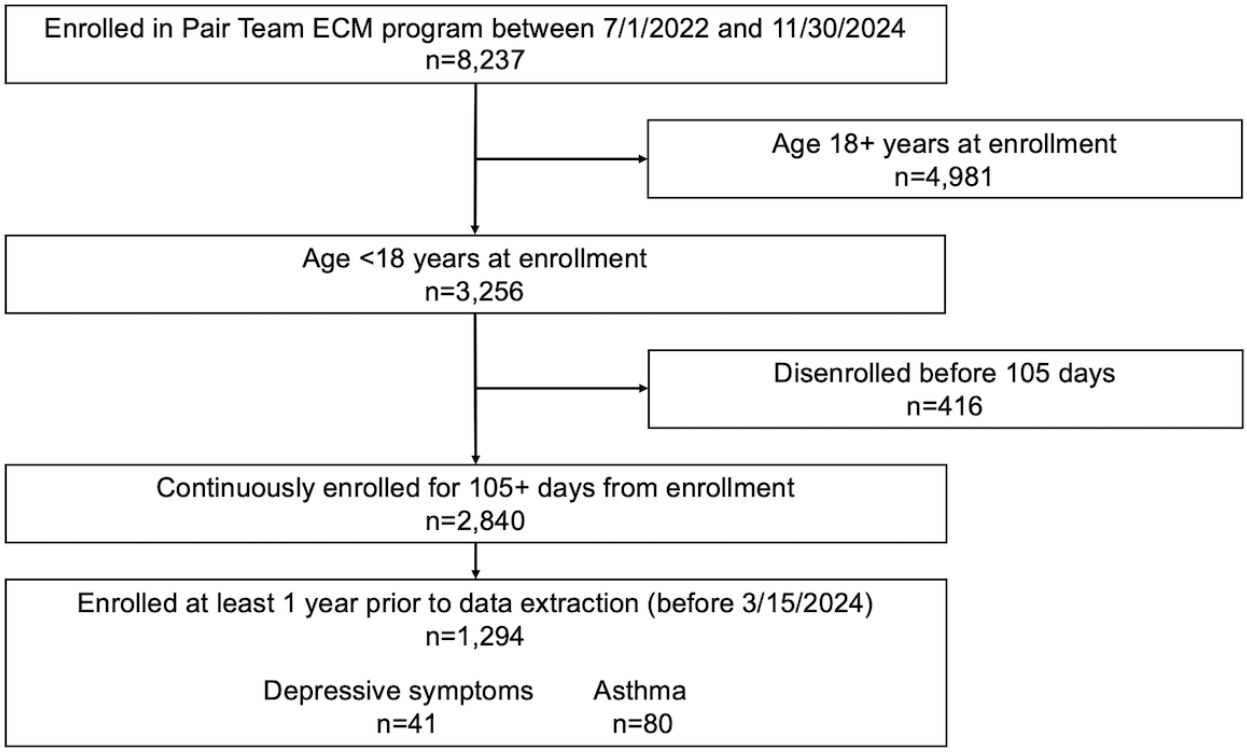
Since the study was a secondary analysis of previously collected, deidentified data, it was deemed exempt from ethics oversight by the WCG Institutional Review Board (1-1952683-1).

Results

Sample Characteristics

A total of 3256 patients under 18 years old enrolled in the Pair Team ECM program between July 1, 2022, and November 30, 2024. Of those, 2840 (87.2%) were still enrolled 105 days later, and 1294 had 12 months of follow-up data (Figure 1). Characteristics for the cohort of 1294 are shown in Table 1. The mean age of the study participants at program enrollment was 8.9 years (SD 5.0), with 35.2% (456/1294) being 12 - 17 years old. The study population was 50.3% (651/1294) female and 46.8% (606/1294) were known to be Hispanic or Latino. The majority (81.8%, 1058/1294) were experiencing homelessness at enrollment and 25.7% (332/1294) met criteria for multiple Populations of Focus. A total of 80 (6.2%) were classified as having asthma at enrollment, and 41 had depressive symptoms at enrollment (9.0% of those 12 - 17 y old, 41/456).

Figure 1. Member enrollment and study participation flow chart.



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Table . Description of study cohort.

Characteristic	Overall (n=1294)
Sex at birth, n (%)	
Female	651 (50.3)
Age, n (%)	
0 - 4	308 (23.8)
5 - 11	530 (41.0)
12 - 17	456 (35.2)
Age (years), mean (SD)	8.9 (5.0)
Race or Ethnic group, n (%)	
Black or African American	101 (7.8)
Hispanic or Latino	606 (46.8)
White	45 (3.5)
Other[a]	44 (3.4)
Unknown	498 (38.5)
Preferred language: Spanish, n (%)	492 (38.0)
Population of focus, n (%)[b]	
HU[c]	188 (14.5)
Homeless	1058 (81.8)
SMI[d]	269 (20.8)
Other	32 (2.5)
Multiple PoF[e]	332 (25.7)
Individuals with an asthma diagnosis, n (%)	80 (6.2)
Individuals with depressive symptoms, n (%)	41 (3.2)[f]

[a]"Other" Race or Ethnic Group includes American Indian or Alaskan Native, Asian, Islander, and Other.

[b]Participants could be part of multiple PoFs; total does not sum to 1294 or 100%.

[c]HU: high utilizers.

[d]SMI: serious mental illness.

[e]PoF: Population of Focus.

[f]Only those age 12 - 17 years were eligible for this cohort; 9.0% of that age group had depressive symptoms.

Program Engagement

As noted above, retention after 3 months of enrollment was 87.2% (2840/3256). Among the 2726 pediatric patients who enrolled in the program at least 6 months prior to data extraction, retention at 6 months was 71.3% (1943/2726). Among the 1491 who enrolled at least 12 months prior to data extraction, retention at 12 months was 57.1% (851/1491). In the first 3 months after enrollment, pediatric members or their parent/guardian engaged with the Pair care team on average 2.8 times per month. Average engagement over 6 months for those enrolled at least 6 months was 2.4 interactions per month, and there were 2.2 interactions per month in the year postenrollment for those enrolled at least 12 months. Most pediatric member or parent or guardian interactions were with LCMs (84.1%, 9436/11215 in the first 3 mo, 86.8%, 24045/27692 over 12 mo). The proportion of interactions that were with RNs or NPs or BHCMs increased over time from 2.7% (307/11215) for each in the first three months to 3.3% (925/27692) with RNs or NPs and 3.2% (888/27692) with BHCMs over 12 months. The remainder of interactions were with outreach or intake specialists or other staff.

Engagement With Health Care

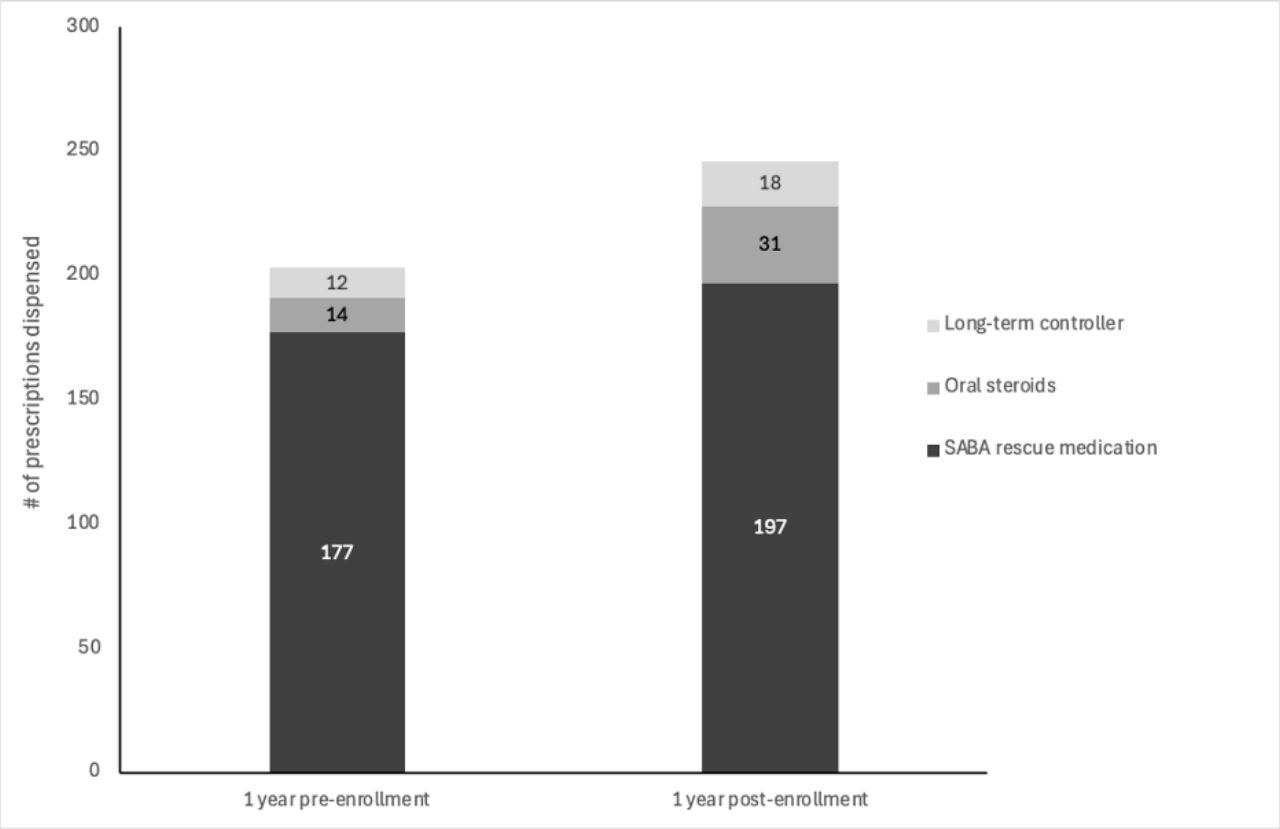
We assessed changes in level of engagement with health care by calculating changes in rates of asthma diagnoses, healthcare visit rates, and medication use between one-year prior to and one-year postenrollment.

The prevalence of an asthma diagnosis in the overall sample increased from 101 (7.8%) in the year prior to enrollment to 129 (10.0%) in the year post (P=.005). For those classified as having asthma at enrollment, prescriptions dispensed increased from 203 to 246, representing an increase of 21% (RR=1.21, 95% CI 1.01 - 1.46, P=.01) from the pre- to postperiod. The increasing trend was seen across medication categories (SABA

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rescue medications, oral steroids, and long-term controllers) (Figure 2).

Figure 2. Asthma medication prescriptions by category.



Health care visit rates for the overall population differed between the year prior to and the year postenrollment. Outpatient visits increased from 3898 to 4159, representing a 7% increase from the pre- to postperiod (RR=1.07, 95% CI 1.02 - 1.11, *P*<.001). Conversely, acute care visits decreased. From the pre- to postperiod, ED visits decreased from 1220 to 1115, representing a decrease of 9% (RR=0.91, 95% CI 0.84 - 0.99, *P*=.002). Inpatient visits were directionally lower postenrollment, decreasing from 60 to 50, representing a decrease of 17% (RR=0.83, 95% CI 0.57 - 1.21, *P*=.14).

For the overall sample (n=1294), antibiotic prescriptions dispensed increased from 563 to 794, representing an increase of 41% (RR=1.41, 95% CI 1.27 - 1.57, *P*=.001) from the pre- to postperiod. Amoxicillin, cephalexin, azithromycin, amoxicillin and clavulanate potassium, and erythromycin were the most common prescriptions dispensed in both the pre- and postperiods.

Behavioral Health Outcomes

In the subgroup with depressive symptoms at enrollment (PHQ-9 >9) and a follow-up PHQ-9, average PHQ-9 score decreased from 15.4 (SD 4.7) at enrollment to 10.2 (SD 6.8) at 3 months follow-up (*P*<.001, n=38) (Table 2). At follow-up, 47.4% (18/38) of the subgroup had a PHQ-9 score categorized as none to mild depressive symptoms (PHQ-9 <10) (*P*<.001), and the percentage reporting any suicidal ideation decreased from 50.0% to 15.8% (*P*<.001). The proportion of patients reporting severe depressive symptoms in this subgroup decreased from 28.9% (11/38) at enrollment to 5.3% (2/38) at follow up (*P*<.001). We assessed change in mental health medication usage for the full cohort of 41 with depressive symptoms at enrollment. Prescriptions dispensed for this cohort directionally decreased from 72 to 52, representing a 28% decrease from the pre- to postperiod (RR=0.72, 95% CI 0.51 - 1.03, *P*=.17).

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Table . Pre- versus postenrollment behavioral health outcomes.

Variables	Enrollment	3-month follow-up	*P* value[a]
Patients with enrollment and follow-up score, n (%)	38 (100.0)	38 (100.0)	—[b]
PHQ-9 score, mean (SD)	15.4 (4.7)	10.2 (6.8)	<.001
Depressive symptom severity, n (%)			<.001
0 - 9: None-mild	0 (0)	18 (47.4)	
10 - 14: Moderate	18 (47.4)	7 (18.4)	
15 - 19: Moderately severe	9 (23.7)	11 (28.9)	
20 - 27: Severe	11 (28.9)	2 (5.3)	
Patients with suicidal ideation, n (%)	19 (50.0)	6 (15.8)	<.001

[a]For continuous variables, a paired *t*-test was used to calculate *P* values; for categorical variables, the Wilcoxon signed-rank test was used.

[b]Not applicable.

Discussion

Principal Findings

Results from this real-world study demonstrate that a multidisciplinary, scalable approach to ECM can meaningfully connect with and engage high-need pediatric Medicaid patients. The Pair Model enrolled over 3000 pediatric patients eligible for ECM in the first two years of the program, and enrollment continues to grow over time as Pair Team scales. Nearly 60% of those who enrolled were still enrolled one year later, and engagement with the care team was sustained over time, with an average of 2.2 interactions per month over the year after enrollment. These results are especially meaningful given that over 80% of those enrolled were experiencing homelessness at the time of enrollment, as populations experiencing homelessness are generally considered difficult to engage [18,19].

The differences seen in asthma diagnoses, health care visit rates, and rates of medication use in the year prior compared to the year postenrollment suggest that the Pair Model facilitates improved access to and better engagement with the healthcare system. Asthma is a condition that is more prevalent in low-income children, and diagnosis is important for proper management [13,20]. The prevalence of a record of asthma diagnosis in this study increased from 7.8% in the year prior to enrollment to 10.0% in the year postenrollment, which aligns with other estimates of asthma rates of 10% in Medicaid pediatric populations [21,22]. This suggests that asthma may have been underdiagnosed in this population prior to enrollment. It is well understood that utilizing primary and preventive care effectively leads to optimal health outcomes and lowers costs, but high ED utilization continues to be a larger problem in Medicaid populations than in commercially-insured populations [22,23]. In this study, we saw that Pair Team program members had lower ED visit rates in the year postenrollment than pre, and shifted to higher rates of outpatient visits in the post-enrollment period. This suggests that their access to and engagement with primary care improved after enrollment. While overuse of antibiotics is a problem, including in Medicaid populations, it is also important that pediatric populations have access to appropriate prescribing. The 41% increase in antibiotic prescriptions dispensed seen in this study corresponds to per-patient rates increasing from 0.4 in the year prior to enrollment to 0.6 in the year postenrollment. This brings antibiotic use in alignment with the national average of 598 prescriptions per 1000 persons for those under 18 years in 2022, and is still materially lower than prescribing rates seen in some other Medicaid populations [24,25]. However, we are unable to definitively say how much of the increase in antibiotic prescriptions is appropriate prescribing as opposed to overuse.

Adolescents experiencing complex social or medical needs, such as homelessness, are at higher risk for mental health challenges than those who are not, yet they often experience barriers to appropriate behavioral health care [19]. These barriers are multifaceted, and impacted by housing situation, access to technology, and cultural disconnection from care providers [26]. The Pair Model's emphasis on bilingual LCMs and BHCMs seeks to address these barriers by fostering trust with patients and referring them to care providers who understand the social factors they are facing. While the sample size for those with depressive symptoms in this study is not large, the improvements in PHQ-9 results are impressive and seen in parallel with directional decreases in medication usage, suggesting that the Pair Model approach of addressing social needs may have a meaningful impact on the mental health status of Medicaid adolescents.

Limitations

This study has several limitations, as is typical of observational studies conducted with real-world data. First, as a one-arm observational study, we did not have a control group, and as such we were unable to examine a cause-effect relationship. Changes in outcomes could thus be attributable in part to regression to the mean and confounding variables. Because of this, we focused our analysis on engagement metrics, and we plan to conduct controlled studies focusing on health outcomes in the future. Second, despite the large overall sample size, the asthma and depressive symptom cohort sizes were small, and as such findings for those cohorts should be interpreted cautiously. Additionally, PHQ-9 scores were only available for

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a subset of the group; however, this was mitigated by the large effect size seen between baseline and follow-up scores. Lastly, we were limited to the data that was available either from the program itself or the HIE partner. While the HIE partner has extensive coverage over provider sites, it does not include every provider site and thus may miss some provider visits. Future analyses could prospectively collect data for outcomes of interest, for example pulmonary function test results for asthma, or utilize a comprehensive medical claims database in order to capture all health care utilization.

Despite these limitations, this study meaningfully strengthens the current evidence base for ECM in high-need pediatric populations. Most of the limited literature on ECM in pediatrics involves children with medical complexity rather than more broadly-defined complex needs [27]. Research on pediatric patients with complex needs is sparse, but some initial studies of care coordination for children and adolescents with special health care needs have demonstrated promising results, just as this study has [28].

Conclusions

In summary, this study demonstrates that a community-integrated, technology-enabled approach to ECM can successfully engage high-need pediatric Medicaid patients. Despite the inability to draw causal conclusions from this study, the study findings, in particular the high retention and engagement rates with the program, improvements in how patients engaged with health care, and improvements in depressive symptoms, provide an early indication that the Pair Model has the potential to improve outcomes for these patients. Future studies should examine additional health outcomes as well as include control groups in order to build a more robust evidence base evaluating this approach to ECM.

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Data Availability

Deidentified data related to these findings can be made available upon reasonable request.

Authors' Contributions

Conceptualization: JLJ, SK, LM, NF
Data curation: LM
Formal analysis: JLJ, LM
Funding acquisition: NF
Methodology: JLJ, SK, LM
Supervision: JLJ, NF
Writing – original draft: JLJ, SK, MSI
Writing – review & editing: JLJ, SK, MSI, LM, NB, MKO, AO, NF

Conflicts of Interest

JLJ, SK, and MSI receive consulting fees from Pair Team. LM, NB, AO, and NF work for and hold equity in Pair Team. MKO has no conflicts of interest to report.

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Abbreviations

ADT: Admission Discharge Transfer
BHCM: Behavioral Health Care Manager
CalAIM: California Advancing and Innovating Medi-Cal
CBO: Community-Based Organization
CCS: California Children's Services
ECM: Enhanced Care Management
ED: emergency department
HIE: Health Information Exchanges
LCM: Lead Care Manager
NP: nurse practitioner
PHQ-9: Patient Health Questionnaire-9
RN: registered nurse
RR: rate ratio
SABA: short-acting beta 2-agonist
SMI: serious mental illness

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Explanatory Factors of Vaccination Dropout Among Children Aged 12 to 23 Months in the Kikula Health Zone, Democratic Republic of Congo: Cross-Sectional Analytical Study

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Abstract

Background: Vaccination is among the most effective public health interventions to reduce childhood morbidity and mortality. Despite World Health Organization recommendations, global immunization coverage has declined in recent years, with the COVID-19 pandemic causing the largest sustained backslide in routine immunization in 3 decades. In the Democratic Republic of Congo (DRC), full immunization coverage remains below 50%, hindered by inequities, supply shortages, and financing delays. In the Kikula Health Zone, administrative reports suggest coverage exceeding 100%, yet independent surveys consistently reveal low completion and high dropout rates between Bacillus Calmette-Guérin (BCG) and measles vaccines. No previous study has specifically examined determinants of dropping out in this setting.

Objective: This study assessed the prevalence and determinants of vaccination dropout between BCG and measles vaccines among children aged 12 to 23 months in the Kikula Health Zone, Likasi, DRC.

Methods: An analytical cross-sectional survey was conducted from April 22 to May 22, 2025, using 3-stage cluster sampling to recruit 300 mother-child pairs. Vaccination status was verified using cards; for children without documentation, caregiver recall and health facility registers were used to minimize misclassification. Structured questionnaires captured sociodemographic data, child characteristics, maternal knowledge, perceptions of services, and health system access. Dropout was defined as receipt of BCG but not the measles vaccine. Bivariate associations were tested using chi-square tests, and multivariate logistic regression identified independent predictors, with robust SEs to account for clustering. Ethics approval was obtained from the University of Kinshasa School of Public Health.

Results: Among 300 children, 115 (38.3%) had dropped out between BCG and measles vaccination, while 185 (61.7%) completed the schedule. Possession of a vaccination card was the strongest predictor: children without a card had 30-fold higher odds of dropout (adjusted odds ratio 30.9, 95% CI 11.6 82.0; $P<.001$). Other factors associated with dropout in bivariate analysis included shorter residence duration (≤5 y), lower maternal education, and nonuse of child health services, although these lost significance in multivariate models. Maternal knowledge gaps were notable: 169 (56.3%) did not know their child's vaccination status and 148 (49.3%) expressed fear of side effects. Service perceptions were generally positive (participants reporting good reception: n=294, 98%), but 108 (36%) experienced waiting times of 1 to 2 hours. The exclusion of undocumented children likely led to underestimation of dropout prevalence.

Conclusions: Vaccination dropout between BCG and measles remains high in the Kikula Health Zone, driven primarily by lack of vaccination cards and maternal knowledge gaps. Administrative coverage data (>100%) mask substantial dropout, underscoring the need for improved documentation, maternal education, and targeted outreach. Programmatic implications include strengthening card management, deploying mobile vaccination units, and enhancing community reminders. Findings highlight the importance of addressing both demand and supply-side barriers to reduce dropout and improve equity in immunization coverage in the DRC.

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KEYWORDS

vaccination dropout; immunization coverage; child health; Democratic Republic of Congo; maternal knowledge; health system factors

Introduction

Vaccination is recognized as one of the most effective public health strategies for reducing childhood morbidity and mortality. The World Health Organization (WHO) recommends that all children receive vaccines against tuberculosis, diphtheria, pertussis, tetanus, poliomyelitis, measles, hepatitis B, *Haemophilus influenzae* type b, pneumococcus, rubella, and yellow fever before their first birthday in endemic countries [1]. Despite these recommendations, global immunization coverage has declined in recent years. Between 2019 and 2021, coverage with the third dose of the diphtheria-tetanus-pertussis vaccine (DTP3) fell from 86% to 81%, leaving 25 million children without full protection, including 18.2 million "zero-dose" children [2]. Similar declines were observed for the first dose of measles-containing vaccine (MCV1), which dropped from 85% to 81% [2]. The COVID-19 pandemic contributed to the largest sustained backslide in routine immunization in 3 decades, disproportionately affecting low- and middle-income countries [3,4].

In the WHO African Region, progress has remained limited. DTP3 coverage increased only modestly from 70% to 74% between 2013 and 2019, while MCV1 coverage declined slightly from 70% to 69% [1]. Updated assessments from 2023 confirm that Africa continues to account for the highest proportion of zero-dose children globally, driven by persistent inequities, service disruptions, and health system weaknesses [5]. In 2021, an estimated 25 million African children were not vaccinated, including 734,000 in the Democratic Republic of Congo (DRC) [1].

In the DRC, the Expanded Programme on Immunization aims to achieve ≥90% coverage for all antigens. The national immunization schedule recommends Bacillus Calmette-Guérin (BCG) at birth; 3 doses of DTP-HepB-Hib at 6, 10, and 14 weeks; and oral polio vaccine, pneumococcal conjugate vaccine, rotavirus vaccine, and measles vaccine at 9 months. However, full immunization coverage remains below 50%. The 2017 - 2018 Multiple Indicator Cluster Survey (MICS) reported that only 35% of children aged 12 to 23 months were fully vaccinated, while 20% had received no vaccines at all [6,7]. Financing delays, recurrent supply shortages, and geographic inequities are major contributors to low coverage [6,7]. Recent multicountry analyses in sub-Saharan Africa confirm that maternal education, socioeconomic status, and health system accessibility remain key determinants of incomplete immunization [8,9].

In the Haut-Katanga province, administrative data suggested that 88.3% of children aged 0 to 11 months were fully vaccinated in 2021. Yet, vaccine-preventable diseases persisted: 1347 measles cases (including 349 zero-dose children), 34 acute flaccid paralysis cases, 101 meningitis cases, 14 neonatal tetanus cases, and 74 cholera cases. The BCG-measles dropout rate reached 11.4%, representing 35,680 children who did not complete their vaccination schedule [10]. In the Kikula Health Zone, administrative coverage was reported at 113.7% in 2022, but independent surveys conducted between 2020 and 2023 revealed that only 26% of children aged 12 to 23 months were fully vaccinated, with no improvement over time [11]. The validated dropout rate in this study was 38.3%, replacing earlier contextual estimates of 26% from prior surveys. This discrepancy between administrative data and field-based findings highlights structural, social, and health system factors influencing vaccination dropout.

No prior study has specifically examined the determinants of vaccination dropout in the Kikula Health Zone, representing a critical evidence gap. Guided by the Andersen behavioral model of health service use [8] and the health belief model [9], which emphasize predisposing, enabling, and perception-related factors influencing health-seeking behavior, this study aimed to assess the prevalence and determinants of vaccination dropout between BCG and measles vaccines among children aged 12 to 23 months in the Kikula Health Zone, Likasi, DRC.

Methods

Study Design and Setting

We conducted an analytical cross-sectional study between April 22 and May 22, 2025, in the Kikula Health Zone, Likasi city, Haut-Katanga province, DRC. The zone includes urban and periurban health areas with heterogeneous access to immunization services. The Kikula Health Zone was purposively selected due to its high vaccination dropout rate and the documented discrepancy between administrative coverage (>100%) and survey-based estimates (<30%).

Study Population and Eligibility Criteria

The study population consisted of children aged 12 to 23 months and their mothers or primary caregivers.

Inclusion Criteria

The inclusion criteria were as follows: children aged 12 to 23 months at the time of the survey, residence in the health zone for 6 months or more, presence of the mother or primary caregiver, and provision of written informed consent.

Exclusion Criteria

The exclusion criteria were as follows: refusal to participate and children severely ill and unable to participate.

Determination of Vaccination Status

Children with vaccination cards had their immunization status verified directly by card inspection, and children without vaccination cards were also included in this study. For these cases, vaccination status was determined through caregiver recall and, when available, verification against health facility registers. This approach ensured that all eligible children were represented in the study while acknowledging the potential for misclassification bias.

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Sampling Strategy

A three-stage cluster sampling technique was applied. First, health areas were selected using probability proportional to size. Second, streets or segments were randomly selected within each health area, with support from community health workers. Third, households were visited systematically (eg, every third household). If multiple eligible children were present, the youngest was selected to reduce recall bias. This approach ensured representativeness despite the absence of a complete sampling frame.

Sample Size

Sample size was calculated using the Schwartz formula for cross-sectional studies:

$$n=Z^2\times P(1-P)/d^2$$

where Z=1.96 (95% confidence level), P=.26 (dropout prevalence from previous Kikula surveys), and Cohen d=0.05 (margin of error).

The initial estimate (n=296) was adjusted for a design effect of 1.5 and rounded to 300 to account for nonresponse. In total, 322 households were approached, and 300 households completed the survey (response rate 93.2%).

Recruitment Procedures

Prior to data collection, meetings were held with health zone authorities and community health workers to explain objectives and obtain authorization. Investigators introduced themselves at households, explained the study, verified eligibility, and obtained written consent. Noneligible or refusing households were skipped according to the sampling interval. Daily supervision ensured adherence to protocol and data quality.

Data Collection

Data were collected using a structured, interviewer-administered questionnaire covering maternal sociodemographic characteristics (eg, age, education, marital status, occupation, religion, and duration of residence), child characteristics (eg, age, sex, and birth order), vaccination status verified by card, maternal knowledge (eg, importance of vaccination, schedule, vaccine-preventable diseases, and adverse events following immunization), perceptions of services (eg, reception, waiting time, information, vaccine availability, and perceived cost), and health system factors (eg, distance to the facility, participation in campaigns, and possession of a vaccination card).

The questionnaire was pretested in a nonselected health area. Investigators received training on ethical procedures, standardized administration, and card verification. Daily debriefings corrected inconsistencies.

Variables

Dependent Variable

The dependent variable was vaccination dropout, defined as receipt of BCG but not the measles vaccine. The dropout rate was calculated using the following formula: dropout rate=(number of children who received BCG but not measles)/(number of children who received BCG)×100. The variable was coded as 1=dropout and 0=no dropout.

Independent Variables

The independent variables included the following: maternal sociodemographics (eg, age ≤25 y vs >25 y; education: none, primary, secondary, and higher; marital status; occupation; religion; and residence ≤5 y vs >5 y), child characteristics (eg, age, sex, and birth order), maternal knowledge (eg, importance, schedule, diseases, and adverse events), perceptions of services (eg, reception, waiting time, information, availability, and cost), and health system factors (eg, distance: <5 km, 5 - 10 km, and >10 km; campaign exposure; and possession of a vaccination card).

Thresholds

Thresholds (eg, maternal age, distance, and residence duration) were based on regional literature and operational practice.

Operational Definitions of Key Variables

Use of child health services was defined as whether the child had ever been taken to a health facility for preventive or curative services (eg, growth monitoring, vaccination, and consultation) in the past 12 months. “Yes” indicated the child received at least one service, while “no” indicated the child had not received any service.

Recourse to child health service was defined as the caregiver’s reported use of formal health services for the child (eg, vaccination sessions, consultations, and campaigns). “Yes” indicated that the caregiver reported attending at least one vaccination session or campaign, while “no” indicated that the caregiver reported never attending.

Possession of a vaccination card was defined as whether the caregiver could present the child’s vaccination card at the time of the survey. “Yes” indicated that the card was available and verified, while “no” indicated that the card was absent, and vaccination status was determined by recall and/or registers.

Data Management

Incomplete questionnaires and cases without vaccination cards were excluded. Data were entered into Epi Info (version 7.2.3.1; Centers for Disease Control and Prevention), cleaned, and then exported to SPSS (version 26; IBM Corp). A partial double-entry procedure was performed to check consistency. No imputation was applied.

Statistical Analysis

Data analysis was performed using descriptive, bivariate, and multivariate analyses:

- Descriptive analysis—frequencies and percentages were calculated for categorical variables, while means or medians were calculated for continuous variables.
- Bivariate analysis—chi-square or Fisher exact tests were used. Variables with P<.20 were retained for multivariate analysis.
- Multivariate analysis—logistic regression was performed to estimate adjusted odds ratios (AORs) with 95% CIs. Robust SEs were used to account for clustering.

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Multicollinearity was assessed using variance inflation factors. Statistical significance was set at $P<.05$.

Extremely high AORs (eg, >30,000) were interpreted cautiously, acknowledging that they likely reflect sparse data or near-perfect separation rather than precise effect sizes.

Ethical Considerations

Ethics approval was obtained from the Ethics Committee of the School of Public Health, University of Kinshasa (ESP/CE/099/2023). Written informed consent was obtained from all participants. Data were anonymized, coded, and securely stored. No financial incentives were provided to participants, in accordance with national guidelines. The study results represented conservative estimates due to the exclusion of children without documented vaccination records.

Results

Overview

Among 300 children aged 12 to 23 months included in the survey, 115 (38.3%) had dropped out between BCG and measles vaccination, while 185 (61.7%) completed the schedule (Table 1).

Most respondents were mothers (295/300, 98.3%). Children were evenly distributed by sex (male: n=153, 51% and female: n=147, 49%). Most mothers were aged 25 years or younger (n=247, 82.3%). Education levels were no schooling (n=7, 2.3%), primary (n=70, 23.3%), secondary (n=207, 69.0%), and higher or university (n=16, 5.3%). Most mothers were housewives (n=230, 76.7%) and married (n=259, 86.3%). Protestant affiliation was predominant (n=164, 54.7%). Duration of residence exceeded 5 years for 174 (58%) mothers, while 126 (42%) had lived in the area for 5 years or less (Table 2).

Table . Vaccination status of children aged 12 to 23 months in the Kikula Health Zone, Likasi, Democratic Republic of Congo, April to May 2025 (cross-sectional survey).

Variables	Participants (N=300), n (%)
Vaccination abandonment	
Yes	115 (38.3)
No	185 (61.7)
Detention of vaccination card	
Yes	220 (73.3)
No	80 (26.7)
Respect for vaccination appointment	
Yes	201 (67.0)
No	99 (33.0)
Use children’s vaccines	
Yes	258 (86.0)
No	42 (14.0)

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Table . Sociodemographic characteristics of mothers or caregivers and children aged 12 to 23 months in the Kikula Health Zone, Likasi, Democratic Republic of Congo, April to May 2025.

Variables	Effective (N=300), n (%)
Child's guardian	
Others	5 (1.7)
Mother or father	295 (98.3)
Sex of the child	
Male	153 (51)
Female	147 (49)
Level of education	
No schooling	7 (2.3)
Primary	70 (23.3)
Secondary	207 (69.0)
Higher or university	16 (5.3)
Daily occupation	
Unemployed	5 (1.7)
Housewives	230 (76.7)
Workers	61 (20.3)
Self-employed	4 (1.3)
Marital status	
Single	17 (5.7)
Married	259 (86.3)
Widow	2 (0.7)
Divorced	22 (7.3)
Religion	
No religion	6 (2.0)
Catholic	95 (31.7)
Protestant	164 (54.7)
Muslim	3 (1.0)
Kimbanguist	11 (3.7)
Ancestral	21 (7.0)
Age (years)	
>25	53 (17.7)
≤25	247 (82.3)
Stays in the quarter or village (years)	
>5	174 (58.0)
≤5	126 (42.0)

Vaccination was considered "very important" by 103 (34.3%) of 300 mothers and "important" by 178 (59.3%) mothers. Only 8 (2.7%) mothers considered vaccination "not important." More than half (n=169, 56.3%) of the mothers did not know their child's vaccination status. Knowledge of adverse events following immunization was reported by 158 (52.7%) mothers, while 142 (47.3%) were unaware. Fear of side effects was expressed by 148 (49.3%) mothers. Nearly all households (n=289, 96.3%) reported low income. Concerns about vaccine safety for the child were expressed by 195 (65%) mothers (Table 3).

Reception at health facilities was rated "good" by 294 (98%) of 300 respondents. Waiting times were less than 1 hour for 163 (54.3%) respondents, 1 to 2 hours for 108 (36%), and more than 2 hours for 29 (9.7%). Information about vaccines was received by 234 (78%) respondents. Distance to facilities was less than 5 km for 223 (74.3%) respondents, 5 to 10 km for 54

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(18%), and more than 10 km for 23 (7.7%). Most respondents (n=271, 90.3%) reported having received information about vaccination campaigns (Table 4).

Table . Maternal knowledge and attitudes toward vaccination among caregivers of children aged 12 to 23 months in the Kikula Health Zone, Likasi, Democratic Republic of Congo, April to May 2025.

Variables	Effective (N=300), n (%)
Importance of vaccination	
Very important	103 (34.3)
Important	178 (59.3)
Not important	8 (2.7)
Moderately important	11 (3.7)
Knowledge of who administers vaccines	
Failing	272 (90.7)
Acceptable	24 (8.0)
Good	4 (1.3)
Child’s vaccination status	
Does not know	169 (56.3)
Knows	131 (43.7)
Knowledge of adverse events following immunization	
Does not know	142 (47.3)
Knows	158 (52.7)
Fear of side effects	
No	152 (50.7)
Yes	148 (49.3)
Cost of living for mothers or child care providers	
Lower	289 (96.3)
Higher	11 (3.7)
Concern about the vaccine for the baby	
No	105 (35.0)
Yes	195 (65.0)

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Table . Perceptions of immunization services among caregivers of children aged 12 to 23 months in the Kikula Health Zone, Likasi, Democratic Republic of Congo, April to May 2025.

Variables	Effective (N=300), n (%)
Reception at health facility	
Bad	6 (2.0)
Good	294 (98.0)
Waiting time (hours)	
<1	163 (54.3)
1 - 2	108 (36.0)
>2	29 (9.7)
Information about the nature of the vaccine used	
No	66 (22.0)
Yes	234 (78.0)
Distance from the house to the vaccination service (km)	
<5	223 (74.3)
5 - 10	54 (18.0)
>10	23 (7.7)
Perceived cost of vaccination	
Free	263 (87.7)
Moderate	35 (11.7)
High	2 (0.6)
Information received about vaccination campaigns	
No	29 (9.7)
Yes	271 (90.3)

Bivariate Analysis

Dropout was significantly associated with the following: duration of residence of 5 years or less (odds ratio [OR] 1.95, 95% CI 1.20 - 3.72; *P*=.007), nonuse of child health services (OR 4.62, 95% CI 2.20 - 9.01; *P*<.001), absence of a vaccination card (OR 44.19, 95% CI 18.98 - 102.91; *P*<.001), and lower maternal education (no schooling: OR 42.0, 95% CI 3.16 - 556.5; *P*=.001 and primary education: OR 7.41, 95% CI 1.56 - 35.1; *P*=.001; Table 5).

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Table . Factors associated with vaccination dropout between Bacillus Calmette-Guérin and measles vaccines among children aged 12 to 23 months in the Kikula Health Zone, Likasi, Democratic Republic of Congo, April to May 2025 (bivariate and multivariate logistic regression).

Variables	Vaccination abandonment		Bivariate analysis (chi-square)		Multivariate analysis	
	Yes (n=115), n (%)	No (n=185), n (%)	OR[a] (95% CI)	*P* value	Adjusted OR (95% CI)	*P* value
Age group (years)						
>25	94 (81.7)	153 (82.7)	0.9 (0.51-1.72)	.83	1.0 (0.4-2.5)	.92
≤25	21 (18.3)	32 (17.3)	1[b]	—[c]	1	—
Stays in the quarter or village (years)						
>5	37 (32.2)	89 (48.1)	1	—	1	—
≤5	78 (67.8)	96 (51.9)	2.0 (1.20-3.72)	.007	1.6 (0.83-3.28)	.16
Use children's vaccines						
No	29 (25.2)	13 (7.0)	4.6 (2.20-9.01)	.001	1.0 (0.38-2.83)	.94
Yes	86 (74.8)	172 (93.0)	1	—	1	—
Possession of a child health or vaccination card						
No	73 (63.5)	7 (3.8)	44.2 (18.98-102.91)	<.001	30.9 (11.6-82.0)	<.001
Yes	42 (36.5)	178 (96.2)	1	—	1	—
Educational level						
No schooling	6 (5.2)	1 (0.5)	42.0 (3.16-556.50)	<.001	3.7 (0.10-142.17)	.48
Primary	36 (31.3)	34 (18.4)	7.4 (1.56-35.06)	.001	2.6 (0.26-24.98)	.42
Secondary	71 (61.7)	136 (73.5)	3.7 (0.80-16.56)	.07	3.7 (0.43-31.93)	.24
Higher or university	2 (1.7)	14 (7.6)	1	—	1	—
Daily occupation						
Unemployed	3 (2.6)	2 (1.1)	1	—	1	—
Housewives	99 (86.1)	131 (70.8)	0.5 (0.08-3.07)	.45	3.1 (0.11-83.13)	.50
Workers	10 (8.7)	51 (27.6)	0.1 (0.02-0.88)	.02	4.0 (0.51-31.82)	.19
Self-employed	39 (33.9)	1 (0.5)	26.0 (1.79-376.32)	.001	10.8 (1.09-106.84)	.04
Marital status						
Single	4 (3.5)	13 (7.0)	1	—	1	—
Married	96 (83.5)	163 (88.1)	1.9 (0.60-6.03)	.26	1.2 (0.17-8.43)	.86
Widow	2 (1.7)	0 (0.0)	ind[d]	—	—	—
Divorced	13 (11.3)	9 (4.9)	4.7 (1.15-19.16)	.03	1.0 (0.26-4.08)	.97
Religion						
No religion	5 (4.3)	1 (0.5)	2.5 (0.10-62.60)	—	1.4 (0.03-77.83)	.86
Catholic	23 (20.0)	72 (38.9)	0.1 (0.01-1.84)	—	3.5 (0.20-63.42)	.39
Protestant	72 (62.6)	92 (49.7)	0.4 (0.03-4.40)	—	2.2 (0.13-38.39)	.57
Muslim	2 (1.7)	1 (0.5)	1	—	4.0 (0.13-116.66)	.43
Kimbanguist	4 (3.5)	7 (3.8)	0.3 (0.01-4.23)	—	4.3 (0.20-92.66)	.35
Ancestral	9 (7.8)	12 (6.5)	0.4 (0.02-4.80)	.005	1.4 (0.03-77.83)	.86
Importance of vaccination						
Very important	39 (33.9)	64 (34.6)	1	—	—	—
Important	61 (53.0)	117 (63.2)	0.9 (0.51-1.41)	—	0.9 (0.42-1.81)	.73
Not important	6 (5.2)	2 (1.1)	4.9 (0.94-25.61)	—	0.6 (0.03-10.30)	.72

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Variables	Vaccination abandonment		Bivariate analysis (chi-square)		Multivariate analysis	
	Yes (n=115), n (%)	No (n=185), n (%)	OR[a] (95% CI)	*P* value	Adjusted OR (95% CI)	*P* value
Moderately important	9 (7.8)	2 (1.1)	7.4 (1.51-35.96)	.005	2.5 (0.28-22.12)	.41
Knowledge of who administers vaccines						
Failing	111 (96.5)	161 (87.0)	0.2 (0.02-2.23)	—	3.8 (0.26 - 56.46)	.33
Acceptable	1 (0.9)	23 (12.4)	0.0 (0.00-0.29)	—	29.6 (1.29 - 680.31)	.03
Good	3 (2.6)	1 (0.5)	1	—	—	—
Child's vaccination status						
Does not know	82 (71.3)	87 (47.0)	2.8 (1.70-4.59)	—	1.7 (0.74-4.05)	.21
Knows	33 (28.7)	98 (53.0)	—	—	—	—
Knowledge of adverse events following immunization						
Does not know	78 (67.8)	64 (34.6)	4.0 (2.42-6.53)	—	1.3 (0.54-3.26)	.53
Knows	37 (32.2)	121 (65.4)	—	—	—	—
Fear of side effects						
No	74 (64.3)	78 (42.2)	2.5 (1.53-4.00)	—	1.4 (0.66-2.82)	.39
Yes	41 (35.7)	107 (57.8)	—	—	—	—
Waiting time (hours)						
<1	82 (71.3)	81 (43.8)	1	—	—	—
1-2	24 (20.9)	84 (45.4)	0.3 (0.1-0.48)	—	0.9 (0.30-2.48)	.80
>2	9 (7.8)	20 (10.8)	0.4 (0.19-1.03)	—	1.3 (0.46-3.78)	.59
Distance from the house to the vaccination service (km)						
<5	82 (71.3)	141 (76.2)	1	—	1.0 (0.265-3.870)	.99
5 - 10	21 (18.3)	33 (17.8)	1.1 (0.59-2.01)	—	1.0 (0.265-3.870)	.99
>10	12 (10.4)	11 (5.9)	1.9 (0.79-4.44)	—	0.9 (0.210-3.829)	.88

[a]OR: odds ratio.

[b]OR=1 indicates the reference category.

[c]Not applicable.

[d]ind: indeterminate (n value too small).

Multivariate Analysis

After adjustment, only possession of a vaccination card remained a strong independent predictor of dropout: children without a vaccination card had an AOR of 30.9 (95% CI 11.6 - 82.0; *P*<.001).

Extremely high ORs and wide CIs should be interpreted with caution. These values likely reflect sparse data or near-perfect separation rather than precise effect sizes.

Discussion

Principal Findings

This analytic cross-sectional study of 300 mother-child pairs in the Kikula Health Zone revealed a validated vaccination dropout rate of 38.3% between BCG and measles vaccines. Possession of a child health or vaccination card was the strongest independent predictor of dropout, with children lacking cards having nearly 31-fold higher odds of incomplete immunization. Other factors, such as shorter duration of residence, lower maternal education, and nonuse of child health services, were significant in bivariate analysis but lost significance in multivariate models, likely due to collinearity and small subgroup sizes. These findings highlight the critical role of vaccination documentation and maternal knowledge in sustaining immunization coverage.

Interpretation in Light of Theoretical Frameworks

The results can be interpreted through the Andersen behavioral model of health service use [8] and the health belief model [9]. Predisposing factors such as maternal age, education, and marital status influenced vaccination behavior, although their effects diminished after adjustment. Enabling factors such as possession of a vaccination card and use of child health services facilitated completion of the schedule. Perceptions such as maternal fear of side effects and lack of knowledge about vaccination status contributed to dropout. These frameworks underscore that

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vaccination behavior is shaped not only by access but also by perceptions and enabling resources.

Perceptions—maternal fear of side effects and lack of knowledge about vaccination status contributed to dropout.

Comparison With Previous Studies

Our findings are consistent with national surveys (MICS 2017 - 2018) reporting low full immunization coverage (<40%) and high dropout rates in the DRC [6,7]. These findings highlight the critical role of vaccination documentation and maternal knowledge in sustaining immunization coverage. Similar associations between maternal education, vaccination documentation, and service use have been reported in other sub-Saharan African settings [5]. However, the magnitude of the effect of card possession in this study (AOR 30.9, 95% CI 11.6 - 82.0) is unusually high, reflecting the centrality of documentation in this context. Extremely high ORs and wide CIs should be interpreted with caution, as they likely reflect sparse data or near-perfect separation rather than precise effect sizes [12].

Implications for Programmatic Action

The discrepancy between administrative coverage (>100%) and survey-based findings (38.3% dropout) highlights systemic weaknesses in data quality [10,11]. Inflated administrative reports may delay corrective measures and misguide resource allocation. Programmatic priorities should include strengthening card management and documentation systems, enhancing maternal education and awareness of vaccination schedules, deploying mobile vaccination units to reach underserved households, improving communication strategies to address fears of side effects, and integrating dropout monitoring into routine supervision to ensure timely corrective action.

These measures are essential to reduce dropout and improve equity in immunization coverage in the DRC.

Limitations

This study has several limitations. First, the inclusion of children without vaccination cards, whose immunization status was determined through caregiver recall and health facility registers, may have introduced misclassification bias. Therefore, the results should be interpreted with caution, although this approach allowed for a more comprehensive assessment of dropout determinants. Second, the cross-sectional design precludes causal inference. Third, some variables lost statistical significance in multivariate analysis due to collinearity and small subgroup sizes, which limits precision. Fourth, the study was conducted in a single health zone, which may restrict generalizability to other settings. Despite these limitations, the sample size (N=300) was adequate to detect significant associations, and the findings provide valuable insights for programmatic action.

Conclusions

Vaccination dropout between BCG and measles remains high in the Kikula Health Zone, driven primarily by lack of documentation and maternal knowledge gaps. Addressing these barriers through improved card management, maternal education, and targeted outreach is critical to strengthening immunization coverage. The findings underscore the need for accurate data, integrated monitoring, and context-adapted interventions to reduce dropout and achieve equitable immunization in the DRC.

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Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request

Authors' Contributions

Conceptualization: BMM (lead)
Methodology: JNK (lead)
Data curation: HTK (supporting), PKWI (supporting)
Formal analysis: FIM (lead), PGM (supporting)
Investigation: PKWI (lead), HTK (equal)
Project administration: FIM (lead), BMM (supporting)
Resources: PGM (supporting)
Supervision: FIM (lead)
Validation: BMM (supporting), JNK (supporting)

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Visualization: HTK (lead), PKWI (supporting)
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Conflicts of Interest

None declared.

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Abbreviations

AOR: adjusted odds ratio
BCG: Bacillus Calmette-Guérin
DRC: Democratic Republic of Congo
DTP3: third dose of the diphtheria-tetanus-pertussis vaccine
MCV1: first dose of measles-containing vaccine
MICS: Multiple Indicator Cluster Survey
OR: odds ratio
WHO: World Health Organization

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Modeling Zero-Dose Children in Ethiopia: A Machine Learning Perspective on Model Performance and Predictor Variables

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Abstract

Background: Despite progress in childhood vaccination, many children in low- and middle-income countries, including Ethiopia, remain unvaccinated, presenting a significant public health challenge. The Immunization Agenda 2030 (IA2030) seeks to halve the number of unvaccinated children by identifying at-risk populations, but effective strategies are limited. This study leverages machine learning (ML) to identify Ethiopian children aged 12-35 months who are at higher risk of being zero dose (ZD). By analyzing demographic, socioeconomic, and health care access data, the study developed predictive models using different algorithms. The findings aim to inform targeted interventions, ultimately improving vaccination coverage and health outcomes.

Objective: This study aimed to develop an ML model to predict ZD children and to identify the most influential predictors of ZD in Ethiopia.

Methods: We examined how well the predictive algorithms can characterize a child at risk of being ZD based on predictor variables sourced from the recent National Immunization Evaluation Survey data. We applied supervised ML algorithms with the survey datasets, which included 13,666 children aged 12-35 months. Model performance was assessed using accuracy, area under the curve, precision, recall, and F_1-score. We applied Shapley Additive analysis to identify the most important predictors.

Results: The Light Gradient Boosting Machine (LGBM), Random Forest, Extreme Gradient Boosting (XGBoost), and AdaBoost classifiers effectively identified most ZD children as being at high risk. Among these, LGBM demonstrated the best performance, achieving an accuracy of 93%, an area under the curve of 97%, a precision of 94%, and a recall of 91%. The most significant features impacting the model included poor perception of vaccination benefits, lack of antenatal care utilization, distance from immunization services, and absence of maternal tetanus toxoid vaccinations.

Conclusions: The developed ML models effectively predict children at risk of being ZD, with the LGBM model showing the best performance. This model can guide targeted interventions to reduce ZD prevalence and address vaccination inequities. Key predictors include access to immunization sites, maternal health service utilization, and perceptions of immunization benefits. By focusing on these vulnerable groups, public health efforts can tackle disparities in vaccination coverage. Enhancing maternal care, raising caregiver awareness, and improving immunization access through outreach can significantly reduce the number of ZD children.

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KEYWORDS

modeling; zero dose; children; machine learning; Ethiopia

Introduction

Child immunization is a cornerstone of public health, essential for safeguarding against life-threatening diseases and promoting the health of future generations [1]. Globally, significant advancements have been made in immunization programs, resulting in higher coverage rates [2] and a corresponding decline in vaccine-preventable disease [3]. However, as of 2023,

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approximately 14.5 million children worldwide didn't receive the first dose of diphtheria, tetanus, and pertussis (DTP1) containing vaccines [4], a widely used indicator of access to immunization services [5]. This high number of zero-dose (ZD) children continues to be a pressing issue, intensifying health inequalities and heightening the likelihood of vaccine-preventable disease outbreaks [6]. These ZD children remain at high risk, creating considerable hurdles for public health efforts [7-9].

In a substantial portion of these ZD children, about 60% are concentrated in 10 low- and middle-income countries, including Ethiopia. Despite notable achievements in improving immunization coverage in Ethiopia, the country ranks third globally for ZD children, following Nigeria and India, accounting for 6% of the world's total [4].

Addressing the issue of children at risk of becoming ZD has emerged as a priority on both national and global agendas [10]. The Immunization Agenda 2030 (IA2030), endorsed by the World Health Assembly in November 2020, aims to reduce the number of ZD children by ensuring that every child is reached by 2030 [5]. However, effectively identifying and reaching these at-risk children poses significant operational challenges, and little is known about what strategies perform best.

Research in Ethiopia has identified various predictors of low immunization uptake, including low education levels and low wealth index [11-13], rural residence [12,14], limited access to health services [15,16], lack of antenatal care (ANC) and postnatal care (PNC) [13,15-18], home deliveries [13-16], absence of maternal tetanus toxoid (TT) vaccination [12,19], and poor caregiver knowledge [16]. However, there is a lack of evidence regarding how well these factors predict ZD status specifically and which factors are most relevant for optimal prediction.

Recent advancements in data science, coupled with available routine immunization data, present new opportunities to identify and reach at-risk children at both subnational and individual levels. Developing a robust algorithm to predict ZD children based on a set of variables could provide a valuable foundation for tailored interventions. Machine learning (ML) has emerged as a transformative tool in public health research particularly suited for this task which can capture complex relationships and interactions between variables [20-22]. Unlike traditional statistical methods that rely on predefined hypotheses, ML models can autonomously identify patterns and relationships within large datasets by learning from data rather than making prior assumptions [20,23,24]. This capability is particularly useful for multifactorial issues such as immunization uptake [25].

Using rule-based ML models can uncover hidden relationships among determinants of ZD children in large datasets, often represented through "if-then" statements that illustrate connections between variables [26]. This application of ML bridges the gap between theoretical research and practical applications, leading to advancements in the health care field [27].

This study aims to use ML algorithms to predict which Ethiopian children aged 12-35 months are at higher risk of being ZD and assess the predictive capabilities of the developed models. Findings from this study may provide actionable insights for policy makers and immunization program actors, informing the development of targeted strategies to effectively identify and reach those most at-risk children.

Methods

Study Design

The data for this study were sourced from the recent National Immunization Evaluation Survey in Ethiopia, which provides nationwide representation [28]. The survey included 11 regions and the 2 city administrations. A 2-stage stratified cluster sampling technique was used to select participants. The first stage is the enumeration areas (EAs), which served as clusters, randomly chosen with an urban-rural stratification approach, and the second stage is households within each EA. Sampling frames were prepared for each region and city administrations by the Ethiopian Statistical Services. The number of EAs required per region and city administration was determined based on the size within the stratum (study regions) and proportion of the Ethiopia population living in urban and rural areas (21.4% urban and 78.6% rural). A total of 468 EAs were randomly selected, comprising 100 from urban areas and 368 from rural regions, resulting in a total sample size of approximately 13,666 households with children aged 12 - 35 months.

We extracted information on immunization status for children aged 12 - 35 months. The vaccination status of children was assessed using 3 sources of information: caregiver reports, home-based vaccination cards, and facility-based records, following World Health Organization guidelines [29]. If a mother or a caregiver presented an immunization card, the child's vaccination status was assessed from that card. In cases where the card was unavailable, data collectors were instructed to verify the information at the nearest health facility if the caregiver reported that their child had been vaccinated. The mother's or caregiver's self-reports were considered only when neither the immunization card nor the facility records were available.

Using the operational definition set by Gavi, we defined a variable ZD status for each child, which is set to 1 if the child did not receive the first dose of the diphtheria, TTs, and pertussis-containing vaccine (DPT1), and set 0 otherwise [30,31].

We included a set of predictor variables or features to capture characteristics that have been associated with ZD status (Table 1). The factors influencing the outcome of interest are grouped into 3 groups: socioeconomic and demographic variables, health service utilization, and perceptions and attitudes. The first group of socioeconomic and demographic variables encompasses individual, household, and community-level characteristics that may affect the outcome of interest. The health service utilization represents the access to and use of various health care services, which can impact immunization status. The third category

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focuses on the perceptions or attitudes that individuals or caregivers have toward the benefits of immunization. All the 3 categories of the variables gathered during the survey.

Table . The predictor variables used for analysis were extracted from the recent National Immunization Evaluation Survey in Ethiopia, 2023.

Category	Description	Response/type of data
Socioeconomic and demographic factor		
Residency	Type of living arrangement	Categorical (urban and rural)
Region	Geographic area of residence	Nominal (eg, Afar, Amhara...)
Religion	Cultural beliefs influencing health behaviors	Nominal or categorical (orthodox, Muslim, protestant, and others)
Marital status	Relationship status of the mother or the caregiver	Categorical (married and living together, married, married but not living together, and not in marital union)
Mother's or caregiver's educational status	Level of formal education attained	Categorical (no, primary, secondary, and higher education)
Occupation of mothers or caregivers	Employment status and type of work	Nominal categorical data
Birth order	Position of a child in relation to their siblings within a family	Categorical (first, second, third, and fourth and above)
Wealth index	Measures economic status	Categorical (poor, middle, and rich)
Health service utilization		
ANC[a] follow-up	History of ANC visits for the index child	Categorical (Yes/No)
History of maternal tetanus diphtheria vaccine	Previous vaccinations received	Categorical (Yes/No)
Distance to immunization site	Perceived impact of distance on immunization access	Categorical ("big problem," "not a problem")
Place of delivery	Location where the child was born	Categorical (Home/Facility)
Postnatal care	Follow-up care received after childbirth	Categorical (Yes/No)
Perceptions and attitudes		
Mother's or caregiver's perceived benefits on immunization	Beliefs regarding the advantages of vaccination	Was Likert (categorized into poor or good)
Trust in health care provider	The belief of mothers or caregivers on the services provided	Categorized into poor or good

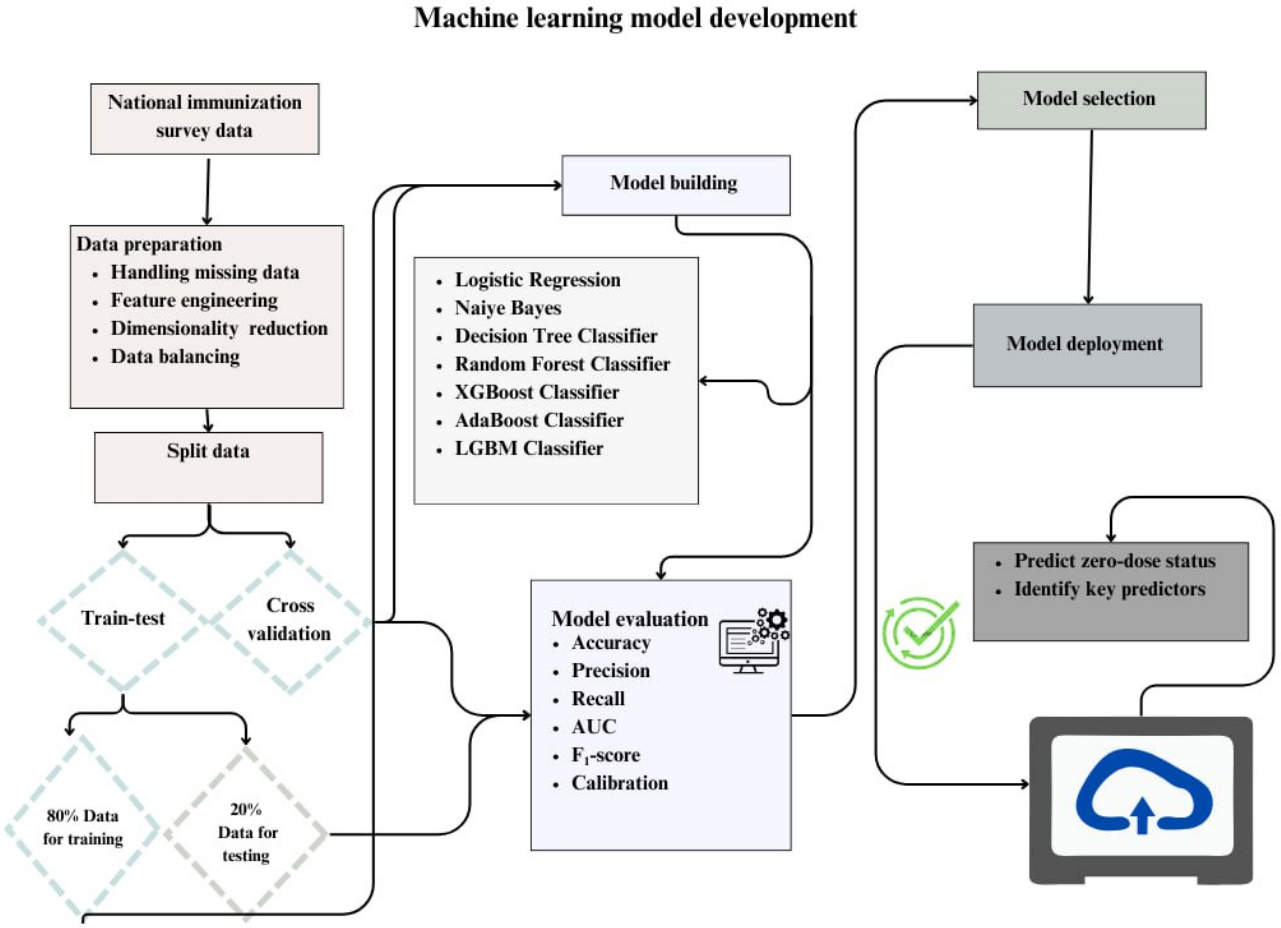
[a]ANC: antenatal care.

Data Preprocessing and Transformation

We implemented several preprocessing steps to enhance model performance. First, we addressed missing values in the independent variables using the k-nearest neighbor approach. We then transformed categorical variables into numerical format through one-hot encoding, which is essential for preparing data for ML models. To standardize feature ranges, we applied minimum-maximum scaling and mean normalization, ensuring comparability among features (Figure 1).

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Figure 1. Data preparation and analysis steps for zero-dose children prediction. AUC: area under the curve; LGBM: Light Gradient Boosting Machine.



We conducted sampling weight as instance weights during the training process for all algorithms. This was done by using the sample_weight parameter in the model's fitting functions, which adjusts the influence of each observation based on its probability of selection.

Next, we conducted a correlation analysis to identify and remove highly correlated features, thereby reducing multicollinearity and enhancing model robustness. Our correlation matrix showed a strong relation between parity and birth order (Figure 2), leading us to compute mutual information scores for each variable (Figure 3). This analysis highlighted ANC utilization and TT vaccination as significant predictors, while features such as marital status were excluded due to their minimal information value. Consequently, we retained birth order and omitted parity based on their scores.

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Figure 2. Correlation analysis matrix for predictor variables for zero-dose children, Ethiopia, 2023. ANC: antenatal care; PNC: postnatal care; TT: tetanus toxoid.

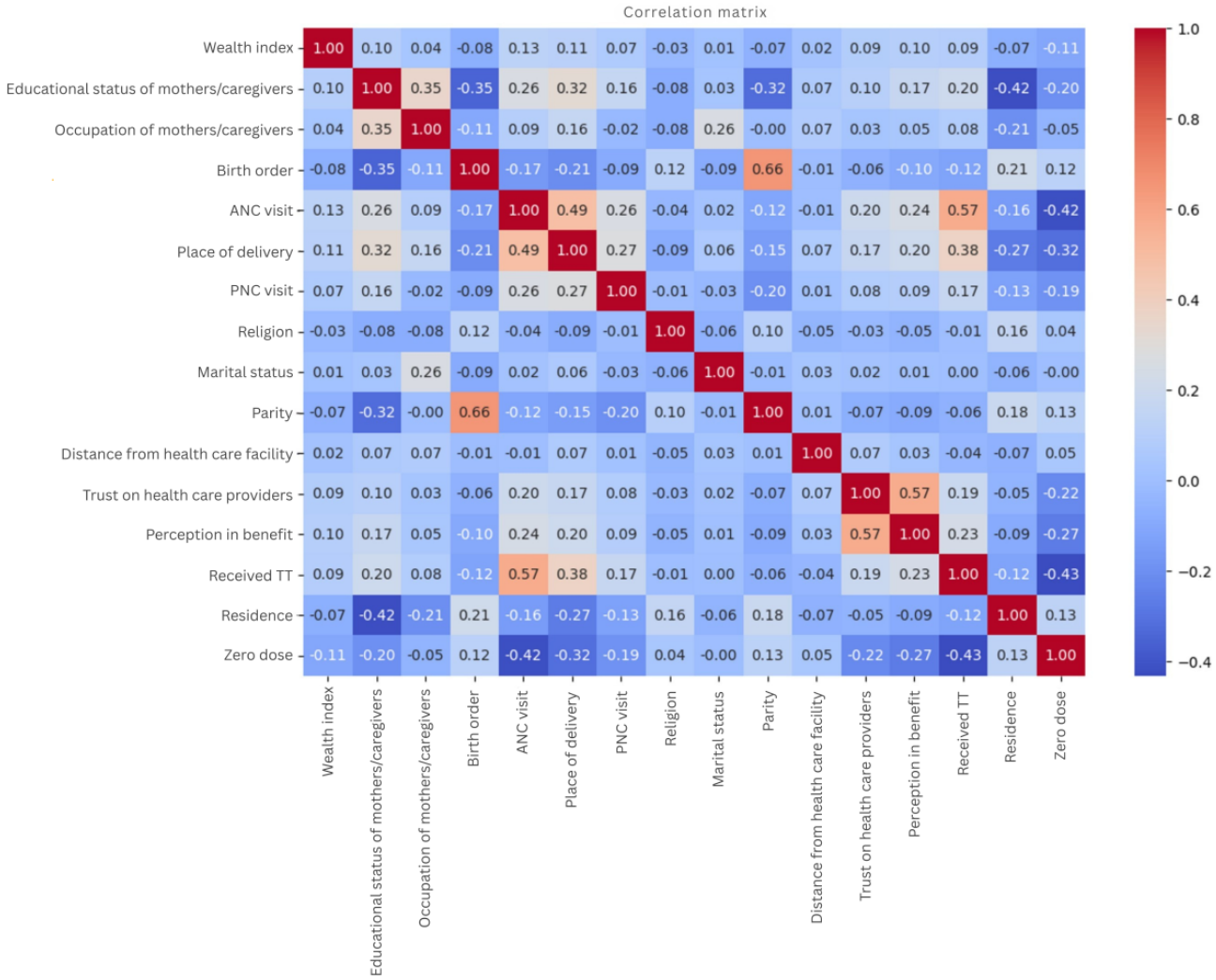
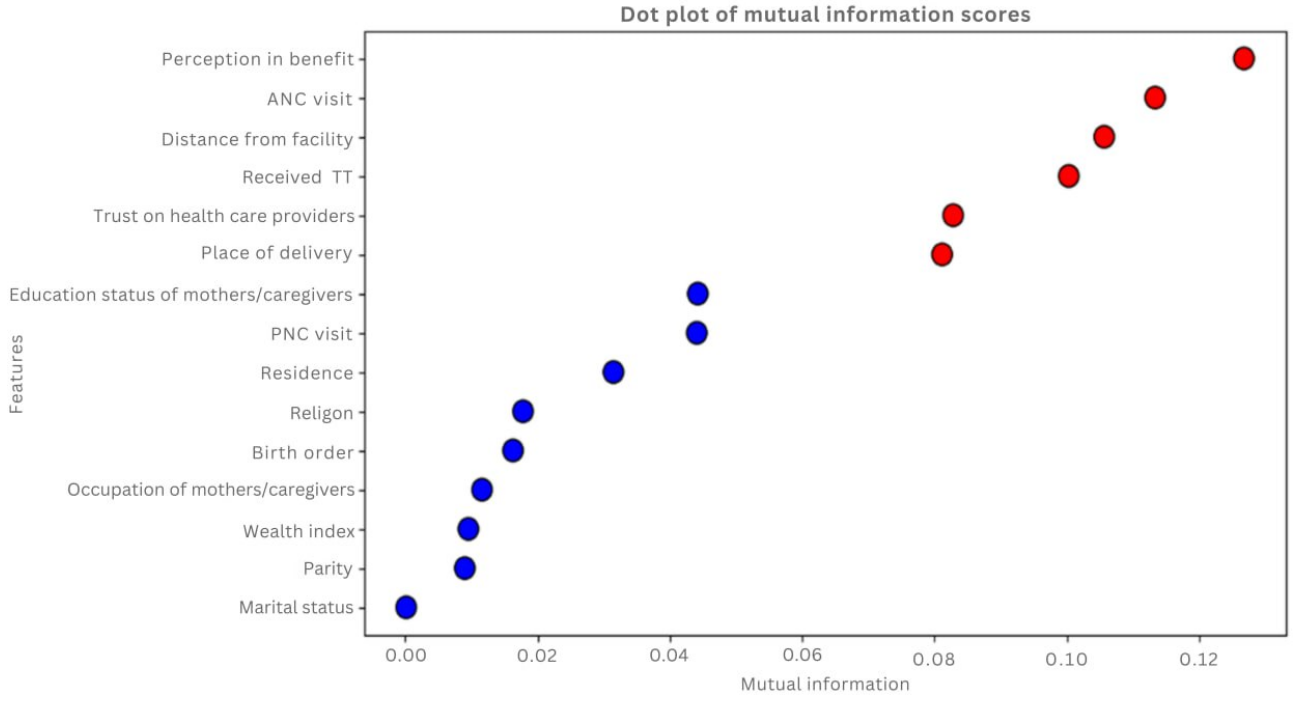


Figure 3. Mutual information score of predictor variables for zero-dose children, Ethiopia, 2023. ANC: antenatal care; PNC: postnatal care.



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For dimensionality reduction, we used Forward Selection, Backward Elimination, and Recursive Feature Elimination methods. We opted for Recursive Feature Elimination due to its effectiveness in identifying the most significant predictors while simplifying the dataset. To address class imbalance, we applied the Synthetic Minority Oversampling Technique, which balanced the dataset from an initial skew of 82% majority and 18% minority to an equal distribution. This balancing supports the development of robust predictive models and mitigates bias toward the majority class (Multimedia Appendix 1).

Model Development

After the preprocessing, we split the dataset into 80% for training and 20% for testing (Figure 1). To avoid overfitting and underfitting, we applied 10-fold cross-validation, dividing the data into 10-folds and using one for validation while training on the others. The final performance is averaged across all folds.

The outcome variable, known as the class, is a binary variable indicating ZD status. A ZD status of 1 denotes a ZD child, while 0 indicates a non-ZD child. We applied supervised learning algorithms to develop a model from the training data to accurately predict this outcome in the test data.

Given the categorical nature of the outcome variable, we used 7 classical classification algorithms: AdaBoost Classifier [32], Logistic Regression [33], Naive Bayes, Random Forest (RF) [34], Light Gradient Boosting Machine (LGBM) [35], Extreme Gradient Boosting (XGBoost) [35], and Decision Tree [36]. These models generate a predicted score between 0 and 1 for each child, which is then classified as ZD or non-ZD based on a defined threshold. Following the initial model comparison, hyperparametric tuning was conducted to further optimize the performance of the best performing algorithm using a RandomizedSearchCV with cross-validation. The search involved 100 iterations with each hyperparameter combination evaluated using 5-fold cross-validation. Finally, the performance of each model was tested before and after balancing the dataset to choose the best predictive model. The model comparison was carried out using the balanced dataset.

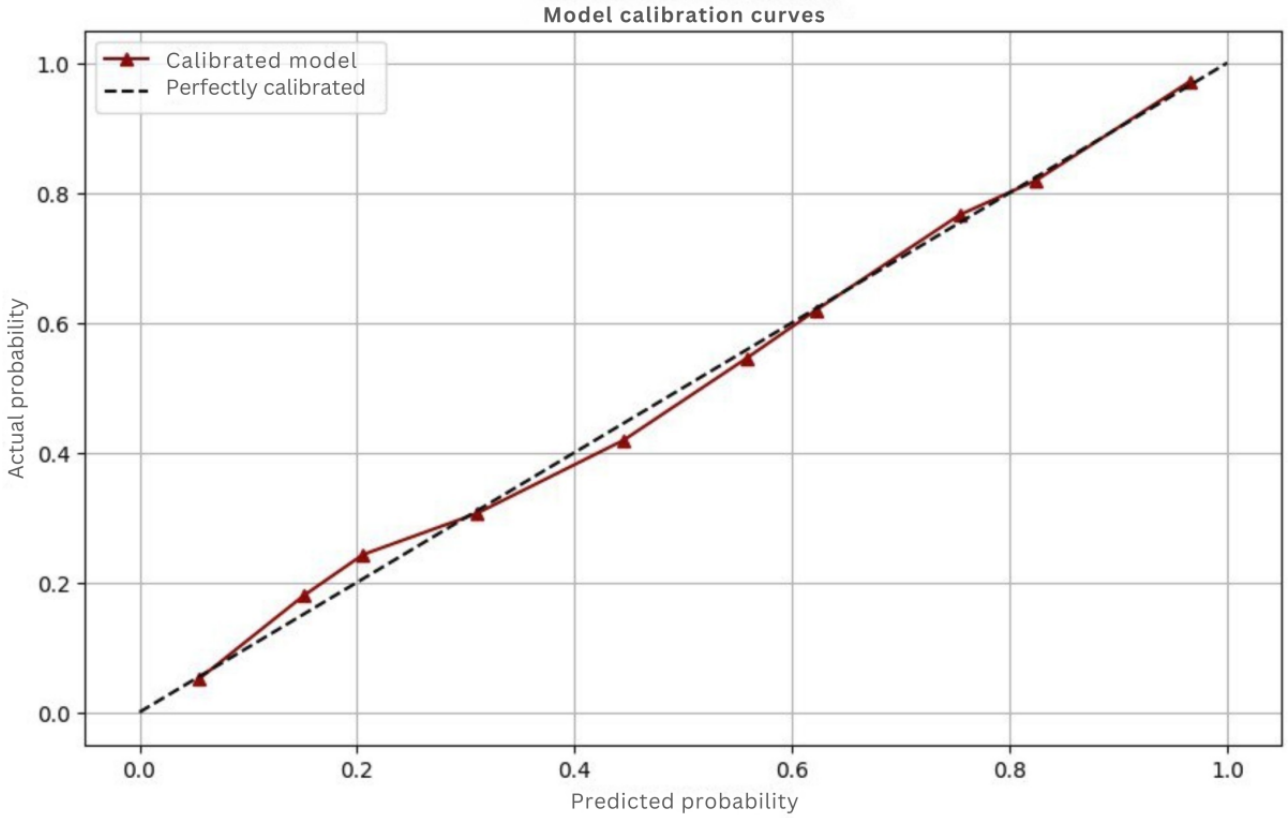
Model Evaluation

We evaluated model performance using both train-test split and cross-validation techniques, emphasizing both discrimination and calibration metrics to compare our classification of ZD status against the true ZD status of each child. Discrimination metrics included accuracy, precision, recall (sensitivity), F_1-score, and area under the curve and area under the receiver operating characteristic curve. Accuracy reflects the proportion of correctly classified instances among all tested cases [37], while precision indicates the ratio of true-positive predictions to all positive predictions [38]. Recall measures the proportion of actual positive cases that the model successfully identifies [39], and the F_1-score provides a balanced assessment of model performance, particularly useful in scenarios with class imbalances. In our application, as the objective is to assess the ability of a model to distinguish between positive and negative classes, area under the curve and area under the receiver operating characteristic curve emerged as the most critical measure, as it evaluates the model's ability to effectively distinguish between positive and negative classes by analyzing the trade-off between sensitivity and specificity [40].

In addition to discrimination metrics, we performed calibration to examine how well the predicted probabilities align with actual outcomes. While a model can demonstrate good discrimination, it may still exhibit biases in its risk predictions [41]. Calibration is essential to ensure that predicted probabilities accurately reflect the likelihood of outcomes. To visualize this alignment, we used calibration curves, which plot predicted probabilities against observed results (Figure 4). An ideally calibrated model would form a 45-degree diagonal line, signifying that predicted probabilities correspond closely to actual outcomes [42].

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Figure 4. Calibration plot.



Important Feature Selection

Our second objective is to identify the most important predictors of ZD children. To achieve this, we used the best-performing ML model to determine the key features associated with identifying ZD cases. We used a unified framework developed by Lundberg and Lee [43], known as SHAP (SHapley Additive Explanations). This approach is based on Shapley values from cooperative game theory, which assign a value to each feature based on its contribution to the prediction, taking into account all possible combinations of features [44]. A waterfall plot is then created to visualize the cumulative effect of individual features on specific predictions, illustrating how each feature influences the final output. In addition, a beeswarm plot summarizes the distribution of SHAP values across multiple instances, revealing the variability and significance of feature contributions.

Rule Generation

We used rule mining techniques to uncover patterns and relationships within our dataset. We used association rule mining to identify correlations between features through Apriori algorithms [45]. In addition, we applied classification rule mining to generate rules that predict class labels, aiding in the identification of key predictors for ZD children, and explored sequential rule mining to capture temporal patterns where relevant. Following the mining process, we generated actionable insights by formulating human-readable rules that outline conditions (antecedents) and outcomes (consequents) [46]. We assessed the quality of these rules using metrics such as confidence and lift to ensure their reliability and relevance [47].

Ethical Considerations

The research was implemented in compliance with national and international ethical principles. The University of Gondar has provided ethical approval (CMHSSH-UOG IRERC/3/7/2024) to conduct this analysis. For this analyses we used the existing data with primary consent. We used deidentified data (summary data without individuals' identity) to ensure confidentiality. We followed the international standard of strengthening the reporting of cross-sectional studies in epidemiology.

Results

Children's and Mothers' or Caregivers' Characteristics

A total of 13,666 samples of children aged from 12 to 35 months were included for analysis. Nearly 57% (7727/13,666) of the children were younger than 24 - 35 months. The majority (10,204/13,666, 74.7%) of the children were from mothers or caregivers who live in rural areas. Half (6986/13,666, 51.1%) of the children were born from mothers who had not had formal education. More than half (6757/12,419, 54.4%) of the children were from mothers who had no PNC follow-up for the index children. The details are shown in Table 2.

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Table . Sociodemographic and economic characteristics of mothers or caregivers of children aged 12 - 35 months in Ethiopia, 2023 (N=1366).

Variables	Frequency	Percentage
Age of the child		
12 - 23 months	5934	43.5
24 - 35 months	7727	56.5
Place of residency		
Rural	10,204	74.7
Urban	3462	25.3
Religion		
Orthodox	4430	32.4
Muslim	6158	45.2
Protestant	2944	21.5
Others[a]	134	1.0
Educational status		
No education	6986	51.1
Primary	3870	28.3
Secondary	1798	13.2
College and above	1012	7.4
Wealth status		
Poor	4558	33.4
Middle	4566	33.4
Richer	4542	33.2
Marital status		
Married and living together	12,765	93.4
Married but not living together	352	2.6
Not in marital union	549	4.0
Birth order		
First	4043	29.6
Second	4830	35.3
Third	2639	19.3
Fourth and above	2154	15.8
Parity		
Primipara	2499	20.1
Multipara (2-4)	6573	52.9
Grand multipara (5+)	3346	27.0
Perceived distance to health facility		
Big problem	5251	38.4
Not big problem	8415	61.6
Perceived benefit on immunization		
Poor	2502	19.3
Good	10,471	80.7
ANC[b] visit		
Yes	10,345	83.3

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Variables	Frequency	Percentage
No	2074	16.7
Place of delivery		
Home	3807	30.6
Health facility	8612	69.4
PNC[c]		
Yes	5662	45.6
No	6757	54.4

[a]Others: Catholic, traditional, and others.

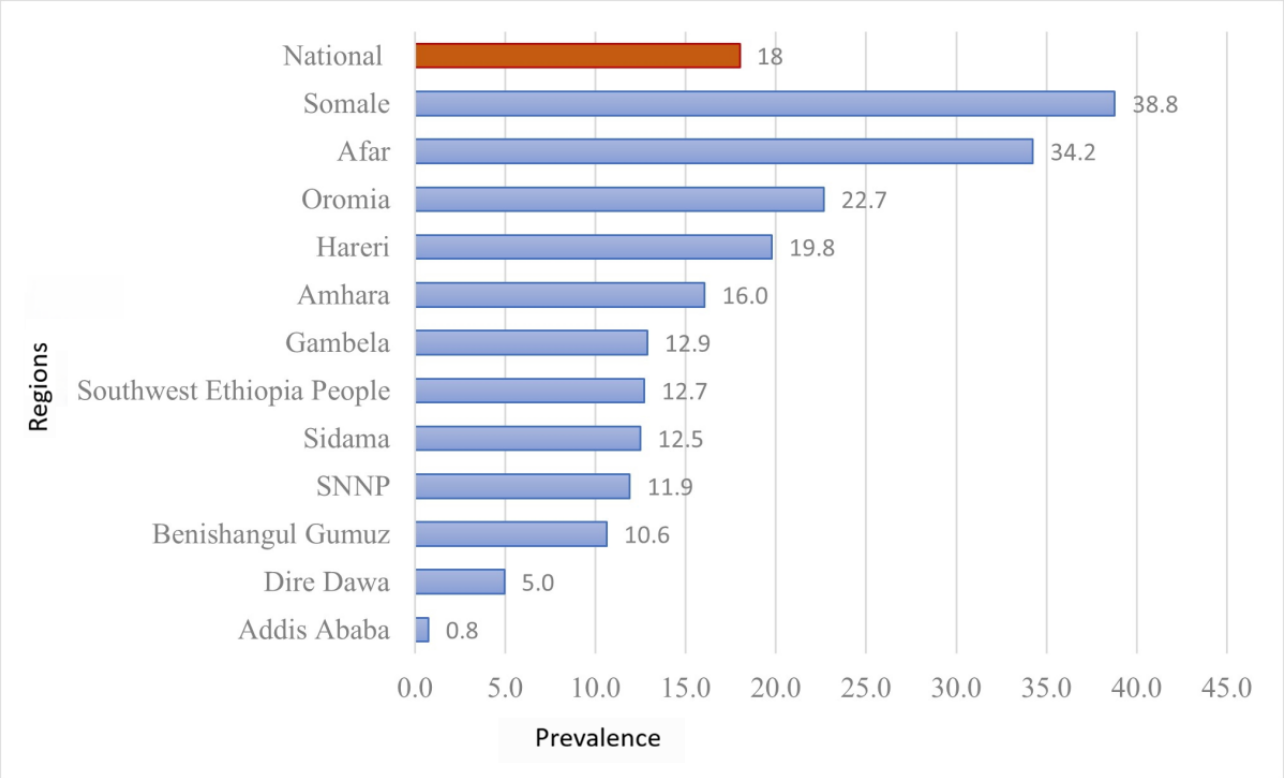
[b]ANC: antenatal care.

[c]PNC: postnatal care.

ZD Prevalence

The overall prevalence of ZD in Ethiopia was 18% (95% CI 17.4% - 18.7%). There were regional variations in the prevalence of ZD children. The higher prevalence was observed in Somali (38.8%), Afar (34.2%), and followed by Oromia (22.7%), and the lowest observed in Addis Ababa (0.8%) and Dire Dawa (5 %) (Figure 5).

Figure 5. Distribution of zero-dose children aged 12 - 35 months across regions in Ethiopia 2023. SNNP: Southern Nations, Nationalities, and Peoples'..



Performance of the Prediction Models

Seven ML algorithms were used to predict ZD status in Ethiopia, with the LGBM yielding the best performance for both unbalanced and balanced datasets (Table 3). It achieved accuracies of 89% and 93% for the unbalanced and balanced datasets, respectively. Most models showed improved accuracy when applied to the balanced dataset, except for Logistic Regression and Naive Bayes. After balancing the data, both XGBoost and LGBM reached an accuracy of 93%. Notably, the LGBM classifier excelled in terms of area under the curve (AUC) (98%) and sensitivity (92%).

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Table . Model performance comparison before and after dataset balancing for predicting zero-dose children in Ethiopia, 2023.

Models and dataset	Accuracy (%)	AUC[a] (%)	Precision (%)	Sensitivity	F_1-score
Logistic Regression					
Unbalanced	88	88	77	48	59
Balanced	81	89	83	77	80
Naïve Bayes					
Unbalanced	85	87	59	63	61
Balanced	79	87	82	73	77
LGBM[b] Classifier					
Unbalanced	89	88	79	53	63
Balanced	93	97	94	91	92
DT[c] Classifier					
Unbalanced	86	75	64	51	57
Balanced	89	91	90	87	88
Random Forest Classifier					
Unbalanced	87	85	70	52	61
Balanced	91	96	91	90	91
XGBoost Classifier					
Unbalanced	88	87	75	52	61
Balanced	93	97	94	90	92
AdaBoost Classifier					
Unbalanced	88	88	77	46	58
Balanced	88	95	89	86	87

[a]AUC: area under the curve.

[b]LGBM: Light Gradient Boosting Machine.

[c]DT: Decision Tree.

Overall, while all ML models performed well on both datasets, those trained on balanced data especially XGBoost and LGBM proved to be more effective in identifying ZD children due to their higher recall and AUC. A comprehensive comparison of the ML algorithms used for ZD children is detailed in Table 3.

After the hyperparameter optimization conducted, the LGBM model achieved robust performance, with an accuracy of 92.4, an AUC of 97.4%, a precision of 93.2%, and a recall of 90.9%. The details are shown in Table 4.

Table . Model performance after hyperparameter tuning for predicting zero-dose children in Ethiopia, 2023.

Model	Accuracy (%)	AUC[a] (%)	Precision (%)	Recall (%)	F_1-score (%)
Logistic Regression	80.8	89.1	82.5	76.9	79.6
Naive Bayes	79.1	87.3	82	73.1	77.3
Random Forest	91.6	96.7	91.9	90.6	91.3
XGBoost	92.2	97.3	93.9	89.8	91.8
AdaBoost	89.6	96.2	90.6	87.8	89.2
LGBM[b]	92.4	97.4	93.2	90.9	92.1
Decision Tree	89.9	94.5	89.5	89.7	89.6

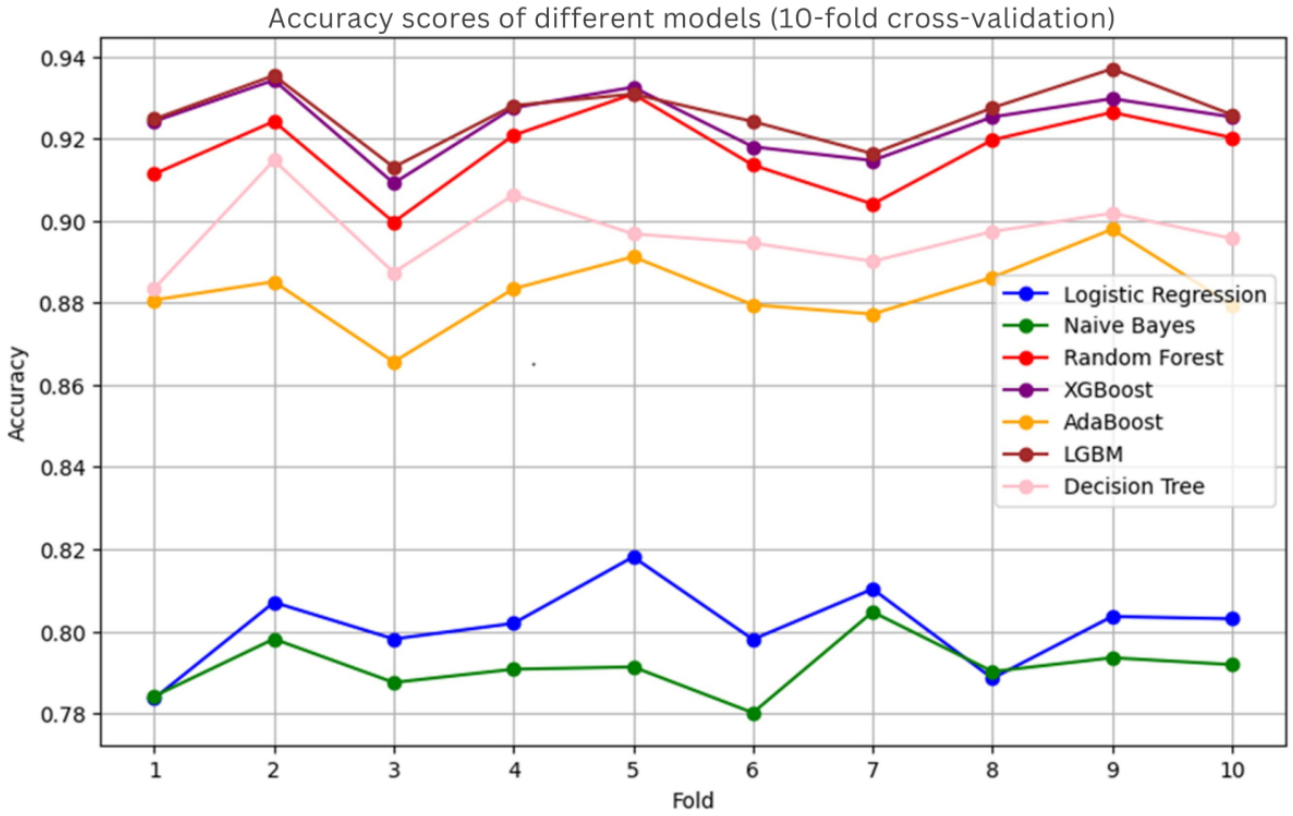
[a]AUC: area under the curve.

[b]LGBM: Light Gradient Boosting Machine.

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After parameter tuning, the models were further evaluated using 10-fold cross-validation, where XGBoost and LGBM demonstrated comparable accuracies of 93% (Figure 6).

Figure 6. Accuracy of models in 10-fold cross-validation after balancing the dataset for predicting zero-dose children in Ethiopia, 2023. LGBM: Light Gradient Boosting Machine.



Predicting ZD

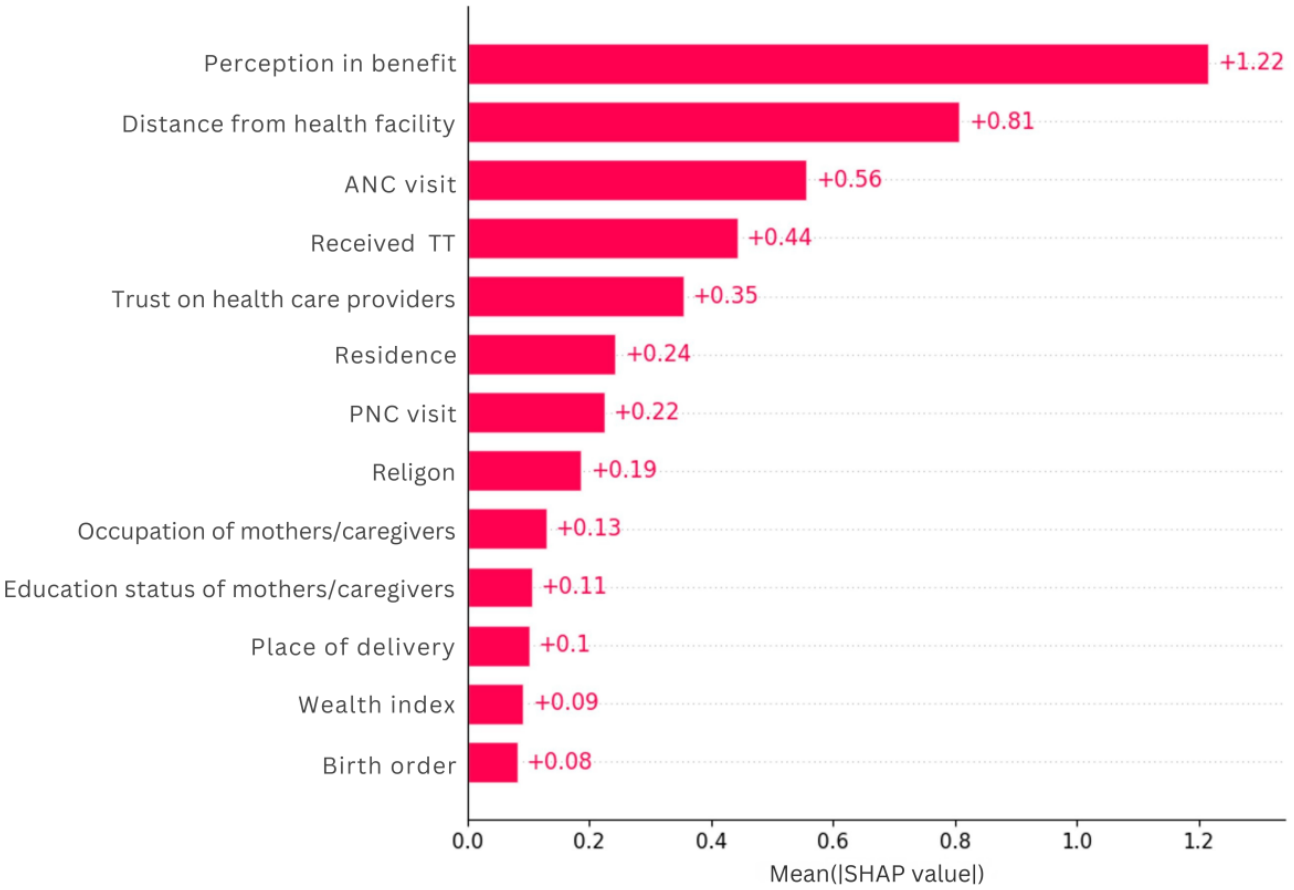
After building the model by using the training dataset, the performance of the LGBM model was evaluated by the testing dataset. From 2181 ZD children, the model predicted 1991 children correctly (true positive), and out of 2300 non-ZD children, the model predicted 2175 children correctly (true negative). However, the model incorrectly classified 190 ZD samples as non-ZD (false positive) and 125 non-ZD samples as ZD (false negative). The Matthews correlation coefficient was r=0.85 and Cohen κ=0.85. Overall, the model predicted with an accuracy of 93%, recall of 91%, F_1-score of 92%, and 94% precision on test data.

Feature Importance

The Shapley Additive analysis identified that mother's or caregiver's perception of benefit of immunization (+1.13), with whether the distance to immunization site (+0.88), whether the mother received ANC (+0.55), whether the mother received TT (+0.42), and whether trust in health providers (0.41) were the most important features followed by place of residence (+0.35), and PNC visit (+0.25). Wealth index, birth order, and place of delivery were the features with low importance (Figure 7).

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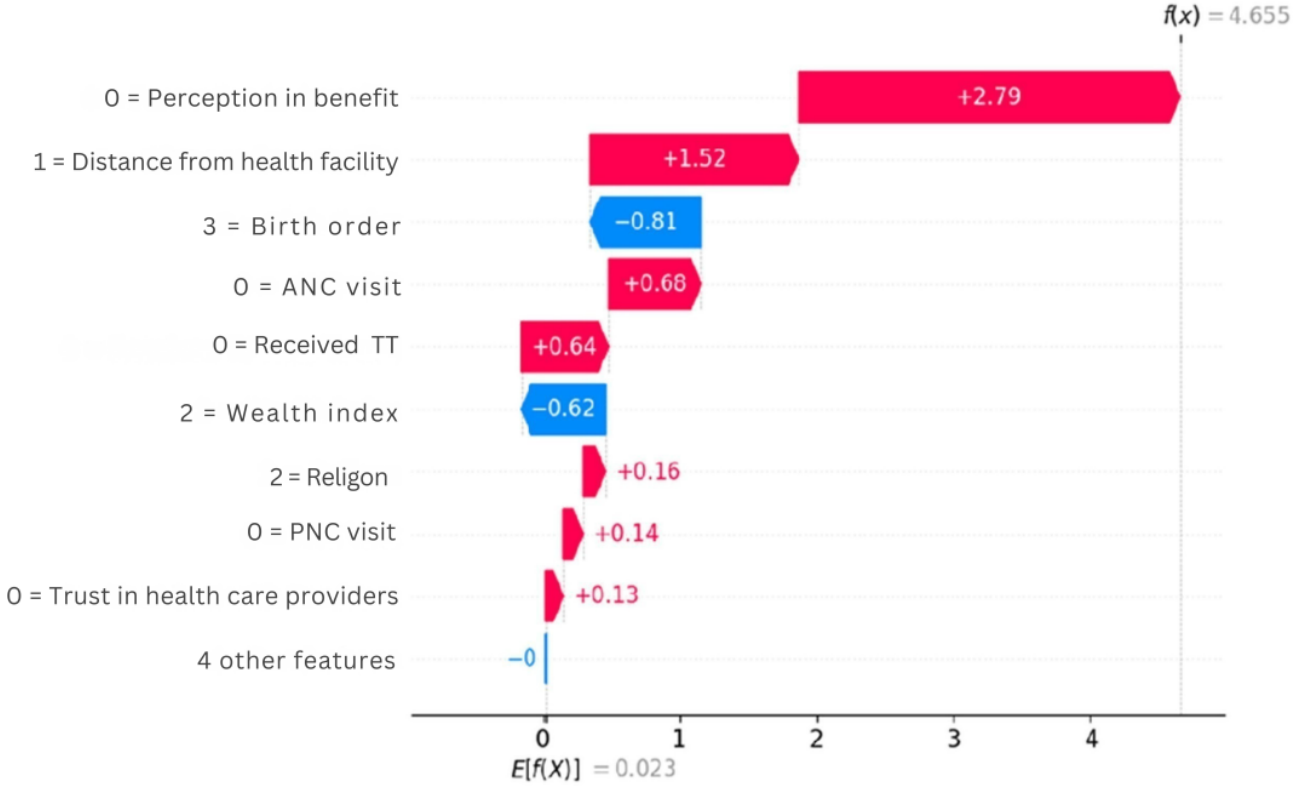
Figure 7. Important features for predicting zero-dose children in Ethiopia, 2023. ANC: antenatal care; PNC: postnatal care; SHAP: SHapley Additive Explanations.



The waterfall chart demonstrates how various factors influence the prediction of ZD vaccination status, starting from a baseline expected value of ($E[f(X)]$=0.023) and culminating in a final prediction of $f(x)$=4.655) indicating that the child is ZD. This indicated that poor perceptions of vaccination benefits, long distances to immunization sites, lack of antenatal and postnatal care visits, absence of TT vaccination, and low trust in health care providers are positively correlated with ZD. Conversely, being in a medium wealth index and having a third birth order is negatively correlated with ZD (Figure 8).

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Figure 8. Waterfall plot of first observation value to predict zero-dose children in Ethiopia, 2023. ANC: antenatal care; PNC: postnatal care.

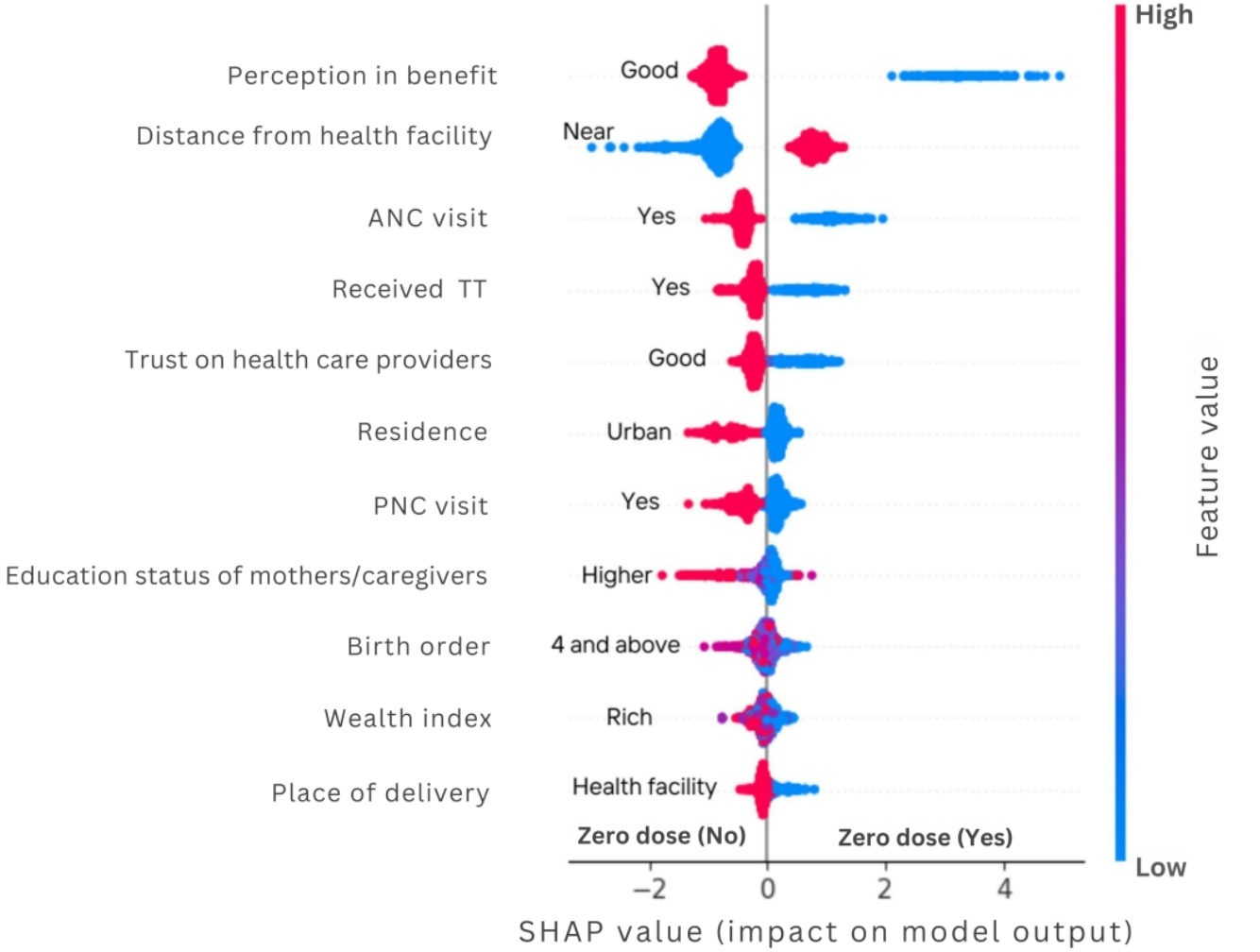


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As shown in Figure 9, the beeswarm plot illustrates the impact of various predictor variables on ZD status, with distinct colors representing risk levels: red dots indicate high-risk values, while blue dots denote low-risk values for the predictor variables. The feature of perception exhibits a wide range of SHAP values, highlighting its significant influence on the model's predictions. A poor perception of the benefits of vaccination notably increases the likelihood of a child being classified as ZD. In addition, distance from health care facilities is strongly associated with ZD status, where far distances correlate with a higher likelihood of being unvaccinated. Other contributing factors include a lack of ANC visits, PNC visits, TT vaccination, low wealth index, low trust in health care providers, and home delivery, all of which contribute to the prediction of the positive class (ZD).

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Figure 9. Zero-dose predictors for Light Gradient Boosting Machine model. SHAP summary plot of top predictors. ANC: antenatal care; PNC: postnatal care; SHAP: SHapley Additive Explanations.



Rule Generation

The rule generation process was done based on important attributes selected by the best performing ML model LGBM. Moving beyond individual feature importance, we used association rule mining to identify complex, multifactorial profiles of ZD children and to rigorously validate the interactions suggested by the SHAP analysis. This generated a set of human-interpretable "if then" rules, each validated by key metrics: support (prevalence of the rule in the data), confidence (conditional probability of the outcome), and lift (strength of the association above random chance). The rule generation process was done based on important attributes selected by the best performing ML model LGBM. The strongest rule (rule 1: lift = 2.17, confidence = 0.90) indicates that children whose caregivers live far from a health facility and have a poor perception of vaccination benefits have a 90% probability of being ZD, a risk 2.17 times higher than random. Rule 2 (confidence = 0.81) shows that combining distance with a lack of ANC and poor trust in providers creates another high-risk pathway, while rule 5 (confidence = 0.79) highlights the potent combination of no tetanus vaccination, no ANC, and distance. Crucially, these rules reveal critical synergies, while SHAP identified "distance" and "ANC" as top individual predictors, rule mining quantified how their combination with other factors (eg, rule 8: no ANC + Far distance, confidence = 0.72) creates a risk profile with a distinctly high probability of the outcome. This provides programmatically actionable insights, demonstrating that interventions must target these intersecting barriers simultaneously rather than in isolation to effectively reach ZD children. A total of 9 association rules were generated, and the details of the rules are shown in Textbox 1.

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Textbox 1. Rule generation and knowledge extraction.

##Rule## 1: Distance from facility_far, Perception in benefit_Poor -> Zerodose_Yes

Support: 0.10897435897435898, Lift: 2.1738917080243128, Confidence: 0.9037974683544304

##Rule## 2: Distance from facility_far, Trust in healthcare provider_Poor, Anc visit_No -> Zerodose_Yes

Support: 0.10134310134310134, Lift: 1.947695283120232, Confidence: 0.8097560975609757

##Rule## 3: Perception in benefit_Poor -> Zerodose_Yes

Support: 0.15262515262515264, Lift: 1.9211552265274243, Confidence: 0.7987220447284347

##Rule## 4: Perception in benefit_Poor, Place Residence_rural -> Zerodose_Yes

Support: 0.10103785103785104, Lift: 1.9138215859030838, Confidence: 0.795673076923077

##Rule## 5: Received TT_No, Distance from facility_far, Anc visit_No -> Zerodose_Yes

Support: 0.13064713064713065, Lift: 1.9099490817552491, Confidence: 0.7940630797773656

##Rule## 6: Received TT_No, Distance from facility_far, Place delivery_Home -> Zerodose_Yes

Support: 0.12606837606837606, Lift: 1.7738986784140967, Confidence: 0.7374999999999999

##Rule## 7: PNC visit_Yes, Distance from facility_far, Anc visit_No -> Zerodose_Yes

Support: 0.10073260073260074, Lift: 1.7406677486668212, Confidence: 0.7236842105263158

##Rule## 8: Distance from facility_far, Anc visit_No -> Zerodose_Yes

Support: 0.17918192918192918, Lift: 1.736658159533137, Confidence: 0.7220172201722017

##Rule## 9: Distance from facility_far, Anc visit_No, Place Residence_rural -> Zerodose_Yes

Support: 0.1108058608058608, Lift: 1.7019862431408919, Confidence: 0.7076023391812866

Discussion

Principal Findings

Using the data from the most recent National Immunization Evaluation Survey in Ethiopia, we applied different supervised machine algorithms to assess how well the models predict whether a child is likely to be ZD and to identify the important predictor variables. We trained and compared 7 ML classifiers on both unbalanced and balanced datasets, using a train-test split, hyperparameter tuning, and 10-fold cross-validation for robust evaluation. A variety of socioeconomic, demographic, and health-related factors were included to enhance the model's predictions and facilitate important feature selection.

Our findings demonstrate that these ML algorithms are effective in identifying children at high risk of being ZD. Among the 7 models tested, LGBM emerged as the top performer, achieving an AUC of 97.4%, recall of 90.9%, accuracy of 92.4%, precision of 93.2%, and an F_1-score of 92.1%. These evaluation metrics underscore the model's strong capability in predicting ZD children. The high AUC indicates the model's effectiveness in distinguishing between children who receive immunization services and those who do not. Notably, a recall of 90.9% signifies that the model successfully identifies 90.9% of ZD children, who are often at greater risk for missing vaccines and vaccine-preventable diseases.

In addition to LGBM, both XGBoost and RF algorithms performed well, each achieving an accuracy of 92.2% and 91.6%, respectively. These results are consistent with previous studies that recognized XGBoost [48] and RF [49] as top performers in similar contexts. While these metrics indicate robust performance for critical health issues such as immunization, it is crucial to validate the model in real-world settings. Such testing will enhance its utility as a tool for guiding public health initiatives aimed at increasing vaccination rates and improving access to essential health care services for unvaccinated children.

Using an ML model, health care workers can pinpoint specific households and communities with ZD children, allowing them to shift from broad campaigns to targeted household visits. By leveraging the model's insights on local perceptions and socioeconomic barriers, they can tailor their communication and services, such as setting up mobile clinics, to overcome specific challenges and efficiently use scarce resources, ensuring that vaccines reach those most in need.

The second objective of the study was to identify important attributes that could predict ZD among children aged 12 - 35 months. Using SHAP analysis, the study found that perception of immunization benefit, ANC utilization, distance from vaccination site, maternal TT vaccination status, and trust in health providers were the most important features to identify at-risk children for ZD.

The top predictor was poor maternal perception with a SHAP value of 1.13 (Figure 7). This indicates that a negative perception of mothers or caregivers increases the likelihood of a child being ZD, likely because parental beliefs directly influence health care decisions regarding vaccination. This finding aligns with previous studies showing that parental beliefs and attitudes significantly affect a child's vaccination status [50,51].

ANC utilization was another important feature, with a SHAP value of 0.55, indicating that a lack of ANC is strongly linked to a child being ZD. This finding is in line with the previous

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similar studies done [48,52,53]. This could be due to the fact that ANC visits enable mothers to access integrated health services, be more likely to receive information on immunization schedules, build trust in the health system, and improve adherence to health services [54-56].

In addition, the study found several important predictors. Maternal TT vaccination was a key factor; mothers who received the TT vaccine were more likely to have their children vaccinated, a finding consistent with studies from Sudan and Bangladesh [57,58]. Postnatal care visit was another important predictor. This service is likely gaining a better understanding of vaccination importance and feeding practices, thus reducing missed vaccinations [59,60]. In addition, maternal education was an important predictor, with uneducated mothers having a higher risk of ZD children than those with at least a primary education, firming up the known link between maternal literacy and vaccination rates and primary education. This finding is in line with previous research linking maternal literacy to vaccination completeness [61-65]. The other finding of this study is rule mining and generation. Using association rule mining with the Apriori algorithm, the study uncovered strong relationships between various socioeconomic, demographic, and health-related factors and ZD status. Key determinants, including distance from health facility, perception of vaccination benefits, trust in health care providers, ANC, place of delivery, place of residency, and TT vaccines were the most important features predicting ZD. Confidence levels for these findings ranged from 71% to 90%, indicating robust associations.

Findings from association rule 1 indicated that the probability of a child being ZD would be 90%, if and only if the mothers or caregivers were far from the health facility and had poor perception on immunization. This may be because mothers or caregivers who are far from the facility may not have access to health education directly or indirectly, affecting health-seeking behavior and health service utilization such as vaccination. The second rule also included poor trust in health care providers and lack of ANC visits as predictors for ZD. A child ZD would be 80% if mothers or caregivers have trust in providers and had no ANC follow-up for the index child.

Strengths and Limitations

This study had several strengths worth mentioning. We used national-level survey data from 463 EAs ensuring generalizability across the country and providing a current snapshot of the ZD situation. A key strength is that our analysis uses various ML algorithms from the field of data science, which significantly aids in identifying and targeting ZD children more effectively. These advanced analytical techniques allow us to process large datasets and uncover insights that may not be immediately apparent through traditional methods. At the same time, this study identified the risk factors of ZD that may help policy makers and planners to design tailored interventions to identify and reach the unvaccinated children.

This study was subject to some limitations. First, although we used national-level data, we did not include data from the Tigray region, which is one of the administrative regions of the country, due to security issues. Second, the study did not include health system side predictors such as availability of vaccination supplies and vaccines. Finally, we could not do external validation for the modes due to the lack of real-world data.

Conclusions

The developed ML models effectively predict children at risk of being ZD and identify associated risk factors. Among these models, the LGBM model demonstrated the best performance in predicting ZD children. Key features linked to ZD status include access to immunization sites, maternal health service utilization (such as antenatal and postnatal care, place of delivery, and TT vaccination), and perceptions regarding immunization.

By implementing ML models, public health interventions can be more precisely targeted at the most vulnerable groups. This approach may address inequities in vaccination coverage by identifying specific sociodemographic, economic, and health-related factors associated with ZD children. Consequently, it aids in the formulation and implementation of effective policies and strategies to improve vaccination rates. Strengthening the continuum of care for mothers, raising awareness among caregivers, and improving immunization access through outreach strategies may help in reducing the high burden of ZD children.

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Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request.

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Authors' Contributions

BFE, KA, SAM, MZ, MKG, and BT conceptualized and designed the study. All authors contributed significantly to the analysis and interpretation of the results. The original draft was written by BFE and reviewed by all authors, who also provided critical revisions for important intellectual content. Each author has read and approved the final manuscript. They have agreed to take personal responsibility for their contributions and to ensure that any questions regarding the accuracy or integrity of any part of the work, even if they were not directly involved, are properly investigated and documented in the literature.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Zero-dose status among children aged 12 - 35 months in Ethiopia, before and after data balancing, using the 2023 survey dataset. SMOTE: Synthetic Minority Oversampling Technique.
[PNG File, 162 KB - pediatrics_v9i1e76712_app1.png]

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Abbreviations

ANC: antenatal care
AUC: area under the curve
DPT: diphtheria, tetanus, and pertussis
EA: enumeration area
LGBM: Light Gradient Boosting Machine
ML: machine learning
RF: Random Forest
SHAP: SHapley Additive Explanations
TT: tetanus toxoid
XGBoost: Extreme Gradient Boosting

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Original Paper

Knowledge, Perceptions, and Practices Regarding Pediatric Tuberculosis: Cross-Sectional Study Among Guardians and Health Care Providers in Kabondo Dianda Health Zone, Democratic Republic of the Congo

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Abstract

Background: Tuberculosis (TB) remains one of the leading infectious causes of morbidity and mortality worldwide, with children representing a particularly vulnerable group. In the Democratic Republic of the Congo, pediatric TB continues to be underdiagnosed and underreported, particularly in rural health zones such as Kabondo Dianda.

Objective: This study aimed to assess the knowledge, perceptions, and practices of guardians and health care providers regarding pediatric TB in Kabondo Dianda health zone by using the knowledge, attitude, and practice framework.

Methods: A descriptive cross-sectional study was conducted in 5 diagnostic and treatment centers between January 2020 and December 2022. Guardians of children diagnosed with TB (163/163, 100%) were recruited exhaustively through facility registers and community health workers, while health care providers (27/27, 100%) were included through convenience sampling. Data were collected using a structured questionnaire adapted from national and World Health Organization guidelines. The instrument was pretested with 15 guardians and 5 health care providers in a neighboring health zone to ensure clarity, cultural appropriateness, and reliability; internal consistency was confirmed with Cronbach α (α=0.82). Composite scores were calculated for knowledge, perceptions, and practices. Descriptive statistics and chi-square and Fisher exact tests were applied, with significance set at $P<.05$.

Results: Guardians demonstrated partial biomedical knowledge: cough was widely recognized as a symptom (123/163, 75.5%); however, misconceptions persisted, with 29% (47/163) attributing TB to supernatural causes and 52% (85/163) believing domestic animals were vectors. Preventive knowledge was limited, with only 26.4% (43/163) mentioning the Bacille Calmette-Guérin vaccination. Care seeking was often delayed, with 38.7% (63/163) consulting only after treatment failure and 25.8% (42/163) after symptom worsening. Health care providers showed higher knowledge scores but limited diagnostic engagement: only 18.5% (5/27) reported routine use of GeneXpert, and 3.7% (6/163) of pediatric cases received HIV screening. Misconceptions were significantly associated with lower knowledge scores among guardians ($P=.03$).

Conclusions: Pediatric TB underreporting in Kabondo Dianda reflects both systemic and behavioral determinants. Applying the knowledge, attitude, and practice framework highlights how cultural beliefs, limited preventive knowledge, and weak diagnostic engagement interact to hinder early detection and management. Strengthening community education, training health care providers on latent TB and HIV coinfection, and improving diagnostic infrastructure are essential to reduce morbidity and mortality among children in rural Democratic Republic of the Congo.

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KEYWORDS

tuberculosis; pediatric tuberculosis; knowledge-attitudes-practices; guardians; health care providers; Kabondo Dianda health zone; Democratic Republic of the Congo; cross-sectional study; public health; diagnostic practices; preventive knowledge; community perceptions

Introduction

Background

Tuberculosis (TB) remains one of the leading infectious causes of morbidity and mortality worldwide. According to the World Health Organization (WHO) Global Tuberculosis Report 2024, an estimated 10.6 million people developed TB in 2023, including 1.2 million children aged <15 years [1]. Children represent a particularly vulnerable group; however, pediatric TB continues to be underdiagnosed and underreported due to its paucibacillary nature and the limited sensitivity of available diagnostic tools [2].

In sub-Saharan Africa, weak health systems, limited health care provider capacity, and low community awareness exacerbate the burden of pediatric TB [3]. In the Democratic Republic of the Congo, TB incidence remains high, with over 220 cases per 100,000 inhabitants in 2023, placing the country among the 30 high-burden nations identified by WHO [1]. Despite national control efforts, pediatric TB has not received adequate attention. In Haut-Lomami province, particularly the Kabondo Dianda health zone, notification rates for pediatric TB remain persistently low (9%-15% between 2016 and 2022) [4]. This underreporting reflects both systemic barriers (limited diagnostic infrastructure and weak referral systems) and behavioral barriers (delayed care seeking and misconceptions about transmission).

Community-level misconceptions are widespread: nearly half of caregivers believe TB is not transmissible, while more than one-quarter attribute the disease to supernatural causes [4]. Knowledge of latent TB is virtually absent among both caregivers and health care providers. Although some health care providers demonstrate high knowledge scores, most remain unaware of latent TB forms, limiting their ability to implement preventive strategies [4]. Care-seeking behavior is also delayed, with many caregivers seeking care only after treatment failure or disease progression. At the facility level, diagnostic capacity is limited: HIV screening is rarely performed, and GeneXpert testing is underused [4].

To guide this study, we adopted the knowledge, attitude, and practice (KAP) framework, which posits that gaps in knowledge and distorted perceptions influence health-seeking practices and ultimately affect disease outcomes [5]. Applying this framework allows us to analyze how caregiver beliefs and health care provider practices interact to shape pediatric TB detection and management in rural Democratic Republic of the Congo.

Knowledge Gap

While pediatric TB is recognized as a neglected issue globally, few studies have systematically assessed the interplay of caregiver perceptions, health care provider practices, and systemic barriers in rural Congolese settings. Existing literature highlights underreporting but does not adequately explain the behavioral and cultural determinants underlying delayed diagnosis and poor management [6,7].

Objectives

This study aims to assess the knowledge, perceptions, and practices of guardians of children and health care providers regarding pediatric TB in Kabondo Dianda health zone using the KAP framework. Specifically, we seek to identify misconceptions and cultural beliefs influencing care seeking, evaluate health care provider diagnostic and preventive practices, and highlight systemic gaps that hinder early detection. By addressing these dimensions, the study contributes to evidence-based strategies for strengthening pediatric TB control and reducing morbidity and mortality among children in resource-limited environments.

Methods

Study Design and Setting

This study used a descriptive cross-sectional design, which is appropriate for generating baseline evidence on knowledge, perceptions, and practices without testing causal hypotheses. The research was conducted in the Kabondo Dianda health zone, Haut-Lomami province, Democratic Republic of the Congo. The zone comprises 19 health areas, of which 5 were designated as diagnostic and treatment centers (CSDTs) by the Provincial TB Coordination Unit. These sites were selected for their strategic location, patient volume, and relevance to pediatric TB surveillance. Data collection took place between November 25 and 30, 2022, covering pediatric TB cases diagnosed from January 2020 to December 2022. As the study period extended over 3 years, recall bias was anticipated and is explicitly acknowledged as a limitation of descriptive studies.

Recruitment and Study Population

Participants were recruited from the 5 CSDTs officially designated by the Provincial TB Coordination Unit in the Kabondo Dianda health zone. Recruitment of guardians was exhaustive: all caregivers of children aged <15 years who had been diagnosed with pulmonary TB between January 2020 and December 2022 were identified through facility registers and community health workers. Of the 166 eligible guardians, 163 were successfully enrolled, while 3 were excluded due to permanent displacement following local flooding. This approach ensured near-complete coverage of the target population and minimized selection bias.

Health care providers were recruited using convenience sampling. All personnel directly involved in TB diagnosis and management at the selected facilities were invited to participate, including medical directors, nurses, laboratory technicians, and TB focal points. A total of 27 health care providers were

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enrolled, representing the full spectrum of staff engaged in pediatric TB services. Although exploratory in nature, this sample reflects the operational realities of TB care in the health zone.

Eligibility criteria for guardians required being the primary caregiver of a child aged <15 years diagnosed with pulmonary TB in one of the selected CSDTs during the study period. Health care providers were eligible if they were actively assigned to the selected facilities at the time of data collection and directly responsible for TB-related services. Exclusion criteria included permanent relocation outside the health zone or refusal to provide informed consent. By combining exhaustive recruitment of guardians with comprehensive inclusion of available health care providers, the study population was designed to capture both community-level experiences and facility-based practices relevant to pediatric TB detection and management.

Data Collection

Data were collected using a structured questionnaire administered via KoboCollect, adapted from national TB guidelines and WHO recommendations. The tool was pretested on 15 guardians and 5 health care providers in a neighboring health zone to ensure clarity, cultural appropriateness, and reliability. Internal consistency was assessed using Cronbach α, which yielded a coefficient of 0.82. The questionnaire contained closed-ended questions covering sociodemographic characteristics, knowledge of TB transmission and prevention, perceptions of severity and stigma, and care-seeking practices. Health care provider–specific items assessed diagnostic capacity, GeneXpert use, HIV screening, and referral procedures.

Instrument Validation

Prior to data collection, the questionnaire was subjected to a pretest to ensure clarity, cultural appropriateness, and reliability. The tool was administered to a sample of 15 guardians and 5 health care providers in a neighboring health zone. Feedback from this pilot exercise was used to refine wording and improve comprehension. Internal consistency was assessed using Cronbach α, which yielded a coefficient of 0.82, indicating good reliability. This validation process confirmed that the instrument was suitable for use in the study population and aligned with WHO recommendations for KAP surveys [1].

Variables and Operational Definitions

Independent variables included type of facility, health care provider profile (qualification and years of experience), guardian characteristics (age, education, occupation, and household size), availability of diagnostic tools, and accessibility of services. Dependent variables included knowledge level, perceptions, practices such as timely versus delayed care seeking, and health care provider performance in screening, referral, and counseling. High knowledge was defined as at least 75% correct responses, based on WHO KAP survey guidelines. Delayed care seeking was defined as seeking care only after symptom worsening or treatment failure. Diagnostic engagement referred to the use of GeneXpert or HIV testing for pediatric TB cases.

Handling of Missing Data

Given the descriptive nature of the study, missing data were managed using a complete-case analysis approach. Partially missing responses were excluded from composite score calculations. Sensitivity analyses confirmed that exclusion did not alter key descriptive findings.

Data Analysis

Data were analyzed using SPSS (version 25.0; IBM Corp). Descriptive statistics such as frequencies, proportions, medians, and IQRs were calculated to summarize participant characteristics and responses. Exploratory associations were examined using $\chi^2$and Fisher exact tests, with statistical significance set at $P<.05$. Composite scores were developed to assess knowledge and perception levels, consistent with descriptive study standards.

Ethical Considerations

Ethics approval for this study was obtained from the ethics committee of the School of Public Health, University of Kinshasa (approval number ESP/CE/205/2024). Written authorization was also granted by the head of the health division of Haut-Lomami Province and the chief medical officer of the Kabondo Dianda health zone. Investigators consistently carried these authorizations during fieldwork and presented them whenever requested by local authorities or participants. Written informed consent was obtained from all participants prior to their inclusion in the study.

Results

Overview

The sociodemographic characteristics of guardians and health care providers are shown in Table 1. Of the 163 guardians, 82 (50.3%) were female, with a median age was 37 (IQR 30-43) years. Farming was the predominant occupation (n=88, 54%), and nearly half lived in households with 5 to 9 members (n=80, 49.1%). Of the 27 health care providers, 22 (81.5%) were male, with a median age of 35 (IQR 10) years. All were officially employed, but only 8 (29.6%) had completed secondary school and 1 (3.7%) had attained university-level education.

Table 1. Sociodemographic characteristics of the guardians and health care providers.

Characteristic	Guardians (n=163)	Health care providers (n=27)
Female sex, n (%)	82 (50.3)	5 (18.5)
Age (years), median (IQR)	37 (13)	35 (10)
Farming occupation, n (%)	88 (54)	0 (0)
Household size: 5-9, n (%)	80 (49.1)	12 (44.4)

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Knowledge of TB Transmission

Knowledge of TB transmission is shown Table 2. Coughing was correctly identified as a transmission route by 75.5% (123/163) guardians and 88.9% (24/27) health care providers. Health care providers demonstrated broader awareness, with 20 (74.1%) citing sneezing, 18 (66.7%) mentioning speaking, and 16 (59.3%) recognizing laughing. Guardians showed limited awareness beyond coughing, with only 36 (22.1%) mentioning sneezing and 12 (7.4%) mentioning laughing. Differences between guardians and health care providers were statistically significant for sneezing (P=.001) and laughing (P<.001).

Table 2. Knowledge of tuberculosis transmission.

Transmission mode	Guardians (n=163), n (%)	Health care providers (n=27), n (%)	*P* value
Coughing	123 (75.5)	24 (88.9)	.12
Sneezing	36 (22.1)	20 (74.1)	.001
Speaking	55 (33.7)	18 (66.7)	.01
Laughing	12 (7.4)	16 (59.3)	<.001

Knowledge of TB Prevention

Knowledge of TB prevention is shown in Table 3. Preventive knowledge was markedly higher among health care providers. All 100% (27/27) identified good nutrition, 26 (96.3%) cited Bacille Calmette-Guérin (BCG) vaccination, and 19 (70.4%) mentioned respiratory hygiene. Guardians reported lower knowledge, with 26.4% (43/163) citing good nutrition, 43 (26.4%) mentioning BCG vaccination, and 18 (11%) citing covering the mouth or avoiding overcrowding. Differences between groups were statistically significant for BCG vaccination and respiratory hygiene (P<.001).

Table 3. Knowledge of tuberculosis prevention.

Prevention method	Guardians (n=163), n (%)	Health care providers (n=27), n (%)	*P* value
Good nutrition	43 (26.4)	27 (100)	<.001
BCG[a] vaccination	43 (26.4)	26 (96.3)	<.001
Covering mouth	18 (11)	19 (70.4)	<.001

[a]BCG: Bacille Calmette-Guérin.

Perceptions of TB Transmission

Among health care providers, 89% (24/27) correctly perceived TB as communicable and transmitted by coughing. In contrast, only 55% (90/163) guardians recognized TB as communicable. Misconceptions persisted: 47 (29%) guardians attributed TB to supernatural causes, and 85 (52%) believed domestic animals were vectors. Even among health care providers, 3 (11%) cited evil spirits, and 25 (93%) implicated animals.

Care-Seeking Practices

Formal health facilities were the first point of care for 49.1% (80/163) guardians and 70.4% (19/27) health care providers. Guardians frequently sought care at pharmacies (n=43, 26.4%) or traditional healers (n=32, 19.6%). Timing of care seeking showed delays: 63 (38.7%) guardians consulted only after treatment failure, and 42 (25.8%) after symptom worsening. Among health care providers, 9 (33.3%) reported initiating care after deterioration. Reasons for choosing facilities included free effective treatment (n=60, 36.8% guardians and n=19, 70.4% health care providers) and accessibility (n=39, 23.9% guardians).

Diagnostic Practices

Despite the availability of diagnostic tools, use was limited. Only 3.7% (6/163) pediatric cases received HIV screening, and 18.5% (5/27) health care providers reported routine use of GeneXpert. These findings confirm systemic gaps in diagnostic engagement.

Discussion

Principal Findings

This descriptive study revealed substantial gaps in knowledge, perceptions, and practices regarding pediatric TB among guardians and health care providers in the Kabondo Dianda health zone. Guardians demonstrated limited awareness of transmission routes beyond coughing, and misconceptions such as attributing TB to supernatural causes or domestic animals were common. Health care providers showed broader biomedical knowledge but still reported beliefs inconsistent with scientific evidence. Preventive knowledge was markedly higher among health care providers, particularly regarding nutrition and BCG vaccination, whereas guardians cited these measures less frequently. Care-seeking practices were delayed, with many guardians consulting health services only after treatment failure or symptom worsening. Diagnostic engagement remained low, with limited use of GeneXpert and HIV screening.

Comparison With Prior Studies

These findings align with previous research in sub-Saharan Africa, which has documented persistent misconceptions about airborne transmission and cultural beliefs attributing TB to nonbiomedical causes [8,9]. Similar studies in rural contexts have shown that delayed care seeking is often driven by poverty, geographic isolation, and reliance on traditional healers [10]. The low use of GeneXpert and HIV screening mirrors national reports from the Democratic Republic of the Congo, where

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diagnostic infrastructure exists but is underused due to limited training and supervision [11]. The disparities between guardians and health care providers in knowledge of prevention echo findings from other African settings, where community-level education remains insufficient [12].

Implications for Practice and Policy

The results underscore the urgent need to strengthen pediatric TB control strategies in rural Democratic Republic of the Congo. Community education campaigns should specifically target misconceptions, emphasizing airborne transmission and the importance of early care seeking. Health care provider training must address latent TB, HIV coinfection, and systematic use of GeneXpert. Health system strengthening is required to improve diagnostic infrastructure, referral pathways, and integration of national guidelines into routine practice. Finally, culturally sensitive communication strategies should be developed, respecting local beliefs while promoting evidence-based practices. Collaboration between community health workers, diagnostic centers, and local authorities can enhance case tracking and reduce stigma.

Limitations

This study has several limitations inherent to descriptive cross-sectional designs. Recall bias may have affected guardian responses, given the 3-year study period. Selection bias is possible due to convenience sampling of health care providers, which limits representativeness. Self-reported data may be subject to social desirability bias. Moreover, the study was conducted in 5 diagnostic centers within Kabondo Dianda and may not reflect practices in other health zones. Despite these limitations, exhaustive sampling of guardians and inclusion of all active health care providers strengthen internal validity.

Conclusions

This descriptive study conducted in Kabondo Dianda health zone highlights persistent gaps in knowledge, perceptions, and practices related to pediatric TB among guardians and health care providers. While health care providers demonstrated relatively higher biomedical knowledge, misconceptions remained, and diagnostic engagement was limited. Guardians showed restricted awareness of transmission and prevention, with delayed care-seeking behaviors, contributing to underreporting and late diagnosis.

By applying the KAP framework, the study underscores how cultural beliefs, limited preventive knowledge, and systemic barriers interact to hinder early detection and effective management of pediatric TB in rural Democratic Republic of the Congo. These findings emphasize the need for targeted community education, health care provider training on latent TB and HIV coinfection, and improved diagnostic infrastructure.

Although limited by recall bias, selection bias, and reliance on self-reported data, this study provides valuable baseline evidence for strengthening pediatric TB control strategies in resource-constrained settings. Future research should explore interventions that integrate culturally sensitive communication with systematic diagnostic practices to reduce morbidity and mortality among children.

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Data Availability

The anonymized dataset used for this study is available from the corresponding author upon reasonable request.

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Authors' Contributions

JDY led the conceptualization of the study, with supporting input from FIM. The methodology was primarily developed by FIM, assisted by PKI. Data curation was conducted by PKI, with support from AM. Formal analysis was led by FIM, assisted by AK. The investigation was carried out by PKI, with equal contribution from AM. Project administration was overseen by FIM, with support from JDY. Resources were provided by AK. Supervision was led by JDD, with support from FIM. Validation was performed by JDY and JDD. Visualization was led by AM, assisted by PKI. The original draft was written by JDY, with supporting contributions from FIM. All authors contributed equally to the review and editing of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

BCG: Bacille Calmette-Guérin
CSDT: diagnostic and treatment center
KAP: knowledge, attitude, and practice
TB: tuberculosis
WHO: World Health Organization

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Original Paper

Health Care Use and Recurrence Rate in Hemolytic Disease of the Fetus and Newborn: Retrospective Cohort Study

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Abstract

Background: Hemolytic disease of the fetus and newborn (HDFN) is a life-threatening condition resulting from maternal-fetal erythrocyte antigen incompatibility. Although anti–Rhesus D (RhD) prophylaxis has reduced RhD-associated cases, HDFN persists due to non-RhD antibodies and gaps in prevention. Population-based data on maternal and neonatal outcomes and recurrence patterns are limited.

Objective: This study aimed to characterize maternal and neonatal outcomes, health care use patterns, and recurrence rates of HDFN across pregnancies.

Methods: We conducted a retrospective cohort study of 464,711 pregnancies within the Kaiser Permanente Southern California system from January 1, 2008, to June 30, 2022. HDFN diagnoses were confirmed using validated natural language processing–assisted manual chart review and followed through 2023. Maternal characteristics, neonatal outcomes, and health care use were compared by HDFN status, and recurrence patterns were evaluated among individuals with ≥2 pregnancies. Chi-square tests and Wilcoxon rank-sum tests were used to compare characteristics between HDFN and non-HDFN pregnancies. Statistical significance was defined as $P<.05$.

Results: Among all pregnancies, 139 of 464,711 (0.03%) were diagnosed with HDFN. Women with HDFN were more likely than those without HDFN to be older (aged ≥35 years; n=42, 30.2% vs n=97,146, 20.9%) and multiparous (n=121, 87.1% vs n=264,766, 57%). Infants affected by HDFN had higher rates of preterm birth (n=40, 28.4% vs n=42,240, 9.5%), low birth weight (<2500 g; n=22, 15.6% vs n=31,740, 7.1%), and neonatal jaundice (n=92, 65.2% vs n=162,465, 36.4%) than non-HDFN infants. Delivery hospitalizations (median 5.0, IQR 2.0-7.5 days vs median 2.0, IQR 1.0-2.0 days) and neonatal intensive care unit stays (median 4.0, IQR 0.0-7.0 days vs median 0.0, IQR 0.0-0.0 days) were longer, and maternal nondelivery hospitalizations were more frequent (n=27, 19.4% vs n=23,228, 5%) among pregnancies complicated by HDFN. Among women with a prior HDFN-affected pregnancy, 83.3% (n=25) experienced recurrence in a subsequent pregnancy. Of these recurrent cases, 32% (n=8) were severe, and 75% (n=6) involved fetal anemia requiring at least 1 intrauterine transfusion.

Conclusions: HDFN was rare but was associated with substantial maternal and neonatal morbidity, including higher rates of preterm birth, increased neonatal intensive care unit admissions, and greater health care use. Recurrence was frequent and clinically significant, underscoring the importance of early surveillance and proactive management strategies.

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KEYWORDS

hemolytic disease of the fetus and newborn; HDFN; alloimmunization; neonatal outcomes; recurrence; health care resource use; perinatal treatment; fetal anemia

Introduction

Hemolytic disease of the fetus and newborn (HDFN) is a life-threatening condition caused by maternal-fetal erythrocyte antigen incompatibility, in which maternal immunoglobulin G alloantibodies cross the placenta and lead to fetal hemolytic anemia [1]. In severe cases, HDFN can result in fetal hydrops, fetal demise, and significant neonatal morbidity. The risk is particularly high for early-onset severe HDFN (≤24 weeks of gestation), which carries an elevated likelihood of stillbirth and adverse neonatal outcomes [2-4].

Widespread implementation of routine anti–Rhesus D (RhD) prophylaxis has substantially reduced RhD alloimmunization [5]. However, HDFN persists because of alloimmunization from non-RhD antigens or gaps in prophylaxis, highlighting ongoing challenges in prevention [5-7]. Current management for high-risk pregnancies includes middle cerebral artery (MCA) Doppler monitoring and intrauterine transfusions (IUTs) to prevent fetal hydrops and anemia-related pregnancy loss [8]. Although IUTs have improved perinatal survival [8], they remain invasive and carry procedure-related risks, including fetal demise, preterm birth, and other complications [2,3].

Alternative approaches, such as intravenous immunoglobulin (IVIG) and plasmapheresis, have been used to delay or reduce the need for IUTs, but outcomes remain suboptimal, and many affected pregnancies still require multiple procedures [8]. Beyond the immediate treatment challenges, recurrence of HDFN in subsequent pregnancies remains a major concern. Prior reports suggest that recurrence is common and may present with earlier onset or greater severity, yet robust epidemiological data remain limited [9].

A prior study suggested that maternal characteristics, along with medical and obstetric factors, may be associated with the diagnosis of HDFN [10]. Despite advancements in fetal monitoring and intervention, population-based evidence remains limited regarding whether HDFN impacts neonatal and maternal health care resource use. Furthermore, recurrence patterns in subsequent HDFN-affected pregnancies have not been well characterized within large integrated health systems. Therefore, this study aimed to (1) describe maternal and neonatal characteristics and health care use associated with HDFN and (2) evaluate recurrence patterns in subsequent pregnancies.

Methods

Ethical Considerations

All study activities were reviewed and approved by the Kaiser Permanente Southern California (KPSC) Institutional Review Board with exemption of informed consent (IRB#13503). The study involved a secondary analysis of existing electronic health record (EHR) data and posed no more than minimal risk to participants.

Study Design

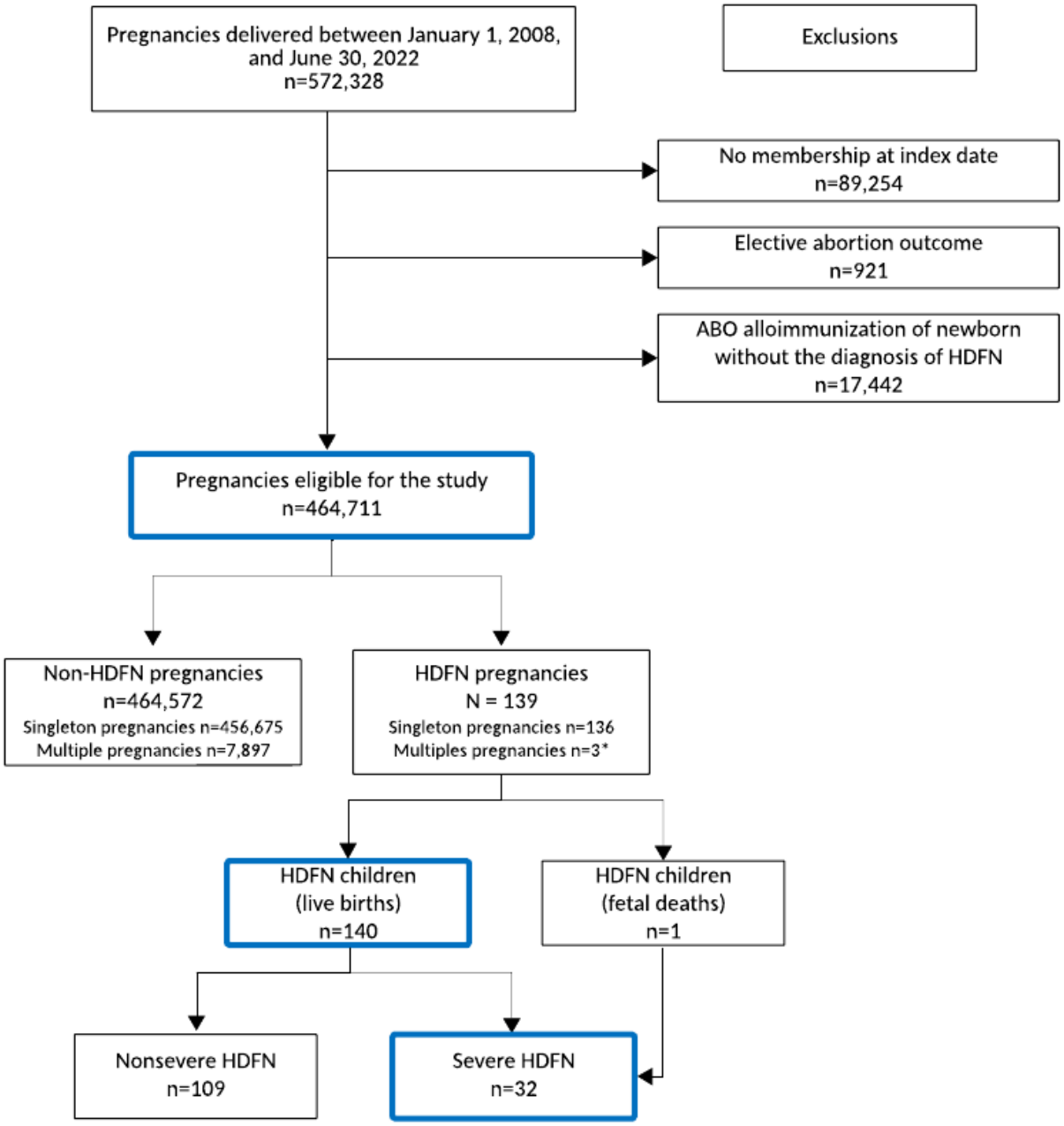
We conducted a retrospective cohort study using EHRs from KPSC, a large integrated health care system serving >4.7 million members across 15 hospitals and 235 medical offices. The KPSC population is racially, ethnically, and socioeconomically diverse and is representative of the Southern California population [11-13]. The KPSC database contains detailed sociodemographic, outpatient, inpatient, medical, and obstetric records, as well as pharmacy and laboratory records.

Study Population

Among 572,328 pregnancies delivered between January 1, 2008, and June 30, 2022, we excluded pregnancies that did not have KPSC membership at the start of pregnancy (n=89,254, 15.6%), those that ended in elective abortion (n=921, 0.2%), and cases with ABO alloimmunization without a confirmed HDFN diagnosis (n=17,442, 3%). The final analytic cohort included 464,711 (81.2%) pregnancies (Figure 1).

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Figure 1. Study cohort composition. *Included 3 twin pregnancies, of which 5 infants had hemolytic disease of the fetus and newborn (HDFN), and 1 infant did not have HDFN.



HDFN Status and Classification

HDFN cases (from 2008 to 2022) were identified using a validated algorithm incorporating the *International Classification of Diseases, Ninth and Tenth Revisions, Clinical Modification* diagnostic and procedural codes, laboratory records, and clinical free-text extraction from KPSC EHRs and were followed through 2023. Trained abstractors conducted comprehensive chart reviews to confirm HDFN status, severity, and recurrence, with uncertain cases adjudicated by our maternal-fetal medicine specialist (MJF). Details of our HDFN identification process, including the natural language processing (NLP)–assisted chart review process, have been published previously [14].

Using structured EHR data (codes, medications, and laboratory results) and NLP-processed notes, candidate HDFN pregnancies were identified using likely indicators of maternal antibodies or titers; maternal or infant HDFN diagnosis, transfusion, or hydrops; infant IVIG; jaundice or phototherapy; and first Rho(D) immune globulin. We adjudicated selected indicator combinations by chart review and excluded cases of ABO alloimmunization alone. Of 464,711 eligible pregnancies, 136 (0.03%) were confirmed as HDFN. Indicator prevalence ranged from 0.02% (n=72; infant IVIG) to 34.53% (n=160,456; jaundice

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or phototherapy) overall and from 32.35% (n=44; infant IVIG) to 100% (n=136; maternal antibody positivity) among cases. Several combinations of 4 to 6 indicators had 100% positive predictive value; 80.88% (n=110) of cases had maternal antibody positivity, maternal or infant HDFN diagnosis, and infant jaundice or phototherapy.

HDFN in Subsequent Pregnancies

We identified subsequent pregnancies among women with ≥2 pregnancies in the KPSC health care system between January 1, 2008, and December 31, 2023. Then, we ordered all pregnancies chronologically using the pregnancy episode start date, with the earliest pregnancy during the study period designated as the index pregnancy. All later pregnancies for the same individual were classified as subsequent pregnancies. For each subsequent pregnancy, HDFN status was determined using the same NLP-assisted manual chart review algorithm applied to index pregnancies.

Maternal and Neonatal Characteristics

Maternal characteristics included age, race or ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, non-Hispanic Asian or Pacific Islander, other or multiple, or unknown), median household income (US <$30,000, US $30,000-$49,999, US $50,000-$69,999, US $70,000-$89,999, US ≥$90,000, or missing) based on US Census Bureau data, and insurance type (Medicaid, commercial, private, or other). Smoking, alcohol, and substance use during pregnancy were assessed, along with reproductive history (parity, gravidity, and prepregnancy BMI [kg/m^2]). Clinical conditions included gestational weight gain (in pounds) and maternal comorbidities, such as asthma, chronic hypertension, pregestational diabetes, renal disease, and autoimmune disorders. We also evaluated obstetric complications, including preterm premature rupture of membranes, small-for-gestational-age or intrauterine growth restriction, and fetal hydrops.

Neonatal characteristics included infant sex, birth weight (grams), gestational age at birth (weeks), and head circumference (centimeters). Perinatal outcomes assessed were preterm birth, fetal death, and Apgar scores <7 at 5 minutes. Neonatal complications evaluated included birth asphyxia, hypoxic-ischemic encephalopathy, jaundice, kernicterus, and cerebral palsy.

Health Care Resource Use

Health care resource use was evaluated separately for pregnant women and neonates. For pregnant women, we examined hospital length of stay, intensive care unit admission, and the timing of prenatal care initiation. Health care encounters, including hospitalizations, emergency department visits, urgent care visits, and outpatient visits, were assessed from pregnancy through 6 weeks post partum. For neonates, we examined the length of delivery hospitalization, neonatal intensive care unit (NICU) admission and length of stay, and health care resource use from delivery through 1 year, including hospitalizations, emergency department visits, urgent care visits, and outpatient visits.

Treatment Modalities

We evaluated both individual and combined treatment modalities among pregnant women, including IUTs, MCA Doppler ultrasounds, RhoGAM, antenatal steroids, magnesium sulfate, group B *Streptococcus* prophylaxis, and plasmapheresis. For neonates, treatment modalities included red blood cell transfusions, exchange transfusions, phototherapy for hyperbilirubinemia, and IVIG.

Statistical Analysis

We analyzed maternal and neonatal characteristics, health care resource use, and treatment patterns according to HDFN diagnosis status. Recurrence of HDFN was examined by estimating the frequency and proportion of pregnancies with a subsequent HDFN-affected pregnancy, including classification by severity and onset. Among recurrent HDFN cases, we described the distribution of gestational age at first IUT and summarized associated clinical features, such as fetal anemia and the number of IUTs performed. We excluded pregestational diabetes, birth asphyxia, hypoxic-ischemic encephalopathy, and cerebral palsy from all analyses due to the small sample size.

For categorical variables, frequencies and percentages were estimated, and comparisons were made using chi-square tests or Fisher exact tests when cell sizes were small. For continuous variables, means and SDs were calculated and compared using Wilcoxon rank-sum tests to account for potentially nonnormally distributed characteristics. Statistical significance was defined as a 2-sided P value <0.05. All analyses were conducted using SAS (version 9.4; SAS Institute Inc).

Results

Pregnancy Cohort

Among 464,711 singleton and multiple pregnancies in KPSC members between January 1, 2008, and June 30, 2022, 139 (3 per 10,000) were identified as HDFN pregnancies. There were 3 twin pregnancies, for which all but 1 fetus was diagnosed with HDFN, resulting in 140 HDFN live births and 1 HDFN fetal death (Figure 1).

Maternal Characteristics

Women with HDFN pregnancies were older (aged ≥35 years; n=42, 30.2% vs n=97,146, 20.9%; P<.007) and had varied racial or ethnic distributions, with a higher proportion of non-Hispanic White women (n=55, 39.6% vs n=125,971, 27.1%) and a lower proportion of Hispanic women (n=57, 41% vs n=213,468, 45.9%; P=.005; Table 1**)**. Medicaid coverage was more common among HDFN cases (n=22, 15.8% vs n=44,561, 9.6%; P=.03), as was renal disease (n=8, 5.8% vs n=8331, 1.8%; P<.001). HDFN cases were also more likely to be multiparous (n=121, 87.1% vs n=264,766, 57%) and multigravida (n=128, 92.1% vs n=326,828, 70.4%; P<.001). Other sociodemographic, behavioral, and clinical characteristics were similar between groups.

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Table 1. Distribution of maternal demographic, medical, and obstetric characteristics among pregnant women by hemolytic disease of the fetus and newborn (HDFN) diagnosis status.

Characteristics	Total pregnancies (N=464,711)	Pregnancies with HDFN (N=139)	Pregnancies without HDFN (N=464,572)	*P* value
Maternal age at index date (years)[a]				<.001
Mean (SD)	29.8 (5.7)	31.7 (5.3)	29.8 (5.7)	
Median	30.0 (12.0-65.0)	32.0 (17.0-43.0)	30.0 (12.0-65.0)	
Maternal age categories at index date (years), n (%)				.007[b]
<20	21,430 (4.6)	3 (2.2)	21,427 (4.6)	
20-29	193,530 (41.6)	43 (30.9)	193,487 (41.6)	
30-34	152,563 (32.8)	51 (36.7)	152,512 (32.8)	
≥35	97,188 (20.9)	42 (30.2)	97,146 (20.9)	
Maternal race or ethnicity, n (%)				.005[b]
Hispanic	213,525 (45.9)	57 (41.0)	213,468 (45.9)	
NH[c] Asian or Pacific Islander	62,045 (13.4)	17 (12.2)	62,028 (13.4)	
NH Black	36,344 (7.8)	10 (7.2)	36,334 (7.8)	
NH White	126,026 (27.1)	55 (39.6)	125,971 (27.1)	
Other or multiple races	5794 (1.2)	0 (0.0)	5794 (1.2)	
Unknown	20,977 (4.5)	0 (0.0)	20,977 (4.5)	
Household income (US $), n (%)				.80[b]
<30,000	17,307 (3.7)	4 (2.9)	17,303 (3.7)	
30,000-49,999	113,957 (24.5)	29 (20.9)	113,928 (24.5)	
50,000-69,999	135,554 (29.2)	43 (30.9)	135,511 (29.2)	
70,000-89,999	96,346 (20.7)	28 (20.1)	96,318 (20.7)	
≥90,000	100,388 (21.6)	35 (25.2)	100,353 (21.6)	
Missing	1159 (0.2)	0 (0.0)	1159 (0.2)	
Insurance type, n (%)				.03[b]
Medicaid	44,583 (9.6)	22 (15.8)	44,561 (9.6)	
Commercial	386,724 (83.2)	103 (74.1)	386,621 (83.2)	
Private	27,385 (5.9)	12 (8.6)	27,373 (5.9)	
Other	6019 (1.3)	2 (1.4)	6017 (1.3)	
Smoking during pregnancy, n (%)				.78[b]
No	453,040 (97.5)	135 (97.1)	452,905 (97.5)	
Yes	11,671 (2.5)	4 (2.9)	11,667 (2.5)	
Alcohol use during pregnancy, n (%)				.59[b]
No	403,999 (86.9)	123 (88.5)	403,876 (86.9)	
Yes	60,712 (13.1)	16 (11.5)	60,696 (13.1)	
Drug use during pregnancy, n (%)				.88[b]
No	446,864 (96.2)	134 (96.4)	446,730 (96.2)	
Yes	17,847 (3.8)	5 (3.6)	17,842 (3.8)	
Prepregnancy BMI (kg/m^2), n (%)				.06[b]
<18.5	9302 (2.0)	2 (1.4)	9300 (2.0)	
18.5-24.9	172,300 (37.1)	52 (37.4)	172,248 (37.1)	

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Characteristics	Total pregnancies (N=464,711)	Pregnancies with HDFN (N=139)	Pregnancies without HDFN (N=464,572)	*P* value
25.0-29.9	121,422 (26.1)	28 (20.1)	121,394 (26.1)	
30.0-34.9	68,732 (14.8)	25 (18.0)	68,707 (14.8)	
≥35.0	54,829 (11.8)	12 (8.6)	54,817 (11.8)	
Missing	38,126 (8.2)	20 (14.4)	38,106 (8.2)	
Gestational weight gain (lb)				.07[a]
Mean (SD)	27.5 (15.9)	26.1 (16.2)	27.5 (15.9)	
Median	27.6	24.0	27.6	
Asthma, n (%)				.38[b]
No	440,344 (94.8)	134 (96.4)	440,210 (94.8)	
Yes	24,367 (5.2)	5 (3.6)	24,362 (5.2)	
Chronic hypertension, n (%)				.05[b]
No	455,405 (98.0)	133 (95.7)	455,272 (98.0)	
Yes	9306 (2.0)	6 (4.3)	9300 (2.0)	
Renal disease, n (%)				<.001[b]
No	456,372 (98.2)	131 (94.2)	456,241 (98.2)	
Yes	8339 (1.8)	8 (5.8)	8331 (1.8)	
Autoimmune disease, n (%)				.31[b]
No	463,441 (99.7)	138 (99.3)	463,303 (99.7)	
Yes	1270 (0.3)	1 (0.7)	1269 (0.3)	
Parity, n (%)				<.001[b]
Multiparous	264,887 (57.0)	121 (87.1)	264,766 (57.0)	
Nulliparous	140,722 (30.3)	12 (8.6)	140,710 (30.3)	
Unknown	59,102 (12.7)	6 (4.3)	59,096 (12.7)	
Gravidity, n (%)				<.001[b]
Multigravida	326,956 (70.4)	128 (92.1)	326,828 (70.4)	
Nulligravida	136,049 (29.3)	11 (7.9)	136,038 (29.3)	
Unknown	1706 (0.4)	0 (0.0)	1706 (0.4)	
Preterm premature rupture of membranes, n (%)				.47[b]
No	458,085 (98.6)	136 (97.8)	457,949 (98.6)	
Yes	6626 (1.4)	3 (2.2)	6623 (1.4)	

[a]Wilcoxon rank-sum *P* value.

[b]Chi-square *P* value.

[c]NH: non-Hispanic.

Neonatal Characteristics and Outcomes

Infants affected by HDFN had lower birth weight and gestational age distributions, with higher proportions born weighing <2500 g (n=22, 15.6% vs n=31,740, 7.1%; *P*<.001) and at 35 to 36 weeks' gestation (n=24, 17% vs n=25,296, 5.7%) or 33 to 34 weeks' gestation (n=12, 8.5% vs n=8753, 2%; *P*<.001; Table 2). Preterm birth was more common among HDFN cases (n=40, 28.4% vs n=42,240, 9.5%; *P*<.001). Head circumference was slightly smaller (mean 33.5, SD 2.26 cm vs mean 34.0, SD 2.72 cm; *P*=.04). Neonatal jaundice occurred more frequently in HDFN cases (n=92, 65.2% vs n=162,465, 36.4%; *P*<.001). Sex distribution and fetal death rates were similar between groups.

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Table 2. Distribution of child characteristics and perinatal outcomes by hemolytic disease of the fetus and newborn (HDFN) diagnosis status.

Characteristics	Total births[a] (N=446,499)	Pregnancies with HDFN (N=141)	Pregnancies without HDFN (N=446,358)	*P* value
Infant sex, n (%)				.22[b]
Female	216,646 (48.5)	59 (41.8)	216,587 (48.5)	
Male	228,476 (51.2)	82 (58.2)	228,394 (51.2)	
Unknown	1377 (0.3)	0 (0.0)	1377 (0.3)	
Birth weight (g), n (%)				<.004[b]
<1500	5982 (1.3)	4 (2.8)	5978 (1.3)	
1500-2499	25,780 (5.8)	18 (12.8)	25,762 (5.8)	
2500-3999	366,607 (82.1)	113 (80.1)	366,494 (82.1)	
≥4000	38,773 (8.7)	4 (2.8)	38,769 (8.7)	
Unknown	9357 (2.1)	2 (1.4)	9355 (2.1)	
Gestational age at birth (weeks), n (%)				<.001[b]
<28	3763 (0.8)	2 (1.4)	3761 (0.8)	
28-32	6270 (1.4)	3 (2.1)	6267 (1.4)	
33-34	8765 (2.0)	12 (8.5)	8753 (2.0)	
35-36	25,320 (5.7)	24 (17.0)	25,296 (5.7)	
≥37	402,381 (90.1)	100 (70.9)	402,281 (90.1)	
Head circumference (cm)				.04[c]
Mean (SD)	34.0 (2.72)	33.5 (2.26)	34.0 (2.72)	
Median (IQR)	34.0 (15.0-97.8)	33.7 (21.0-37.5)	34.0 (15.0-97.8)	
Preterm birth, n (%)				<.001[b]
No	402,035 (90.0)	100 (70.9)	401,935 (90.0)	
Yes	42,280 (9.5)	40 (28.4)	42,240 (9.5)	
Missing	2184 (0.5)	1 (0.7)	2183 (0.5)	
Fetal death, n (%)				.71[b]
No	444,315 (99.5)	140 (99.3)	444,175 (99.5)	
Yes	2184 (0.5)	1 (0.7)	2183 (0.5)	
5-minute Apgar score <7, n (%)				.35[b]
No	435,606 (97.6)	138 (97.9)	435,468 (97.6)	
Yes	6083 (1.4)	3 (2.1)	6080 (1.4)	
Missing	4810 (1.1)	0 (0.0)	4810 (1.1)	
Neonatal jaundice, n (%)[d]				<.001[b]
No	283,942 (63.6)	49 (34.8)	283,893 (63.6)	
Yes	162,557 (36.4)	92 (65.2)	162,465 (36.4)	
Kernicterus, n (%)				<.001[b]
No	446,494 (100.0)	141 (100.0)	446,353 (100.0)	
Yes	5 (0.0)	0 (0.0)	5 (0.0)	

[a]Includes 3 twin pregnancies, of which 5 children had HDFN and 1 child did not have HDFN (Figure 1).

[b]Chi-square *P* value.

[c]Wilcoxon rank-sum *P* value.

[d]This includes all neonatal jaundice with kernicterus cases.

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Health Care Resource Use in Pregnancy

Women with HDFN pregnancies had longer hospital stays (median 3.0, IQR 2.0-4.0 days vs median 2.0, IQR 1.0-3.0 days; *P*<.001) and initiated prenatal care later, with more patients beginning care in the second trimester (n=21, 15.1% vs n=23,175, 5%) or third trimester (n=5, 3.6% vs n=2477, 0.8%; *P*<.001; Table 3). Nondelivery hospitalizations were more common among HDFN cases (n=27, 19.4% vs n=23,228, 5%; *P*<.001). Urgent care visits were less frequent (n=23, 16.6% vs n=116,021, 25%; *P*=.02), while emergency department visits were similar between groups.

Table 3. Health care use among pregnant women based on hemolytic disease of the fetus and newborn (HDFN) diagnosis status.

Health care use	Total pregnancies (n=464,711)	Pregnancies with HDFN (n=139)	Pregnancies without HDFN (n=464,572)	*P* value
Length of hospital stay during each pregnancy (days)				<.001[a]
Mean (SD)	2.4 (2.9)	3.6 (3.2)	2.4 (2.9)	
Median (IQR)	2.0 (1.0-3.0)	3.0 (2.0-4.0)	2.0 (1.0-3.0)	
Timing of prenatal care initiation, n (%)				<.001[b]
First trimester	398,818 (85.8)	110 (79.1)	398,708 (85.8)	
Second trimester	23,196 (5.0)	21 (15.1)	23,175 (5.0)	
Third trimester	3482 (0.8)	5 (3.6)	2477 (0.8)	
No prenatal care or unknown timing	39,215 (8.4)	3 (2.2)	39,212 (8.4)	
Health care use during each pregnancy, n (%)				
Hospitalizations (excluding delivery admission)	23,255 (5.0)	27 (19.4)	23,228 (5.0)	<.001[b]
Emergency department visits	107,560 (23.2)	35 (25.2)	107,525 (23.1)	.57[b]
Urgent care visits	116,044 (25.0)	23 (16.6)	116,021 (25.0)	.02[b]

[a]Wilcoxon rank-sum *P* value.

[b]Chi-square *P* value.

Neonatal Health Care Resource Use

Children with HDFN had longer delivery hospitalizations (median 5.0, IQR 2.0-7.5 days vs median 2.0, IQR 1.0-2.0 days; *P*<.001) and longer NICU stays (median 4.0, IQR 0.0-7.0 days vs median 0.0, IQR 0.0-0.0 days; *P*<.001) than those without HDFN (Table 4). NICU admission within 4 weeks of birth was more frequent among HDFN cases (n=85, 60.7% vs n=45,739, 10.3%; *P*<.001). Emergency department, urgent care, and outpatient visit frequencies were similar between groups.

Table 4. Health care use among children based on hemolytic disease of the fetus and newborn (HDFN) diagnosis status.

Health care use	Total live births (n=444,315)	Pregnancies with HDFN (n=140)	Pregnancies without HDFN (n=444,175)	*P* value
Length of delivery hospitalizations (days)				<.001[a]
Mean (SD)	2.9 (7.9)	7.4 (11.6)	2.9 (7.9)	
Median (IQR)	2.0 (1.0-2.0)	5.0 (2.0-7.5)	2.0 (1.0-2.0)	
Length of NICU[b] stay during the delivery hospitalization (days)				<.001[a]
Mean (SD)	1.5 (8.2)	6.7 (12.5)	1.5 (8.1)	
Median (IQR)	0.0 (0.0-0.0)	4.0 (0.0-7.0)	0.0 (0.0-0.0)	
Health care use from delivery to 4 week postpartum, n (%)				
NICU stay	45,824 (10.3)	85 (60.7)	45,739 (10.3)	<.001[c]
Emergency department visits	17,579 (4.0)	4 (2.9)	17,575 (4.0)	.50
Urgent care visits	78,083 (17.6)	30 (21.4)	78,053 (17.6)	.23
Outpatient visits	424,789 (95.6)	130 (92.9)	424,659 (95.6)	.11

[a]Wilcoxon rank-sum *P* value.

[b]NICU: neonatal intensive care unit.

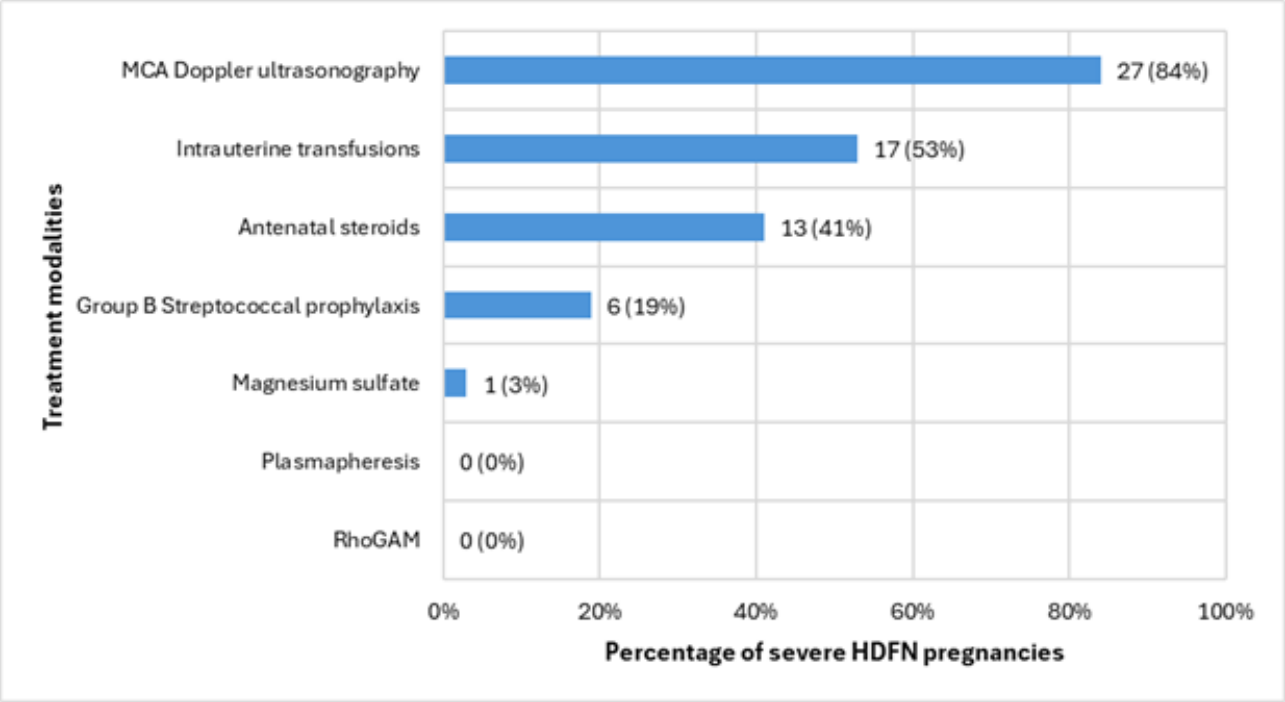
[c]Chi-square *P* value.

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Treatment Modalities

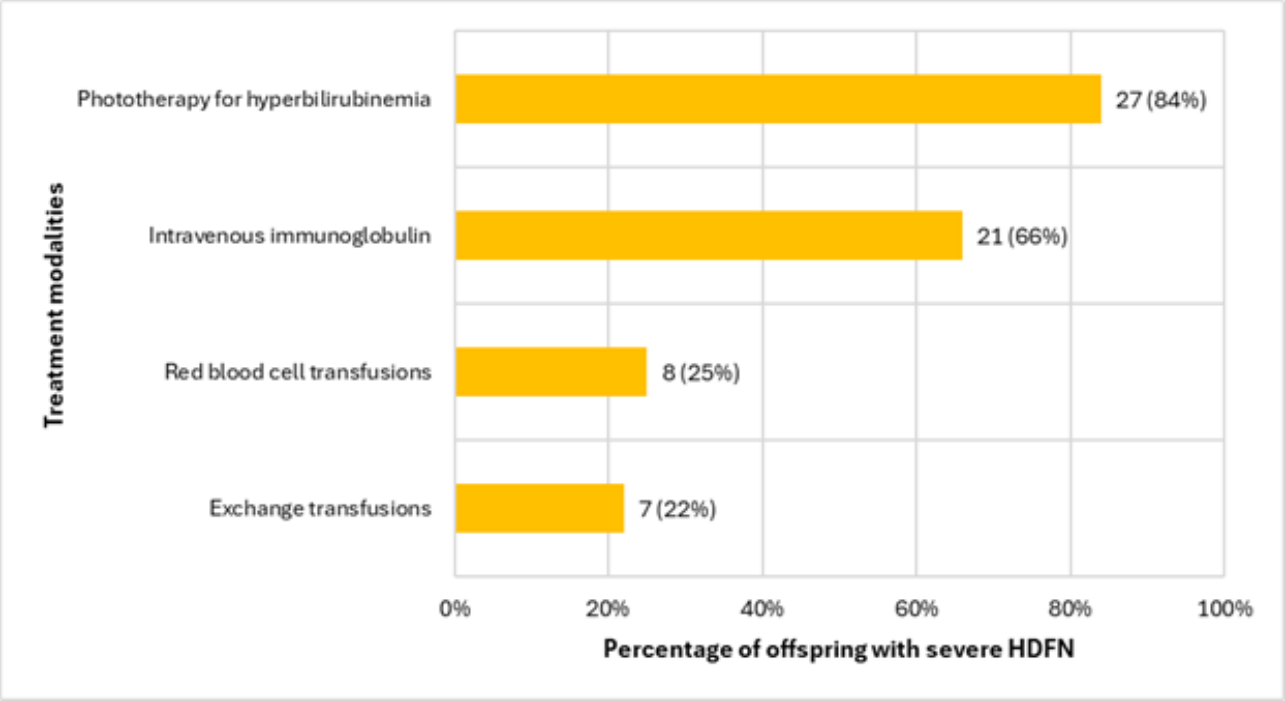
Figure 2 shows the frequency and percentage of treatment modalities for severe HDFN pregnancies (n=32, 100%). MCA Doppler ultrasound was the most frequently used modality among severe HDFN pregnancies (n=27, 84%), followed by IUT (n=17, 53%) and antenatal steroids (n=13, 41%). Group B *Streptococcus* prophylaxis was used in a smaller proportion of cases (n=6, 19%), while magnesium sulfate was rarely used (n=1, 3%). Plasmapheresis and RhoGAM were not used in this severe HDFN cohort.

Figure 2. Distribution of treatment modalities among pregnancies with severe hemolytic disease of the fetus and newborn (HDFN; N=32). MCA: middle cerebral artery.



Among offspring with severe HDFN, phototherapy for hyperbilirubinemia was the most common treatment (n=27, 84%), followed by IVIG (n=21, 66%). Red blood cell transfusions (n=8, 25%) and exchange transfusions (n=7, 22%) were used less frequently (Figure 3).

Figure 3. Distribution of treatment modalities among offspring with severe hemolytic disease of the fetus and newborn (HDFN).



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Subsequent Pregnancies

Overall, 0.05% (53/101,623) subsequent pregnancies were affected by HDFN, with the majority occurring among those with a prior HDFN-affected pregnancy. The recurrence of HDFN in a subsequent pregnancy was substantially more common among pregnancies with a prior history of HDFN than among those without prior HDFN (12/16, 75% vs 41/101,607, 0.04%; *P*<.001).

Limiting the analysis to women with a prior HDFN-affected pregnancy who conceived again, recurrence was common: 83.3% (25/30) experienced HDFN in the next pregnancy, while 16.7% (5/30) did not (Table 5). Most recurrent cases were classified as nonsevere (n=17, 68%), although approximately one-third were severe (n=8, 32%). Among severe recurrences, onset occurred more often after 24 weeks of gestation (n=5, 62.5%). Evidence of fetal anemia was observed in 75% (n=6) of severe cases, necessitating at least 1 IUT.

Table 5. Hemolytic disease of the fetus and newborn (HDFN) status, severity, and management in subsequent pregnancies among women with a prior HDFN diagnosis.

Characteristics	Subsequent pregnancies, n (%)
HDFN status of the subsequent pregnancy (n=30)	
Non-HDFN pregnancy	5 (16.7)
HDFN pregnancy	25 (83.3)
HDFN severity among recurrent cases (n=25)	
Nonsevere HDFN	17 (68)
Severe HDFN	8 (32)
Onset among severe cases (n=8)	
Early onset (≤24 weeks of gestation)	3 (37.5)
Late onset (>24 weeks of gestation)	5 (62.5)
Documented fetal anemia[a]	6 (75)
≥1 intrauterine transfusion	6 (75)

[a]Fetal anemia was defined as a fetal hemoglobin level <0.84 multiples of the median. Fetal hemoglobin (g/100 ml) was calculated by dividing hematocrit (%) by 3.

Discussion

Principal Findings

In this large retrospective cohort study, we characterized maternal and neonatal outcomes, health care use, and recurrence patterns associated with HDFN. Although HDFN was rare, affected pregnancies demonstrated notable differences in clinical presentation and health care use, and recurrence in subsequent pregnancies was frequent.

Maternal Characteristics, Neonatal Outcomes, and Health Care Use

HDFN pregnancies differed from unaffected pregnancies across several maternal and neonatal characteristics. Mothers with HDFN were older and more frequently multiparous, consistent with alloimmunization developing over multiple pregnancies. Neonates affected by HDFN had higher rates of preterm birth and low birth weight and were substantially more likely to require NICU care, with longer delivery and NICU hospital stays. These findings reflect the substantial burden of hemolysis-related anemia and hyperbilirubinemia, which often necessitate specialized postnatal care.

Health care use was elevated in pregnancies affected by HDFN. Women experienced more nondelivery hospitalizations and initiated prenatal care later, suggesting potential gaps in early detection and management. Neonates required significantly greater inpatient resources, amplifying the strain on NICU services. Together, these patterns underscore the complex care needs associated with HDFN and highlight the substantial burden on both obstetric and neonatal services.

HDFN Recurrence in Subsequent Pregnancies

A key contribution of this study is the rates of HDFN recurrence. Among individuals with ≥2 pregnancies, 83.3% had HDFN in a subsequent pregnancy, and approximately one-third of recurrent cases were severe. Reported HDFN recurrence rates vary by cohort definition and outcome threshold. With recurrence defined as any HDFN in any subsequent pregnancy among women with a prior HDFN (EHR indicator or NLP phenotype) diagnosis, our rate is higher than the 56% treatment-requiring proportion reported among subsequent pregnancies of RhD-immunized women in Sweden [15], consistent with our higher-risk entry criterion and broader outcome. In severe cohorts, recurrence can be even higher: among women with a prior history of IUT and a subsequent antigen-positive fetus, 86% required repeat IUT [9]. Most recurrent cases demonstrated clinical features consistent with significant fetal anemia, including high frequencies of documented anemia and the need for IUTs. Recurrent cases that required IUTs often underwent treatment at earlier gestational ages than initially affected pregnancies, reflecting accelerated alloimmune fetal anemia in later pregnancies. These findings support current clinical observations that alloimmunization can lead to earlier and more clinically significant fetal disease in subsequent pregnancies. However, the presence of both severe

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and nonsevere recurrences suggests heterogeneity in disease expression.

Clinical Implications

Our findings have important implications for antenatal counseling and management. Given both the high recurrence pattern and the potential for early or severe disease in subsequent pregnancies, enhanced surveillance strategies may be warranted. Early referral to maternal-fetal medicine, closer monitoring of antibody titers, and earlier MCA Doppler assessment may help identify high-risk pregnancies before significant fetal anemia develops. The observed variability in recurrence severity also supports individualized monitoring plans rather than uniformly escalating surveillance.

Furthermore, EHR-based algorithms could be developed to flag women at risk for HDFN recurrence at prenatal care intake, enabling early review of prior history, timely laboratory testing, and consideration of early intervention to optimize outcomes. Moreover, population-based studies are needed to clarify long-term neonatal outcomes and quantify the health care costs associated with HDFN across the perinatal period. Further research should also evaluate whether early maternal biomarkers or alloantibody trends can better predict severity or recurrence to guide the timing of surveillance and intervention. Studies of antenatal treatment strategies may help determine approaches that delay or reduce the need for IUTs. Finally, prospective multicenter investigations could validate these findings and explore long-term neurodevelopmental outcomes in affected neonates, addressing critical gaps in the current evidence.

Strengths and Limitations

A major strength of this study is the large, demographically diverse, population-based cohort with comprehensive EHR data, enabling robust identification of HDFN cases and recurrence patterns. The manual chart review and adjudication process further strengthened data accuracy. However, our study is not without limitations. As this was a descriptive study, our findings should be interpreted accordingly. The retrospective design of this study may limit data capture in the EHR; therefore, misclassification of HDFN status, its severity, onset timing, and clinical features, such as fetal or neonatal anemia, is possible, particularly when documentation in health records was incomplete. Furthermore, future studies with larger samples and more events are needed to support multivariable regression modeling and adjustment for potential confounders. Although we used NLP-assisted manual chart review with adjudication to improve case ascertainment, cases from pregnancies managed in contracting hospitals (outside KPSC) may have been missed. This study was conducted within a single integrated health care system, which, while racially and socioeconomically diverse, may limit generalizability to nonintegrated health care settings.

Conclusions

HDFN remains a clinically significant condition associated with substantial perinatal morbidity and elevated health care use. Recurrence in subsequent pregnancies was common, and many recurrent cases exhibited severe fetal anemia requiring early IUT. These findings underscore the importance of timely identification, targeted surveillance strategies, and continued research aimed at improving antenatal management and reducing the burden of disease.

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Conflicts of Interest

MJF received unrelated research support from the Garfield Memorial Fund and Hologic Inc. CM is an employee of Johnson & Johnson. DG received unrelated research support from the National Institutes of Health–National Institute of Child Health and Human Development, the Garfield Memorial Fund, Hologic Inc, and the Centers for Disease Control and Prevention. All other authors declare no other conflicts of interest.

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Abbreviations

EHR: electronic health record
HDFN: hemolytic disease of the fetus and newborn
IUT: intrauterine transfusion
IVIG: intravenous immunoglobulin
KPSC: Kaiser Permanente Southern California
MCA: middle cerebral artery
NICU: neonatal intensive care unit
NLP: natural language processing
RhD: Rhesus D

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Original Paper

Codevelopment of a Digital Screening and Intervention Tool to Improve Lifestyle Habits in Children: Focus Group Study With Parents and Clinicians

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Abstract

Background: Chronic preventable diseases represent a major burden in Canada, often rooted in unhealthy behaviors established during childhood. Despite recommendations for routine screening, most children are not assessed due to clinical barriers. This paper presents the early development of Project DISCO, a self-administered, digital preappointment tool to screen for and support healthy lifestyle behaviors, including physical activity, sleep, nutrition, and screen time, in children aged 2 to 12 years.

Objective: This study aimed to explore clinicians' and parents' needs and past experiences with health technology; integrate their insights into the development of a digital tool for promoting health behaviors; and evaluate the usability, relevance, and acceptability of this tool.

Methods: Three semistructured focus group and interview sessions were conducted with primary care clinicians and parents. Participants were recruited at the Groupe de Médecine de Famille Universitaire Saint-Hubert using purposive and convenience sampling: clinicians were recruited internally, whereas parents of children aged 2 to 12 years were invited via emails sent by clinic staff. Data were analyzed using a combination of inductive and deductive approaches. Findings informed iterative refinements throughout the codevelopment of the digital tool for promoting healthy lifestyle behaviors in children.

Results: A total of 8 participants took part in 6 discussions, including 5 parents of children aged 3 to 12 years and 3 primary care clinicians. Hybrid thematic analysis identified six themes: (1) the potential of a digital tool to promote healthy habits in pediatrics; (2) implementation challenges and opportunities, including integration of the tool into clinical workflow; (3) adherence to and engagement with the tool, with suggestions for reminders and involvement of nurses; (4) perceived limitations and improvement of the screening tool, particularly the nutrition and sleep questionnaires; (5) feedback on the screening report and intervention emphasizing clarity and actionable guidance; and (6) perceived clinical value and opportunity costs. Insights from these discussions guided refinements of the digital tool.

Conclusions: The findings support the tool's relevance and inform its ongoing development. A feasibility study is planned prior to a randomized controlled trial.

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KEYWORDS

pediatrics; screening; intervention; lifestyle behavior; qualitative study; digital tool

Introduction

In Canada, chronic preventable diseases cause 65% of all deaths [1], affect 44% of Canadians, and account for 58% of the annual health care budget [2]. Unhealthy lifestyle behaviors such as physical inactivity, excessive screen time, unhealthy diet, and poor sleep hygiene are key contributors to chronic preventable conditions, including obesity, diabetes, cardiovascular disease, several types of cancer, and psychological illnesses [3-9]. These behaviors often originate in childhood and tend to track into adulthood [9-11] and cluster [5,12-14].

Despite recommendations for systematic screening by several organizations, including the Canadian Task Force on Preventive Health Care [15-17], most children are not screened for lifestyle behaviors. Barriers include limited clinician time, competing priorities, fear of upsetting families, and low perceived self-efficacy of clinicians [18-22].

Digital preappointment screening can help overcome these barriers [23-26]. Compared to traditional methods, it is more time efficient, scalable, and generally well accepted by clinicians and families [23,24,26-32]. In pediatrics, digital screening, brief intervention, and referral to treatment (SBIRT) has helped address adolescent substance abuse [31,33-35] by identifying risky behaviors, initiating behavior change, and connecting patients to support resources [36,37]. Similar tools have been developed for parents to support childhood obesity in primary care [38].

Active stakeholder involvement is essential in developing screening and intervention tools [39-41]. Parents can help ensure the tool's relevance and fit within real-life family contexts [42], whereas clinicians inform its feasibility and acceptability in practice [31,43,44]. For example, an intervention to support young adults with type 1 diabetes was codeveloped with patients, researchers, and health care professionals, helping identify priorities and concrete strategies to improve care [45].

This study sought to develop, alongside stakeholders, a tool to target health behaviors in children. Specifically, the primary objective of this study was to refine a screening and intervention tool using end user feedback obtained through focus groups [46]. This paper describes the codevelopment and refinement through structured focus groups with parents and clinicians of a self-administered digital preappointment screening and intervention tool targeting physical activity, sleep, nutrition, and screen time in children aged 2 to 12 years in general pediatric primary care.

Methods

Preliminary Data and Tool Development

This study is part of a larger research program that was initiated between October 2021 and November 2022, with a needs assessment conducted with 114 families at the Groupe de Médecine de Famille Universitaire Saint-Hubert, a suburban family medicine group [47]. This needs assessment confirmed clinicians' interest in obtaining more information about children's lifestyle behaviors, highlighted the prevalence of unhealthy behaviors in this population, and revealed parents' interest in the development of a preappointment screening tool for lifestyle behaviors. The current manuscript describes the subsequent step of tool refinement through focus groups with parents and clinicians.

A first iteration of our SBIRT tool used three inputs: (1) literature on behavioral science frameworks, including nudges and comparisons that improve real-world decision-making [48,49] and health behavior change [49,50] supported by evidence on physical activity [51,52] and nutrition [53-55] in adults and promising pediatrics data [56]; (2) input from clinicians and family partners [25,35,57-59]; and (3) existing tools such as the RIPPLE (Resource Information Program for Parents on Lifestyle and Education) program, an eHealth SBIRT tool developed by Ball and van Mierlo [25,38,58,60] to prevent pediatric obesity.

More specifically, behavioral sciences were used to inform both the structure and the content of the tool given the promise of this domain to strengthen pediatric nutrition interventions. Insights into cognitive biases and parental motivation—which can be sought through the health behavior screening process by inquiring about motivation to change and beliefs about their children's behaviors relative to group averages—can enable the development of more targeted and effective strategies that support the long-term adoption of healthy eating behaviors in children [49]. Although primarily focused on dietary habits, these strategies are broadly applicable to health behavior change. In this study, we sought to leverage these behavioral science insights through promising approaches such as personalized risk communication [61], the "fresh start effect" [62,63], implementation intentions [64,65], fostering internalization of healthy behaviors [66,67], and strengthening self-regulation [68-70]. The use of these frameworks seeks to enable enhanced parental engagement and facilitate the integration of behavior change into daily family life, notably by establishing a concrete and specific link between a health behavior and the action required to improve it, which may support the repetition of healthier behaviors and eventual automatization [49].

SBIRT Content and Description

Following the standard approach in the literature [25,38,60], our tool consists of 3 main sections: screening questionnaire, brief intervention, and referral to resources (Table 1).

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Table 1. Screening, brief intervention, and referral to treatment tool core components.

Components	Description
Screening	• Parents complete a digital, self-administered questionnaire covering the family's demographic information and the child's health behaviors (physical activity, sleep, nutrition and screen time). The questions were informed by the results of a prior needs assessment.
Brief intervention	• After screening, families receive a personalized report summarizing all behaviors and highlighting those not meeting national health guidelines. • Feedback, codeveloped with Evolution Health (van Mierlo, CEO) and family partners, includes behavioral strategies (eg Specific, Measurable, Achievable, Relevant, Timebound (SMART) goals and nudges). • Age-appropriate educational materials are emailed, and results are shared with clinicians to support counseling.
Referral to resources	• For each behavior not meeting the guidelines, parents receive a curated list of community resources tailored to their child's age and needs. • These resources, selected with input from health care professionals and parent partners, are shared with parents based on the behaviors they indicate interest in changing on the brief, personalize report page.

Tool Refinement: Focus Groups

The focus group discussions served the primary objective of the study: the development and refinement of our screening and intervention tool using end user feedback [46]. Specifically, the focus groups were intended to (1) gain insights into the needs of clinicians and parents regarding a digital tool aimed at promoting healthy behaviors; (2) explore participants' past experiences with health technology; (3) integrate insights obtained from the first focus group into the tool development process; and (4) assess the perceived usability, relevance, acceptability, and accuracy of the developed tool. In the first and second focus groups, participants engaged with static mock-ups of the interface, which included the intended questions for each health behavior, and discussed and refined the visual outputs. This led to the fully operational screening and personalized intervention tool evaluated in the third focus group. During this focus group, participants interacted with the working interface, including the full screening questionnaire; immediate personalized feedback reports; comparative normative data displays; color-coded results across physical activity, sleep, nutrition, and screen time domains; and embedded links to actionable resources and follow-up guidance. The interactive tool is available on the operational DISCO platform [71].

Participants and Recruitment Process

Two groups of participants were recruited from the Groupe de Médecine de Famille Universitaire (GMF-U) of Saint-Hubert: (1) primary care clinicians and (2) parents or legal guardians of children who are patients of the GMF-U of Saint-Hubert. Purposive and convenience sampling strategies were used to ensure rich, relevant data while promoting in-depth discussion.

Clinicians were recruited through an internal invitation sent by the management of the family medicine clinic. Parents were recruited via email invitations relayed by clinic staff to those with upcoming appointments for children aged 2 to 12 years. Eligibility criteria included being a parent or legal guardian of a child in that age range and being fluent in French or English.

Data Collection

Three semistructured focus groups (August 2024, November 2024, and March 2025), each lasting 60 to 90 minutes, were conducted. Clinicians participated in person in August and virtually thereafter, whereas parents joined virtually in all sessions (via Microsoft Teams). Due to availability constraints, 8 sessions were held as individual interviews. One clinician and 1 parent participated in all 3 focus groups, whereas others joined a single session.

Discussions explored users' experience with the digital health tool; perceived usability and relevance of the prototype; satisfaction; and suggestions for content, format, and delivery (Multimedia Appendix 1). Iterative refinement of the tool was based on feedback collected throughout the sessions. For example, after the first session, visual mock-ups were developed based on user expectations; the second session focused on reactions to various features (eg, feedback messages); and the third session examined acceptability and emotional responses to the tool. All data were collected and analyzed in French and translated into English for reporting.

Data collection continued until thematic saturation was reached, defined as the point when themes became repetitive across groups and no new themes emerged during iterative coding. At this stage, participants' contributions reinforced and stabilized existing themes. In this study, saturation reflects internal coherence rather than statistical representativeness [72]. The same saturation criteria were applied to both parents and clinicians.

Data Analysis

All focus group recordings were transcribed verbatim and reviewed for accuracy. An iterative, hybrid analysis—combining inductive and deductive approaches—was conducted. Deductive codes were elaborated using a published framework covering 7 constructs of usability, acceptability, and satisfaction (affective attitude, burden, perceived effectiveness, ethicality, coherence, opportunity costs, and self-efficacy) [73]. Furthermore, initial coding involved open coding aiming to identify emerging meaning units (ideas, experiences, and suggestions), followed by axial coding to identify conceptual relationships and central themes.

Data were analyzed at the group level using thematic analysis to describe and interpret patterns of meaning [74]. The process was managed using Microsoft Excel. To ensure coherence and

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transparency, the coder conducted systematic internal checks through repeated readings, comparison of the codes across cycles, and iterative refinement of the categories. Emerging themes were also discussed with the research team to strengthen analytic credibility [75]. Following a sequential cocreation approach inspired by the development of the RIPPLE pediatric obesity prevention tool [25,38,58,60], emerging themes from participants' feedback guided refinements to the tool, including clarifying content, improving ergonomics, and simplifying usability.

Ethical Considerations

This study received ethics approval from the research ethics boards of the Centre intégré de santé et de services sociaux de la Montérégie-Centre and the Sainte-Justine University Hospital Centre (application MP-04-2024-889 – DISCO – Focus Groups).

All participants provided informed consent prior to taking part and consented to the use and publication of their data. Each participant received a compensation of CAD $25 (US $18) per session.

Data were stored securely on the servers of Research Centre of the Sainte-Justine University Hospital Centre.

Results

Overview

Six discussions were conducted with a total of 8 participants, including 5 parents of children and 3 clinicians. Sessions were held either as individual interviews or dyadic discussions. All participants were female except for 1 clinician. Clinicians were family physicians with 5 to 6 years of professional experience. Participating parents had 1 to 3 children aged between 3 and 14 years.

Potential of the Digital Tool for Promoting Healthy Habits in Pediatrics

Parental Experiences With Digital Health Tools

Participating parents reported previous use of various digital tools to support their children's health, including platforms such as Dialogue (a telemedicine app) [76], smartwatches (for activity and sleep tracking), *Naître et grandir* (a government-sponsored parenting education website) [77], and *Rendez-vous santé Québec* (an online medical appointment–booking platform) [78]. Tools with simple, concrete guidance were particularly valued. One parent shared the following:

> *[The information is] written in a way that is very understandable for the general public, so it's very simple, very concise, with concrete examples.*

Several participants expressed concerns over tools perceived as overly commercial, simplistic, or lacking credibility. Some worried that digital tools disrupt the parent-child relationship:

> *I don't necessarily want a tool, a robot, to replace that connection with my child.*

They emphasized the importance of professional interfaces, quality assurance, and rigorous linguistic review in both French and English. One parent noted the following:

> *...small typos are fine, but blatant errors diminish the value of the questionnaire and makes it look less professional.... It makes the results seem less valid.*

Identified Needs for a Digital Tool

Parents described specific content needs for a digital lifestyle intervention tool, notably the desire for tailored guidance on complex topics such as eating behaviors and sleep challenges. They emphasized the following:

> *If you don't seek out information, you just do what you can, but you don't really know what the best practices are [...] [guidance] should come directly to us, you know, so we don't have to go looking for it.*

Clinician Perspectives on Automation and Screening

Clinicians generally supported automated lifestyle habit screening to reduce clinical burden. One stated the following:

> *In a perfect world, it wouldn't be the family doctor conducting lifestyle habit screening.*

They saw value in the tool providing personalized information while underscoring the importance of follow-up dialogue:

> *Our role is then to discuss how to apply it concretely in daily life [...] like motivational interviewing.*

Some participants supported broader automation, comparing the tool to mental health self-care platforms:

> *More programs designed to be accessible to the public, encouraging them to try self-care interventions. The more information you provide—especially if it's increasingly personalized and from reliable sources—the better. I fully support that.*

Implementation Challenges and Opportunities

Workflow Integration

Clinicians highlighted several barriers to completing the tool in the clinic. Filling it out in the waiting room was seen as unrealistic due to time constraints, late arrivals, and the difficulty of managing young children. Additionally, receiving results via email limited clinicians' ability to review them in time for the consultation.

To improve integration, clinicians strongly preferred embedding the tool in the electronic medical record, describing it as a straightforward and efficient solution. One noted the following:

> *...if it's a result [in the electronic medical record], [...] we have no choice but to read it, otherwise, it will always stay highlighted as an incomplete task note. This definitely encourages clinicians to check it out.*

Feasibility and Added Value in Clinical Practice of Use Prior to the Appointment

Participants agreed that it would be more practical to send the questionnaire before the appointment, ideally alongside the appointment confirmation, so that clinicians can review it

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beforehand and tailor the visit. Some emphasized the importance of doing so even for walk-in visits, where vulnerable families may be reached unexpectedly:

> *That's often where we catch them, especially since parents usually come for regular check-ups up to the age of 3-4, and after that, we tend to lose them.*

This suggests that the tool could help maintain contact with families beyond early childhood, when routine follow-ups become less frequent.

Adherence to and Engagement With the Tool

Challenges

Maintaining long-term engagement, a prevalent issue in the digital health literature [79,80], was a shared concern. Both clinicians and parents noted that, after the age of 2 years, appointments become infrequent, making regular follow-up difficult. Motivation was seen as key: "I'd need to be fully committed," said one parent. Engagement also tended to decrease with subsequent children:

> *...it's nice when it's your first child [...] then parents lose interest.*

Clinicians saw value in a follow-up system to track engagement and identify families at risk of dropping off.

Suggested Solutions

Reminders Linked to Appointment

Implementing email notifications that encourage parents to schedule follow-up appointments to discuss lifestyle habits after long gaps between visits was suggested:

> *Email notifications could help.*

Involvement of Nurse Practitioners

As they often see families more regularly, they could reinforce messages and ensure continuity.

Motivational Prompts and Progress Tracking

Parents welcomed the idea of periodic check-ins:

> *[If I am] asked, "Do you agree to receive the link again in a few weeks to check your progress?" Then, yes, I'd definitely do it.*

Trusted Framing

Parents stressed the importance of the tool appearing credible and tied to a medical source (eg, physician's office or public health institution).

Multichild Usability

A suggested addition was the ability to complete the tool for more than one child at a time.

Perceived Limitations and Improvement of the Screening Tool

Sleep Habit Screening

Clinicians initially found the sleep section too limited, focusing mainly on duration with little attention to sleep hygiene. One noted that sleep problems often emerge indirectly, such as through academic or attention issues. A suggested addition was "Has the teacher reported any fatigue, sleepiness, or attention problems with your child?" to better capture underlying concerns.

Nutrition Screening

Both parents and clinicians found the initial emphasis on sugar-sweetened beverages (SSBs) too narrow. One parent noted the following:

> *There are many other aspects of nutrition that are more relevant to me than sugary drinks.*

A clinician also observed that dietary discussions often go beyond SSBs, pointing out that "Parents are very concerned about the amount of food that is eaten" and that "it's surprising how often families don't eat together."

Key nutrition-related challenges raised by parents included the following:

- Food exploration and parental education: exposure to disliked foods is still important, especially between the ages of 0 and 5 years
- Picky eating: a common source of stress in early childhood
- Time constraints and meal planning: balancing work and family limits time for healthy meals
- Teenager autonomy: teenagers make more independent and sometimes less healthy choices

Tool Revisions and Validation

After the first focus groups, the screening tool was revised to incorporate parent feedback. Sleep-related questions were revised to better capture sleep hygiene and overall sleep quality. While the original questionnaire included limited content, the updated version encompasses a broader range of dimensions, such as daytime sleepiness, napping patterns, regularity of bedtime routines and schedules, characteristics of the sleep environment (eg, independent sleep and presence of screens), sleep onset (autonomy and latency) and nighttime disturbances (eg, cosleeping behaviors). Similarly, the nutrition section was broadened to reflect overall dietary behaviors and the mealtime environment. Although it previously included a single item on SSB consumption, the revised version expanded to food-related behaviors and environment and, as such, included questions on meal regularity, family meal practices, dietary quality (eg, fruit, vegetable, and protein intake), beverage choices, screen use during meals, child involvement in food preparation, meal planning practices, and parental feeding strategies. Language was simplified, and examples were added for clarity (Multimedia Appendix 2).

In the second set of focus groups, these changes were well received. A clinician described the updated items as "excellent, very detailed," noting the following:

> *Eating behavior is really interesting. [...] [and] relevant.*

A parent highlighted the focus on "observable behaviors" and appreciated the educational aspect:

> *It tells me, "this is what a sleep routine is." It kind of educates me at the same time as giving advice.*

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Feedback on Screening Report and Intervention

Presentation and Content of the Screening Results

Participants responded positively to the screening report's format and tone. Clinicians appreciated the inclusion of all behavior domains regardless of the results and the clear, color-coded layout:

> *Presenting all four sections, regardless of the results, is very positive [...] The positive approach to encouraging them and the available resources are very well designed.*

The tool was considered simple and accessible for most families. The report's emphasis on autonomy was also valued:

> *It's really good to let the parent decide which area they want to be informed about because having 3 or 4 areas to work on [can be a lot], [...] [this way, they can] take small steps on their own with your recommendations.*

Relevance and Usability of the Information

Parents appreciated receiving individualized and contextual data, especially charts comparing their children's behavior with national guidelines and clinic averages:

> *The comparative aspect is still fun, because we say we shouldn't compare ourselves, but at the same time, we all like to compare.*

However, the phrase "Top 10% of the clinic's most performing children" was criticized for being too competitive:

> *It should be about healthy lifestyle habits, not performance.*

Opinions varied on the level of detail in the graphs: some wanted more specificity (eg, types of activities, frequency, and age group distinction), whereas others felt that the current indicators (individual scores, recommendations, and averages) were sufficient. The relevance and appropriateness of within-clinic comparisons were also questioned by 1 participant.

Intervention and Resources

Participants valued the clarity, concreteness, and relevance of the resources. One parent said the following:

> *It's informative to know the impacts it has. The healthy goals. I also like seeing that, for example, the link for a tax credit provides information that we don't have. The resources are clickable on one of the links. It's very comprehensive, so it's interesting.*

They appreciated "immediate, applicable solutions," such as links to recipes or planning tools. Suggestions included practical tips for limiting screen time and integrating local resources by postal code (eg, green spaces and cycling paths). The intervention was seen as supportive of gradual, realistic change:

> *Sometimes it's nice to [...] take small steps by ourselves with the recommendations. I think that's the whole point.*

Overall, participants responded positively to the behavioral approaches included in the intervention.

Feedback on Encouragement Messages and Follow-Up

Tailored follow-up messages were seen as essential, particularly for families whose results did not improve. One parent noted the following:

> *...if [it has not worked] what can we do to help these families if it hasn't worked? [...] maybe we haven't seen improvements because you've maintained the same behavior. Did you know that there is another approach or reference?*

Personalized resources, whether to maintain progress or adjust strategies, were deemed essential to sustaining motivation.

Perceived Clinical Value and Opportunity Costs

Clinicians found the refined version of the tool efficient and user-friendly:

> *I really like that the recommendations for clinicians take only 20 seconds to read.*

Its brevity was seen as a strength that facilitated dialogue:

> *It opens the door for discussion.*

Both clinicians and parents viewed it as time-saving and accessible. One parent noted the following:

> *It's straightforward. [...] you don't really feel like filling out long tools while waiting in the clinic. I think you mentioned 15 minutes to complete it, but it felt more like 5.*

Clinicians highlighted three key strengths of the tool: (1) time savings ("It will save us time...and it aligns with a motivational interviewing approach since you've already started the work"), (2) initiation of the behavior change process ("prompting them to come with an answer, a rationale, or a potential solution at the next appointment. I think that could be beneficial"), and (3) increased parental engagement ("I think it's good to send this to all parents in any consultation context; I think it can be a good opportunity to just raise their awareness").

However, the tool's perceived value varied by family. Parents with prior knowledge or motivation felt that it might be too basic, whereas those with less awareness could find it overwhelming:

> *If it's for families who are already looking to improve behaviors, it might not go far enough for them. But for a family that really has no idea and needs to make changes, it might feel overwhelming.*

Discussion

Principal Findings

Through our focus groups aimed at refining our digital screening and intervention tool to promote healthy lifestyle habits in children, we found that the tool's key features, such as personalized, immediate, and normative feedback and access to concrete resources, were consistently valued by participants and align with known drivers of engagement and sustained behavior change [81,82]. Overall, parents reported feeling that the tool's questions were relevant and that the approach to offering support in behavior change and tailoring follow-ups,

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as well as the resources offered, was helpful and acceptable. Clinicians found the refined version of the tool efficient and user-friendly, and while they expressed concerns about barriers to completing the screening in the clinic, they felt that it was relevant to use a tool of this nature to perform lifestyle behavior screening between appointments and that the data presented were insightful, especially as clinical follow-up becomes less frequent as children grow older.

The elements of the intervention that were guided by behavioral science principles, such as comparisons to peers and norms and personalized feedback, were well accepted by participants. The persuasive potential of behavioral sciences relies on modifying choice architecture (ie, the decision-making context in which individuals act [83]). These interventions aim to guide behaviors toward outcomes considered beneficial while preserving freedom of choice as no options are removed or restricted [84]; therefore, guiding behaviors without unduly influencing or exerting coercive pressure that may limit informed decision-making [85]. In our development of the tool and implementation of strategies from behavioral science frameworks, we carefully considered the balance between behavioral effectiveness and respect for autonomy [86] and, through our focus group discussions, ensured that we elicited any autonomy-related concerns from stakeholders about the intervention; none were raised.

Overall, our study highlights the potential of a codeveloped digital tool for screening and promotion of healthy lifestyle habits in pediatric primary care. The participatory approach enabled iterative refinement based on clinicians' and parents' input, ensuring high acceptability, usability, and relevance (Multimedia Appendices 2 and 3).

While the integration of stakeholders supports participatory design, organizational factors such as timing of distribution, follow-up mechanisms, appointment coordination, and communication between families and professionals must be addressed for effective clinical implementation. These align with known implementation challenges in feedback-based interventions, where mode, frequency, and source of feedback influence the impact [87]. Future phases of this research project will leverage the early insights gleaned in this study and seek to address them to elucidate the most effective path forward.

As mentioned by participants, equitable access remains challenging, especially for families facing structural barriers (eg, financial constraints, fragmented services, and logistical difficulties). To address this, the tool was codeveloped with parents and clinicians, and tailored strategies with concrete support were prioritized to reduce contextual barriers and foster engagement [88]. Still, the recruitment process may have introduced selection bias as participating clinicians were likely more engaged in lifestyle-related screening and some parents may have been more motivated or available. The small sample size of this study and the self-selected nature of participants (all from a single clinical site) further limit the generalizability of the tool in development.

This could limit the tool's applicability to less engaged or more vulnerable populations—the very groups for whom equitable access is most critical. However, the primary objective was to gain insights into key concepts essential for tool development rather than produce exhaustive results. Future phases of this program of research will involve implementing and evaluating the tool in more generalizable settings, including through open-label testing in larger and more diverse populations, and using the screening and brief intervention tool to facilitate access to lifestyle behavior screening, all while collecting data on feasibility and acceptability from a more diverse population, leading to eventual implementation in clinical and other pediatric settings.

Verbatim translation from French into English may have introduced bias; efforts were made to preserve meaning within feasibility constraints [89]. Additionally, the sample size and the mix of focus groups and individual interviews may have influenced interaction dynamics, although the consistency of perspectives across formats strengthens the credibility of the findings [90].

Despite these limitations, this study lays a strong foundation for future work. Subsequent phases will include a feasibility study and broader engagement with stakeholders to assess the tool's adaptability. This will be followed by a pilot study and a randomized controlled trial to rigorously evaluate the tool's effectiveness in improving pediatric health outcomes.

Conclusions

To our knowledge, no similar preappointment screening tool exists in general pediatric care. This study provides early evidence on the feasibility and relevance of a codeveloped digital tool to promote healthy lifestyle behaviors in pediatric primary care. Its participatory design and user-valued features support its potential for future evaluation and implementation. This work represents the initial phase of its development. Future phases of the project will evaluate tool completion rates, repeat engagement, uptake across clinic-specific instances, and workflow integration metrics. Secondary outcomes will include changes in parent-reported child lifestyle behaviors across physical activity, sleep, nutrition, and screen time domains. These next-stage outcomes are guided by the broader implementation principle that, while there are an increasing number of validated tools and evidence, dissemination remains a major barrier to real-world reach and impact. In this context, infrastructure determines equity and access, and future phases will specifically assess the scalability of deployment across various settings, including pediatric clinics, family medicine groups, and nonclinical environments such as schools and community centers, particularly to reach children and families who may not otherwise have timely access to traditional care settings [91].

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Acknowledgments

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Data Availability

The datasets generated or analyzed during this study are not publicly available due to confidentiality concerns given the small number of focus group participants but are available from the corresponding author on reasonable request.

Authors' Contributions

Conceptualization: OD (lead), MK (equal), TP (equal), TvM (equal), AM (supporting)
Data curation: AM (lead), TP (supporting)
Formal analysis: AM (lead), OD (supporting), TP (supporting)
Funding acquisition: OD (lead), TP (equal)
Investigation: AM
Methodology: OD (lead), TP (equal), AM (supporting)
Project administration: OD (lead), TP (equal)
Resources: OD (lead), TP (equal), AM (supporting)
Software: TvM
Supervision: OD
Validation: OD (lead), TP (equal), MK (supporting), TvM (supporting)
Visualization: AM
Writing—original draft: AM (lead), TP (supporting)
Writing—review and editing: AM (lead), MK (equal), OD (equal), TP (supporting)

Conflicts of Interest

None declared.

Multimedia Appendix 1
Detailed guides of the different focus group discussions.
[DOCX File , 55 KB - pediatrics_v9i1e84304_app1.docx]

Multimedia Appendix 2
Detailed version of the screening questionnaire included in the DISCO tool.
[DOCX File , 36 KB - pediatrics_v9i1e84304_app2.docx]

Multimedia Appendix 3
Screenshots of interfaces and visuals included in the DISCO tool.
[DOCX File , 1053 KB - pediatrics_v9i1e84304_app3.docx]

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Abbreviations

GMF-U: Groupe de Médecine de Famille Universitaire
RIPPLE: Resource Information Program for Parents on Lifestyle and Education
SBIRT: screening, brief intervention, and referral to treatment
SSB: sugar-sweetened beverage

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Original Paper

Feasibility of a German High-Frequency Neonatal and Pediatric Intensive Care Dataset (AIx-Neo-Guard Dataset): Secondary Data Cohort Study

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Abstract

Background: Available information about existing neonatal and pediatric intensive care datasets is scarce.

Objective: The objective was to evaluate the feasibility of a monocentric high-frequency dataset of neonatal and pediatric intensive care patients in a cohort study.

Methods: This study included patients treated in the neonatal and pediatric tertiary care intensive care unit at Uniklinik RWTH Aachen, Germany. The dataset comprised high-frequency data on bedside monitoring and ventilation, CO_2 monitoring, laboratory results, important diagnoses and interventions, patient characteristics, and manual annotations (including procedures, eg, intubation and X-rays; and states and illnesses, such as episodes of apnea of prematurity and patient-ventilator asynchronies).

Results: In total, 400 admissions (227 neonatal and 173 pediatric) from 359 patients were included between September 2024 and January 2026. Of these, 28 neonates were extremely preterm, 34 were very preterm, 68 were moderate to late preterm, and 97 were term infants, with an overall median gestational age of 35 (IQR 31-38) weeks and a median birth weight of 1805 (IQR 1446-3251) g. The pediatric population comprised 34 infants aged younger than 1 year, 45 toddlers aged 1 to 5 years, 43 children aged 6 to 12 years, and 51 adolescents aged 13 to 18 years, with a median age of 10.6 (IQR 1.2-13.0) years and a median admission weight of 22 (IQR 11-50) kg. Overall, 77% (400/517) of all eligible patients were enrolled in the study. The dataset comprised 3600 patient days with more than 20,000 manual annotations (approximately 3 TB) and has been used for multiple use cases.

Conclusions: The high temporal resolution allows for detailed characterization of patient states. To our knowledge, there are no published descriptions of comparable European high-frequency neonatal or pediatric intensive care datasets. We share information about our dataset to encourage cross-institutional cooperation. The multicenter pooling of data or federated learning increases possible use cases by enabling new research questions or the development of more robust algorithms.

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KEYWORDS

critical care; database; pediatrics; neonatology; pediatric intensive care units; neonatal intensive care units; mechanical ventilation; data warehousing

Introduction

Approximately 12% of neonates and 13% of hospitalized children require treatment in an intensive care unit (ICU) [1,2]. Although there have been advances in neonatal and pediatric research in the last decades, many common treatment strategies are still not evidence based [3]. Scientific findings from studies in adult populations are rarely validated on pediatric data [4].

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Furthermore, they often cannot be transferred to pediatric patients due to substantial differences in pathophysiology [5]. Despite frequently unknown risks, this results in the widespread off-label use of medication, accounting for up to 50% of prescriptions [6]. This gap of knowledge is particularly problematic because childhood is a critical period for disease development, with long-lasting implications on personal health [7,8].

Neonatal and pediatric intensive care research is challenged by a heterogeneous patient population (eg, with a wide weight range) and small sample sizes [9-11]. Ethical considerations, legal frameworks, and parental uncertainty often obstruct study participation [12]. It can be conflicting to find a balance between protecting the most vulnerable patients by avoiding stress associated with clinical trials on the one hand and obtaining scientific evidence for adequate therapies on the other hand [13]. This leads to recruitment challenges with limited funding and persistently low study enrollment of less than 50% of eligible patients [14-16].

Secondary data research refers to the use of preexisting data that were collected for other purposes and are reused for scientific investigations [17]. It is time-, cost-, and resource-efficient and often faces fewer bureaucratic obstacles than experimental studies [18]. Among others, data can be used for complication detection, clinical decision support, quality analysis, and individualized medicine [19]. It can be helpful in gaining a deeper insight into the effects and side effects of off-label treatments [20]. Despite their advantages and the opportunity to address a variety of unanswered research questions, secondary data are still underused [21].

Data storage solutions for high-frequency intensive care data (such as the Philips Data Warehouse Connect) have been commercially available for almost a decade and are increasingly used. It can be assumed that this is also true for pediatric and neonatal intensive care data, although only very few such datasets are openly available. The storage capacity of these systems exceeds that of *conventional* patient data management systems (PDMSs) by several orders of magnitude. It allows for storing not only numerical but also waveform data at sampling frequencies up to 500 Hz. In turn, this enables researchers to reconstruct critical clinical situations at a high temporal resolution. We established a Data Warehouse Connect system and conducted a study of our pediatric and neonatal patient cohort beginning in August 2024. With regard to data composition, pediatric and neonatal intensive care treatment is characterized by above-average lengths of stay and relatively low patient counts [22]. This poses a dilemma for data research: the limited patient numbers demand cross-institutional data pooling for many research questions [23]. At the same time, low patient counts make it particularly difficult to comply with data protection requirements for anonymized data such as k-anonymity [24]. Our institutionally approved data protection concept therefore demands only sharing anonymized data with third parties for defined purposes with a restricted user circle under contractual protection. The execution recommendations of the Technology and Methods Platform for Networked Medical Research e.V. also advise against the disclosure of anonymized data in public-use files unless “based on general life experience or the current state of scientific knowledge, it is practically impossible to link the data to a specific individual” [25]. The primary objective is to publish the dataset. We hope that, as we move closer to concepts such as the European Health Data Space—including the needed underlying legal perspective—we will be in a position to make the data available to the community in the future. Until then, we see collaborative research as a viable option. This approach allows AI algorithms to be trained independently at different locations using locally available data, such that only model parameters are shared and no explicit patient data are exchanged; this approach is known as federated learning [26]. Another option is to perform external validation for the developed algorithms.

We present our project and metadata with two objectives: (1) to enable potential collaboration partners in our field to determine the extent to which our data and research activities align with their own and (2) to demonstrate that meaningful secondary data analysis can be conducted under the challenging conditions of contemporary neonatal research, even in single centers, and to motivate others to engage in this field [27].

Methods

Study Design

AIx-Neo-Guard is a collaborative project of the neonatal and pediatric ICU of Uniklinik RWTH Aachen, Germany, and the Chair of Embedded Software of RWTH Aachen, Germany. The project is conducted as an observational cohort study and was prospectively registered at the German Clinical Trials register (DRKS00033228). The study is conducted in accordance with the Declaration of Helsinki [28] and the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) statement guidelines for reporting observational studies [29]. Data collection started in September 2024 and has no scheduled end date.

Ethical Considerations

The study was approved by the local ethics committee (Ethik-Kommission an der Medizinischen Fakultät der Rheinisch-Westfälischen Technischen Hochschule Aachen [RWTH Aachen]; approval EK 24-213). The German Health Data Utilization Act grants an exemption from individual parental informed consent, as only data that are regularly used for diagnostic and therapeutic purposes are collected. Openly available information about ongoing studies at an institution needs to be provided to enable the exemption, and parents can actively revoke study participation.

Setting

Data are collected at the neonatal and pediatric tertiary care ICU of Uniklinik RWTH Aachen, Germany. The ward offers 9 beds, each equipped with the capability to provide respiratory support. Annually, approximately 350 patients aged 0 to 17 years are treated on the ward.

Participants

All eligible patients treated in the ICU are included in the dataset. Patients are excluded if their parents object to data

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processing or study participation. Furthermore, technical issues can lead to unintended exclusion.

Variables

The dataset incorporates monitoring and ventilation data, laboratory results, patient characteristics, selected diagnoses and interventions, and manual annotations. An overview is given in Table 1. Waveform data are stored at 125 Hz, except for electrocardiogram (ECG) data, which are stored at 500 Hz. Numerical data are recorded with a sampling rate of 1 Hz.

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Table 1. Available parameters with their temporal resolution and source.

Category and examples	Availability or resolution	Source
Vital signs		Bedside monitoring
Heart rate	1 Hz	
Respiratory rate	1 Hz	
ECG[a]	500 Hz	
Chest impedance	125 Hz	
Body temperature	1 Hz	
Arterial waveform and pressure	125 Hz	
Noninvasive blood pressure	Intermittent	
Ventilation data		Ventilator
Settings		
FiO_2[b]	1 Hz	
PEEP[c]	1 Hz	
Waveforms		
Airway pressure	125 Hz	
Airway flow	125 Hz	
Measurements		
Measured PEEP	1 Hz	
Tidal volume	1 Hz	
CO_2 monitoring		Bedside monitoring
End-tidal	62.5 Hz	
Transcutaneous	1 Hz	
Laboratory results	Intermittent	PDMS[d]
Blood gas analyses		
Blood count		
Serum chemistry		
Urine analyses		
Patient characteristics	One time	PDMS
Sex		
(Gestational) age		
Admission weight		
Umbilical cord pH		
Maternal age		
Manual annotations	Partially	PDMS and manual data analyses
Apnea of prematurity		
Times of medical imaging		
Nursing		
Important interventions		
Intubation		
Time of death		
Patient-ventilator asynchrony		
Body positioning	Partially	Paper documentation

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Category and examples	Availability or resolution	Source
Prone position		
Kangaroo care		

[a]ECG: electrocardiogram.

[b]FiO_2: fraction of inspired oxygen.

[c]PEEP: positive end-expiratory pressure.

[d]PDMS: patient data management system.

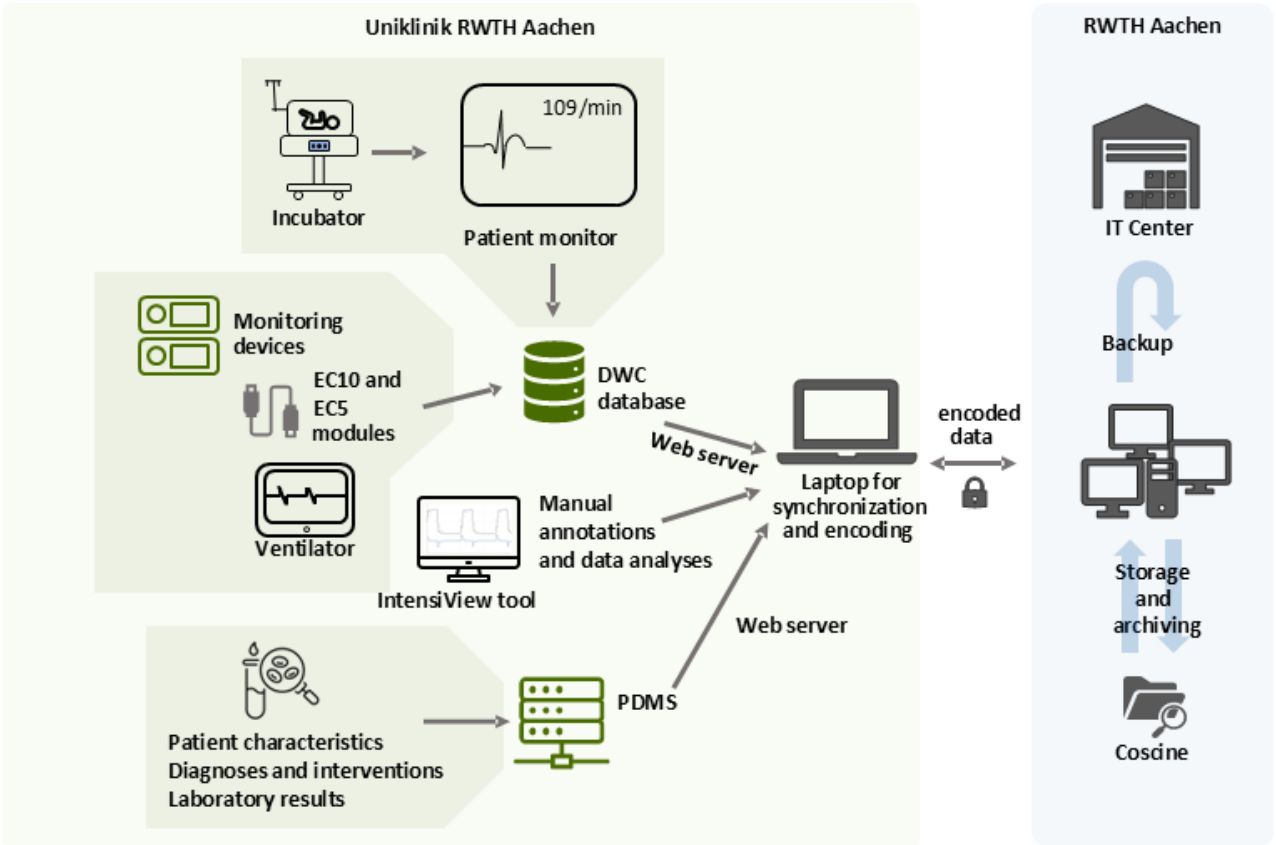
Data Sources and Management

The bedside monitoring is conducted using a Philips IntelliVue X2 monitor (all Philips devices provided by Philips GmbH Market DACH) connected to an IntelliVue MP70 monitor. A Sentec Digital Monitor with V-Sign sensor (SENTEC AG) is used for transcutaneous CO_2 monitoring. Ventilatory support is supplied by a Leoni plus or Elisa ventilator (Löwenstein Medical). The ventilators and CO_2 monitoring are connected to the bedside monitoring using Philips IntelliBridge EC5 ID modules connected via a local area network cable to IntelliBridge EC10 modules. EC10 modules are connected to the monitor by a module rack M8048A. All monitoring and ventilation data are retrieved after storage from the Philips Patient Information Center iX using Philips Data Warehouse Connect, version C.03.

Parameters derived from the PDMS (CGM Medico [CompuGroup Medical SE and Co KGaA]) are extracted manually and retrospectively added to the dataset. These comprise patient characteristics (eg, admission weight and sex), diagnoses, laboratory results, body positioning, and interventions (imaging, intubations and extubations, operations, and nursing care). Results from manual data analyses are annotated using a project-intern visualization and annotation tool (refer to the IntensiView Tool section). These annotations included patient-ventilator asynchronies, apnea of prematurity, exact time of blood sampling, disconnection of ventilators or monitoring devices, or suctioning.

All data, including timelines, are stored in a coded form in a database hosted by the Chair of Embedded Software. The hospital intern patient identifiers are encoded using a randomly generated 32-character universally unique identifier. The encoding table is stored in an access-protected file at Uniklinik RWTH Aachen and only accessible to clinical investigators. A data flowchart is provided in Figure 1.

Figure 1. Data flowchart. DWC: Data Warehouse Connect; PDMS: patient data management system; RWTH: Rheinisch-Westfälische Technische Hochschule.



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IntensiView Tool

The IntensiView tool (RWTH Aachen University) is a project-specific software developed by the Chair of Embedded Software. The tool is developed in C++ using the Qt Framework to easily deploy across operating systems. A PHP-based backend is used to communicate with the database. IntensiView is used for data synchronization, visualization, annotation, and export. Visualization can be adapted to the user's requirements by changing colors, adapting the number of plots with freely selectable axes, and switching between column and line diagrams. The annotations can then be added manually or automatized using detection algorithms and are inserted into the database. A screenshot is shown in Figure 2.

An annotation search tool enables the user to reload episodes with specific annotations directly. All data can be exported in CSV format. Additionally, external time-series data and annotations can be easily imported and visualized.

A plug-in interface offers standardized access to the data loaded in the IntensiView tool to integrate new functionality, such as detection algorithms that support current research questions. The tool offers a variety of plug-ins for data analyses, for example, an ECG analysis tool, parameter calculation (eg, mean and median, calculation of airway volume curve from the flow curve, and calculation of airway resistance and compliance from ventilator pressure and flow waveform data), and the creation of ventilator loops.

Figure 2. Screenshot of the IntensiView tool for the visualization, annotation, and export of clinical data.



Bias

We included all eligible patients to avoid selection bias. All patients were treated according to local standards. The study participation did not alter diagnostics and treatment. Monitoring and measurements were conducted by the same type of measuring devices in all patients to minimize detection bias.

Study Size

The aim was to include all neonatal and pediatric intensive care patients at Uniklinik RWTH Aachen. Due to limited staff resources, short-stay patients may sometimes not be included because they are discharged before a clinical investigator can link their patient identifiers with the corresponding patient data.

Quantitative Variables

The following variables were stored in a categorized fashion: sex, age or gestational age, admission weight, admission weight percentile, and type of annotation.

Statistical Methods

Descriptive statistics, including medians, IQRs, and frequency distributions, were computed to characterize the dataset. No inferential statistical analyses were conducted. Statistical analyses were performed using SPSS (version 29.0.0.0; IBM Corp).

Data Access and Cleaning Methods

Only the clinical investigators who were directly involved in patient treatment had access to the linking file with the identifiers and were able to access the decoded data at all times. The other project partners had unlimited access to the coded dataset.

After synchronization, the data were reviewed for completeness and consistency. Data cleaning involved identifying missing or incomplete values, ensuring consistency across variables, and resolving any discrepancies. Data anomalies, such as outliers (eg, *z* scores >3), were detected manually or by statistical means. Where appropriate, missing data, duplicate entries, and outliers were removed prior to analyses.

Linkage

Data were not linked across multiple databases.

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Results

There were 517 ICU admissions during the study period (17 months as of January 27, 2026). Of these, 117 admissions could not be included due to technical issues (primarily Data Warehouse Connect downtime or faulty linkage between intern patient identifiers and Data Warehouse Connect) or missing linkage between patient identifiers and patient data, resulting in a dataset comprising 400 admissions from 359 individual patients.

In total, 227 admissions were attributable to neonatal patients. Of these, 28 were extremely preterm (<28 weeks), 34 very preterm (28+0 to 31+6 weeks), 68 moderate to late preterm (32+0 to 36+6 weeks), and 97 term (≥37 weeks). In total, 173 pediatric admissions were included (34 infants aged <1 year, 45 toddlers aged 1-5 years, 43 children aged 6-12 years, and 51 adolescents aged 13-18 years).

A total of 57.8% (231/400) of admissions were contributed by male study participants. Of the 359 patients, 31 (8.6%) had multiple admissions and 9 (2.5%) had more than 2 admissions. Mortality was 3.6% (14/400) in the study cohort. Median length of stay was 2 (IQR 1-8) days. In total, approximately 3600 patient days were incorporated in the dataset. Patient characteristics are shown in Table 2.

More than 20,000 annotations were added manually to the dataset. The most frequent annotations are active expiration against the ventilator (n=4083, 20.4%), nursing (n=2926, 14.6%), ineffective efforts during expiration (n=1221, 6.1%), apnea of prematurity (n=1271, 6.4%), and time of medical imaging (sonographies: n=185, 0.9% and X-rays: n=153, 0.8%).

So far, the dataset comprises 3 TB of data (implemented using MariaDB as the database management system) and has been used for multiple research questions. A high time resolution was required to address these subjects. An overview is given in Table 3.

Table 2. Patient characteristics.

	Neonatal	Pediatric	Total
Number of admissions, n/N (%)	227/400 (56.8)	173/400 (43.3)	400/400 (100)
Number of patients, n/N (%)	225/359 (62.7)	134/359 (37.3)	359/359 (100)
Number of readmissions, n/N (%)	2/227 (0.9)	39/173 (22.5)	41/400 (10.3)
Gestational age (wk), median (IQR)	35 (31-38)	N/A[a]	N/A
Age (y), median (IQR)	N/A	10.6 (1.2-13.0)	N/A
Male sex, n/N (%)	131/227 (57.7)	100/173 (57.8)	231/400 (57.8)
Length of stay (d), median (IQR)	11.75 (1-12.75)	2 (1-7)	2 (1-8)
Mortality, n/N (%)	10/227 (4.4)	3/173 (1.7)	14/400 (3.6)
Birth weight (g), median (IQR)	1805 (1446-3251)	N/A	N/A
Admission weight (kg), median (IQR)	N/A	22 (11-50)	N/A

[a]N/A: not available.

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Table 3. Published studies conducted with AIx-Neo-Guard data.

Subject	Data type	Patient group	Number of patients	Number of annotations	Publication
IEE[a]	• Airway flow curve	Mechanically ventilated neonates	10	2665	[30]
IEE	• Airway flow curve	Mechanically ventilated neonates	10	2665	[31]
Breath classification	• Airway flow and pressure curve	Mechanically ventilated neonates	18	6304	[32]
Hypoglycemia and hyperglycemia	• ECG[b] • Blood glucose	Neonates	12	251	[33]
Lung model	• Peak inspiratory pressure • PEEP[c] • FiO2[d] • Respiratory rate • Blood gas analyses	Neonates	11	460	[34]
$tcPCO_2$[e]	• tcPCO2 • Blood gas analyses	Neonates	12	172	[35]

[a]IEE: ineffective efforts during expiration.

[b]ECG: electrocardiography.

[c]PEEP: positive end-expiratory pressure.

[d]Fi_IO_2: inspired oxygen fraction.

[e]$tcPCO_2$: transcutaneous CO_2 monitoring.

Discussion

Key Results

In this collaborative project, we successfully established a monocentric high-frequency database of neonatal and pediatric intensive care patients. The dataset incorporates 400 admissions with a total of 3600 treatment days and more than 20,000 manual annotations. We store data from bedside monitoring, ventilation, laboratory results, patient characteristics, and a variety of manual annotations. There is currently no published description of comparable European high-frequency datasets for neonatal and pediatric intensive care patients.

Interpretation

There are various existing databases incorporating neonatal or pediatric ICU data. Many of these databases contain patient-level data but do not provide high-frequency data [36]. The Pediatrix BabySteps Data Warehouse is a large database of more than 1 million neonatal patients [37]. It contains patient data and characteristics recorded on a daily basis. Many of these data are also included in our database. We collect a variety of additional variables, many of which are captured with high temporal resolution at the second or subsecond sampling levels.

Previously published intensive care databases have paved the way for secondary data analyses. The most commonly used datasets are the Medical Information Mart for Intensive Care-III (MIMIC-III) and MIMIC-IV databases [38,39]. These databases contain medical and demographic data from more than 350,000 ICU patients and have been used in more than 2000 secondary data analyses [40]. However, pediatric patients only constitute a small proportion of the MIMIC-III cohort and were completely excluded from MIMIC-IV. The MIMIC-III Waveform Database [41] extends the clinical data from MIMIC-III by waveform data from approximately 30,000 ICU patients, including 7870 neonates. However, only a subset of these recordings has been matched with the clinical data from MIMIC-III [42]. Comparing the IDs from the matched subset with the original one, we found only 6 neonatal patients with both clinical and waveform data.

Specific pediatric datasets exist: the Pediatric Intensive Care database, for example, incorporates data from more than 12,000 neonatal and pediatric patients [43]. Among others, it provides vital signs, medications, laboratory measurements, and lengths of stay. However, these are stored at low recording frequencies (ie, at 1-minute intervals). The investigation of pathophysiologic conditions often benefits from much higher data resolutions [44].

An example of such a high-frequency dataset is the Preterm Infant Cardio-Respiratory Signals Database [45]. It incorporates 1.6 GB of high-resolution data of ECG and chest impedance from 10 spontaneously breathing premature infants. However, the small sample size and restricted parameter set limit its potential applications.

For pediatric patients, a Canadian group established a database of approximately 1200 patients treated in a pediatric ICU [46]. The researchers collected data at higher frequencies compared to other available databases. The data were recorded every 5 seconds from the bedside monitors and every 30 seconds from the ventilators. This represents a major advancement for research

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involving high-frequency data. However, this time resolution does not allow a reconstruction of waveform data such as ECG or the airway pressure waveform. In previous analyses, we developed algorithms for detection of ineffective efforts during expiration. They constitute one of the most prevalent forms of patient-ventilator asynchronies [47] and result in prolonged mechanical ventilation and length of stay [48]. The detection algorithms are based on synchronous breath-by-breath waveform analyses of airway flow, which requires a very high time resolution. To the best of our knowledge, there are no descriptions of neonatal or pediatric datasets that can provide high-frequency data with an equivalent parameter set for a comparable sample size in Europe.

An approach for collecting high-frequency data was developed for The Hospital for Sick Children in Toronto, Canada, establishing a new data collection system for waveform storage and retrieval [49]. The database used (AtriumDB) holds waveforms from more than 5300 patients. The paper focuses on the technical development and compression techniques, giving only a short overview of the available data. Furthermore, only waveform data were stored through the described setup, without additional data relevant for intensive care.

Besides the high-resolution monitoring and ventilation data, the AIx-Neo-Guard dataset incorporates important diagnoses, laboratory results, patient characteristics, and manual annotations. This enables a detailed reconstruction of patient states and dynamic physiological changes. In particular, machine learning approaches benefit from such a dataset. The large number of manual annotations can be used to train detection algorithms for highly relevant complications. Furthermore, the unlabeled data can be used for unsupervised or self-supervised learning approaches to detect anomalies, identify clusters, or train foundation models. The integration of high-frequency physiological signals with clinical variables offers an important platform for clinically meaningful and translational research. The dataset opens important opportunities toward outcome-oriented research and enhances pathophysiologic understanding [50]. For example, using detection methods for ineffective efforts based on waveforms together with information on the patient's state can deepen our understanding of the effects of patient-ventilator asynchrony on the patient's outcome.

Limitations

The most important limitation is the single-center study design. First, it limits the available study population. Furthermore, diagnostic and treatment practices are based on local standards, which may introduce institutional and performance bias. We are preparing to collaborate with other centers to increase the available data and reduce the influence of local practices. Joint research across institutions is also desirable to allow the validation of algorithms (eg, for clinical decision support) on external data. This can contribute to enhancing the generalizability of results derived from a particular dataset.

So far, the dataset does not incorporate all relevant information on diagnostics and treatment. Fluid management and medication, for instance, are not yet integrated into the parameter set. Furthermore, the duration, for example, of nursing care is not labeled. This, in turn, is a current limitation for the possible use cases of the dataset. Predictive modeling and causal inference often require this valuable information to provide reliable estimates. The legal framework and ethics approval permit the storage of all variables related to diagnostics and treatment in the ICU. We extend the number of collected parameters continuously and plan to incorporate fluid management and medication data in the future.

Due to the rapid growth of data, there are insufficient staff resources to manually annotate the full dataset. The annotations are continuously extended and improved to enhance the quality of data. The set of annotations may furthermore also be enhanced by automated annotation using machine learning approaches. As previous analyses specifically focused on respiratory events, respiratory annotations are overrepresented compared to nonrespiratory annotations. These annotations will have to be made prior to use for nonrespiratory use cases. The data quality is furthermore hampered by technical issues. Occasionally, the ventilator fails to connect to the central monitoring interface. Resolving this issue would require restarting the ventilator. However, during mechanical ventilation, such an intervention would not be ethically justifiable because it could jeopardize the safety of critically ill patients. Similarly, the patient identifiers must be linked to the patient data on the bedside monitor to include the patient in the dataset. The limited staff resources do not allow a clinical investigator to be present at all times to carry out this step. This problem therefore systematically affects short-stay patients who require only short-term treatment or observation (such as those with transient tachypnea of the newborn, those recovering from operative procedures, or those admitted for intoxications). These episodes result in missing valuable data. This introduces a relevant selection bias toward more severe and longer-stay patients and has an impact on the representativeness of the dataset. Specifically, the overrepresentation of infants with longer or more severe courses will influence descriptive analyses and downstream modeling based on this cohort. As a result, findings derived from this dataset should be interpreted as reflecting the subset of neonatal ICU patients for whom complete data capture was feasible, rather than the entire admitted population.

Finally, the dataset was established to promote secondary data analyses. Secondary data research is always prone to bias due to unmeasured confounding and missing data. As the data were collected for a different purpose, the available data do not always meet the requirements of a specific research question, for example, if parameters of interest are missing. In these cases, other data sources must be sought. We hope to reduce this source of bias by pooling data with other centers in the future, increasing the set of available parameters, and continuing data collection and annotation. While secondary data research can support evidence-based medicine, interventional trials are sometimes still necessary.

Future Work

We are currently working on machine learning algorithms to automatically detect and correct time stamps for nursing rounds and blood sampling. These are the first steps toward an

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automated improvement of data quality, as these interventions inevitably lead to data anomalies, such as noisy ECG.

To further extend the dataset, information from pregnancy medical history is currently being integrated into the database for all neonates. In the future, the dataset will be further enriched with microbiological data (eg, results from blood cultures) and more comprehensive information on fluid management and medication administration. This will help improve the interpretability and increase the number of research questions that can be addressed using the dataset.

By sharing these database descriptions, we hope to encourage cross-institutional cooperation and invite all interested researchers to contact us, for example, to conduct external validation of algorithms. We hope that collaborations will promote the multicenter pooling of data and thereby enhance the available data. Larger study cohorts and datasets can improve statistical power and are particularly important for investigating rare diseases, for which adequate sample sizes are often difficult to achieve in single-center studies.

Using federated learning could also leverage the described dataset without the need for direct data sharing. Federated data access enables privacy-preserving development of AI algorithms across institutions and could create a pathway toward more robust foundation models for neonatal and pediatric intensive care.

Conclusions

We successfully established a monocentric high-frequency neonatal and pediatric intensive care dataset. The available data have been used for various use cases, with further analyses ongoing. Secondary data research can substantially reduce the need for experimental studies and contribute to evidence-based medicine. We hope that ongoing European Union legislation (European Health Data Space) will create a legal framework for the multicenter pooling of data. This would represent a major advance, as it could rapidly increase the available data, counteract bias, and thereby expand research opportunities and improve generalizability.

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The authors declare that no generative AI was used.

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Data Availability

Data are available from the corresponding author upon reasonable request.

Authors' Contributions

Conceptualization: LSO, MS
Data curation: LSO
Formal analysis: LSO
Funding acquisition: AS, MS
Methodology: LSO
Project administration: AS, MS
Resources: LSO, MS, TO
Software: AS, CLO
Supervision: MS
Validation: CLO
Visualization: LSO
Writing – original draft: LSO
Writing – review and editing: AS, CLO, MS, TO

Conflicts of Interest

None declared.

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Abbreviations

ECG: electrocardiogram
ICU: intensive care unit
MIMIC-III: Medical Information Mart for Intensive Care-III
PDMS: patient data management system
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

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Original Paper

Caregiver Perspectives on Electronic Portal Use in Integrated Primary Care: Qualitative Study

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Abstract

Background: Pediatric patient care portals through electronic health records (EHRs) provide opportunities to enhance patient care. However, challenges exist for making portals usable, and few studies have examined qualitative experiences of caregivers when using integrated primary care (IPC) services for their children.

Objective: This study aimed to qualitatively examine barriers to and facilitators of using electronic patient portals in integrated behavioral health care.

Methods: Data were collected from 7 caregivers of pediatric patients (0-7 years old) during focus groups. Interview data were analyzed qualitatively and coded by an interdisciplinary group. An iterative approach identified overarching themes within the following Consolidated Framework for Implementation Research (CFIR) domains: outer setting, inner setting, and characteristics of individuals.

Results: Overall, caregivers found the portal beneficial. Six themes emerged during thematic analysis. Outer setting themes were “lags and barriers to care” and “connections with outside providers.” Inner setting themes were “putting the ‘human’ in ‘human-centered design’” and “virtual access to information.” Characteristics of individuals themes were “flexibility” and “personalization.”

Conclusions: The current study sheds light on caregiver perceptions of electronic portal use. Patient portals are an effective and well-received tool for patients with developmental delays and families accessing behavioral health information. Future targets for improvement include personalization, equitable access, and reach beyond single institutions.

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KEYWORDS

electronic patient portal; integrated primary care; developmental behavioral pediatrics; pediatric primary care; health equity; behavioral health

Introduction

Facilitating between-visit communication between pediatric care providers and patient caregivers improves patient outcomes across various pediatric conditions [1,2]. Effective and accessible mechanisms facilitate pediatric care provider and patient communication, particularly in the delivery of interdisciplinary care [3] given the multiple providers involved in coordinating care. Integrated primary care (IPC) links behavioral health care clinicians to medical physicians through the embedded delivery of prevention, assessment, and treatment services [4]. IPC services can be colocated appointments, delivered within the context of scheduled medical visits, and/or implemented through communications and supports between

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visits. Many integrated service delivery models rely on features within the electronic health record (EHR) to improve engagement, increase adherence, and open lines of communication between pediatric care providers and caregivers [5-7]. However, previous research has found that traditional primary care EHR systems may not have all the capabilities that behavioral health clinicians need, such as the ability to track behavioral health goals, administer electronic behavioral health screeners, and communicate effectively with other primary care physicians [8,9]. The absence of these functionalities may disrupt workflows and could lead behavioral health care clinicians to keep their own records outside of the EHR [10]. Modalities of virtual care have become widely used across health systems in the wake of COVID-19 and play a particularly important role in the delivery of behavioral health services [11].

With greater access to technology, patient care portals embedded within the EHR have been increasingly used as a mode of communication between pediatric care providers and caregivers. Embedded EHR portals are typically an "opt-in" electronic space where patients, patients' caregivers, and pediatric care providers can communicate with other medical providers and staff regarding scheduling, nonurgent medical concerns, laboratory findings, orders, and referrals. It has been estimated that 60% of health care systems implement portals as an element of patient care and communication [12]. Patient adoption rates of portals were estimated to be 15% to 30% and growing following the COVID-19 pandemic, representing an area of promise for health care communication [12,13]. The American Academy of Pediatrics has highlighted the potential of EHRs to improve patient access to health information, facilitate preventative health, and support disease management [14]. In the context of IPC, portals can play an important role in screening; assessment; and facilitating aspects of care such as communication with multiple physicians involved in care, the provision of links to video visits, and a means of connecting patients with applications for symptom monitoring [8]. EHR portals tend to be well received by patients and caregivers, who endorse ease of use [15] and high ratings for satisfaction [16,17].

Despite the utility and ubiquity of patient portals in pediatric care, challenges exist in the uptake and reach of portal technology among underrepresented and marginalized patient populations [18]. Such inequities have been documented among economically disadvantaged and racialized groups [13,19]. For example, African American families and children on Medicaid are less likely to have a portal account set up when available [20]. There is limited research on the potential barriers to portal use among marginalized patient groups. Understanding how families navigate health care communication and their perceived benefit from technology in the delivery of health care may help make health care technology more accessible and user-friendly. Creating an EHR that works effectively for all medical and mental health care clinicians in integrated practices can be difficult [21]. Patient voices are often left out of the conversation when institutions make decisions about the adoption and implementation of patient-facing platforms [22], which may perpetuate or amplify existing disparities in pediatric behavioral health care [23]. User experience designs highlight that user voices can be leveraged to more readily align technologies with user needs, desires, and goals.

The current study aimed to begin filling in gaps in understanding marginalized patients' and caregivers' qualitative experiences with patient care portals when used in the context of IPC service delivery and developmental screening. We hypothesized that caregivers and families experience both barriers to and facilitators of portal-based care at the systemic, institutional, and individual levels. By identifying root causes of barriers and facilitators at each level, this work can inform the development of a multilevel toolkit to facilitate patient access to care and serve as a first step in research to refine EHR experiences for IPC.

Methods

Setting and Overall Study Design

This study was a collaborative effort that included clinician researchers across multiple service delivery divisions, including IPC, developmental behavioral pediatrics (DBP), and general pediatrics. This study took place in a culturally and ethnically diverse primary care clinic at a Midwest academic medical center. Most families served within the clinic depend on publicly funded insurance and face many barriers to care (ie, financial, social, logistical, and cultural). The setting included the use of a patient portal that allowed families to receive notifications about appointments, access clinical care through video visits, schedule and reschedule appointments, send and receive messages to and from pediatric care providers, complete behavioral health questionnaires before their visits, request their medical record for mental health appointments, submit release of information forms for outside medical and school providers to talk with third parties (eg, schools and mental health clinics), and access resources (eg, patient education materials and community mental health resources). A qualitative research design was used involving focus groups to explore participants' perceptions and experiences, allowing for in-depth discussions and identification of shared themes and insights. We used the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines to ensure a rigorous qualitative methodology [24]. Data were coded, analyzed, and interpreted using the Consolidated Framework for Implementation Research (CFIR) [25] to provide a structured approach for identifying key factors influencing the implementation of the patient portal across both internal and external systems of care.

Procedures

CFIR

Focus group questions were developed, and qualitative analyses were conducted using the CFIR. The CFIR is a flexible framework that is adaptable to a variety of study methods. The CFIR includes 5 constructs: intervention characteristics, outer setting, inner setting, characteristics of individuals, and process. The study team identified 3 CFIR domains that were most relevant to this study: outer setting, inner setting, and characteristics of individuals. As this study did not analyze the effects of an intervention, the other 2 domains (ie, intervention

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characteristics and process) were not included in the qualitative analysis.

The focus group questions centered on facilitators and barriers in the outer setting, inner setting, and characteristics of individuals domains. Questions were open-ended and probed about caregivers' experiences and preferences as well as facilitators of and barriers to their children receiving care, especially those related to the use of the patient portal. The focus group questions were developed using an iterative process: each interview informed the script for the following focus group to delve deeper into different areas mentioned by the previous groups.

Recruitment

We completed a retrospective chart review of the EHR from January 2023 to March 2023 to identify families with children aged 0 to 7 years who had received IPC or DBP care to inquire about participation in this study. Families from this chart review and other patients who were suggested by IPC and DBP providers were contacted via phone call to determine their interest in participating in this study. The IPC and DBP clinics were embedded in a racially and ethnically diverse clinic with approximately 66% of children served by Medicaid. This clinic is affiliated with a Midwestern academic medical center. Families were then approached via phone call with a research assistant and provided with study details and next steps for participation if interested. Our sample, therefore, included participants from multiple recruitment methods and a convenience sample of interested families. Caregivers who expressed interest in participating were given the option of taking part in in-person or virtual groups, and they provided their preference for time of day. Given that this study was institutional review board exempt, caregivers verbally assented to the study via phone and were enrolled after indicating that they would like to participate in the study.

Inclusion criteria were caregivers with 1 or more children receiving behavioral health services (IPC or DBP), aged 0 to 7 years, and who were perceived as having a behavioral or developmental concern needing more care as identified by a pediatric care physician. Exclusion criteria were caregivers who did not speak or understand English sufficiently.

In total, 28 caregivers were approached via phone about participating in this study, of whom 16 (57.1%) indicated that they would like to attend. Groups were formed by matching caregivers' modality (ie, virtual or in person) and time of day (morning, midday, or afternoon) preferences. Three to 6 caregivers were scheduled for each focus group. Caregivers were contacted via phone to provide focus group details and confirm that the date and time worked for their family. A total of 87.5% (14/16) of the caregivers confirmed that they were able to attend one of the focus group offerings. The caregivers were called the day prior to the focus group to ensure that it still worked for their family. Of the 14 caregivers who confirmed, 7 (50%) completed interviews, and 7 (50%) who were scheduled for interviews did not attend. It is unclear why these 7 caregivers were unable to attend. The research assistant attempted to call the families 10 minutes after the focus group began to ask them whether they needed assistance logging on to the virtual link. The groups took place from January 2023 to April 2023.

Focus Groups

An in-person focus group and 2 virtual focus groups were led by a parent advocate and community partner trained in reflective practices, whereas the third virtual focus group was led by the research assistant. The parent advocate told the participants that their passion for helping on this project came from their own children with disabilities and their desire to help other families receive the medical care they needed for their own children. The in-person focus group took place at a local library, whereas the virtual focus groups were conducted from wherever the caregivers desired. The parent advocate and research assistant were given interview guides with sample questions and prompts that were created by the authorship team. Two children were also present at the in-person group along with 2 researchers. As the Zoom (Zoom Video Communications) focus groups took place wherever the caregivers desired, there may have been other individuals listening who were not directly involved in the focus group. Each participant engaged in a single focus group.

All focus groups were recorded and transcribed. The virtual focus groups were video recorded, whereas the in-person focus group only recorded audio. Field notes were taken both during and after the focus groups. Transcripts were not returned to participants for comment and/or correction. Interested caregivers were placed in focus groups based on availability and modality preference (in person vs virtual). A Zoom link was sent to the primary email of the caregivers participating in the virtual focus groups. After low attendance to the first virtual focus group, caregivers in the subsequent groups received a reminder email 1 week before, a reminder call within 48 hours of the focus group, and a call 10 minutes after the focus group began if they were not on the Zoom link to double-check whether the technology was working. In some cases, the Zoom link needed to be resent. After families were identified for inclusion in the study, a chart review was conducted to determine the children's race and ethnicity, age, sex, and insurance provider.

Ethical Considerations

This study was overseen by the University of Michigan Institutional Review Board (HUM00215154) and was deemed "not regulated." Caregivers provided verbal consent upon scheduling the focus groups. At this time, they were informed that this was an optional qualitative improvement project and that they could leave or withdraw from the study at any time. Researchers deidentified transcripts; the transcripts were housed in a secure, protected health information drive; and any documents containing protected health information were password protected. Caregivers were also notified that their information would be deidentified when the findings were published. Participants received a US $60 Visa gift card for taking part in this study.

Qualitative Analysis

The CFIR was used to categorize responses relevant to implementation in combination with grounded theory methods to allow novel themes to emerge. After each focus group, the

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research team met as a group and independently read the transcripts to discuss major themes that emerged from each relevant CFIR domain. A coding tree was developed within the CFIR domains, with 2 themes per domain. The research team consisted of 3 physicians (MD), 2 licensed psychologists (PhD), and 1 research assistant. Two of the physicians were developmental behavioral pediatricians, and 1 was a primary care pediatrician. The 2 PhD psychologists were integrated behavioral health psychologists. The research assistant was a PhD candidate in clinical psychology. All members of the research team identified as women, were from a diverse range of backgrounds (Asian, Black, Middle Eastern, and White), worked at an academic medical center, and had experience working on qualitative research within IPC. The participants knew that the researchers consisted of physicians and psychologists within an academic medical center. The focus group transcripts were read by all 6 researchers to create themes and identify example quotes. Two researchers (one of the physicians and one of the psychologists) returned to the transcripts to code for themes iteratively. Following each focus group discussion, we discussed the conceptual depth of themes and agreed through collaborative consensus. After completing 4 focus group interviews, it was decided that adequate conceptual depth and data saturation were achieved. Data were managed in Microsoft Excel. The outer setting domain involves how well the institution connects and communicates with outside referrals and agencies. For this study, many barriers were identified in the outer setting, including structural barriers to accessing the portal and portal resources. The inner setting domain details how well the institution connects and communicates within the organization. Many strengths were identified in the inner setting, including benefits and opportunities for portal use. The characteristics of individuals domain included aspects of caregivers' own preferences or personality that aided or hindered portal use and their preferences for communicating with pediatric care providers through the portal. Many structural barriers existed for caregivers' participation in this study, contributing to a small sample size. However, in the tradition of qualitative research, high information power was achieved through the narrow aim, dense specificity, use of an applied theory, strong dialogue, and case analysis [26].

Results

Overview

One in-person and 3 virtual 90-minute focus groups were hosted involving 7 caregivers of children 2 to 7 years of age. One focus group only had 1 caregiver attend, but the other 3 had multiple caregivers in attendance. All 7 caregivers were female. The children receiving behavioral health services were of Black (n=3), White (n=3), and other (n=1) races. (see Table 1 for demographic information). Participants provided feedback to the research team about clinic changes that they would like to see.

Table 1. Electronic medical record demographic information (N=7).

Variable	Participants, n (%)
Patient age (y)	
2	1 (14.3)
3	1 (14.3)
4	1 (14.3)
5	2 (28.6)
6	0 (0)
7	2 (28.6)
Child sex	
Male	3 (42.9)
Female	4 (57.1)
Child race	
Black	3 (42.9)
White	3 (42.9)
Other	1 (14.3)
Insurance	
Public	1 (14.3)
Private	6 (85.7)

Caregivers generally described positive experiences with the portal, which helped them better access their children's health care and connect with their behavioral health care clinicians. Caregiver access and comfort with their children's patient portal was revealed as the most influential variable to their behavioral health care experience. Caregivers who could access their children's EHR portal shared that they liked the ability to schedule and see appointments, receive appointment reminders,

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and communicate with pediatric care providers. Conversely, parents who identified portal access as a barrier reported difficulties using technology and limited access due to their children's age and/or their caregiver status. Overall, 6 themes were identified, which we categorized into the outer setting, inner setting, and characteristics of individuals domains of the CFIR (Table 2).

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Table 2. Themes and constructs with example quotes.

Construct	Description	Example quotes
Outer setting		
Lags and barriers to care	This theme emerged as a concept that referred to systemic factors shaping caregivers' access to care.	• "...if you have to call for an appointment, a lot of times with the call center you have to wait or they transfer me to the wrong people and then I spend easily an hour on the phone trying to figure out what his appointment is or following up on a referral that didn't get placed." • No portal access for foster parents: "And because they're not fully adopted, they are not allowing me to use the portal. And not being able to use the portal is unfair from my standards...." • Rescheduling leading to delays in services: "It could be long, long wait times to get another appointment back. It could be six weeks, it could be eight weeks.... And especially with early intervention, because with early intervention, every day lost is a day you can't get back."
Connections with outside medical and behavioral health providers	This theme referred to caregivers' desire for care coordination between medical and behavioral health providers using the EHR[a] patient portal.	• "I'm a fan. In fact, I think that there should be like a universal one [portal system], because it shouldn't be.... That's the one hassle I've had. And I get like why these privacy laws are there and whatnot.... Can we streamline this please and make life simple for everybody?"
Inner setting		
Putting the "human" in "human-centered design"	This theme refers to the various ways in which the portal can be used as a tool for medical information, accessing pediatric care providers, and coordinating their children's care.	• "I do [use the portal], as much as possible. That's why I don't want to go see a doctor anywhere else because it makes my life easy." • Difficulties with setting up the portal: "What I don't like about it is I just had my son and nobody has showed me how to sign up for the portal. I mean, they gave me a piece of paper, but I'm like, I'm a more show me type person, so show me how to access this patient portal."
Virtual access to information	This theme refers to the overarching ways in which families seek information on the internet to make medical decisions.	• Parent describing behavioral health videos sent through the portal: "Because at least the video is easy to you just watch and you can follow what their actions. I mean, it's just my own opinion."
Characteristics of individuals		
Flexibility	This theme emerged from caregivers' desire to have a responsive medical system that suits each unique family system.	• "I like in-person just 'cause I mean, I feel like if it's relating to my kid, she probably needs to be present and she's not going to be present for a virtual meeting. [Chuckle] That's not going to happen." • "And she called me at home before the holiday and said, 'I just wanna make sure, is there anything else? Did you think about what I said? Is there anything more for you? How he is....' And my heart just melted. I said she didn't have her nurse or you know, some other person. She called me. I felt like so great."
Personalization	This theme emerged from caregivers' need for tailored and individualized care.	• "That's an interesting question. I think it's probably situational specific because what if it's something I have questions about, or what if it's something that requires a dialogue for understanding? Because this is all.... Even though I'm in it for like two and a half plus years now, it's still new territory to me. I'm learning every day about my child and what she needs and how to help her and how to deliver it, and the best delivery method and mode that she responds to that's best for her. So if it's like a social activity I would almost think social instruction would be, whether it's over the phone or by video...would be super beneficial. And but if it was something more like, little tips or tricks for improving fine motor skills, I would see how a worksheet delivered through the portal would be suffice."

[a]EHR: electronic health record.

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Outer Setting Themes

In the outer setting, themes identified were "lags and barriers to care" and "connections with outside medical and behavioral health providers." Lags and barriers to care emerged as a concept that referred to systemic factors shaping caregiver access to care. Caregivers generally viewed the portal favorably to reduce the lags and barriers to care, such as allowing for easy scheduling and rescheduling of appointments, but some families were not provided with equitable access, especially those providing care for foster children. Some of the lags and barriers to care were mentioned 11 times during the focus groups and included long waits for the call center, no portal access for foster parents, and delays in care when parents needed to reschedule appointments. The lags and barriers to care were perceived as critical. For example, a caregiver stated the following:

> *...with early intervention, every day lost is a day that you can't get back.*

As represented by the theme "connections with outside mental and behavioral health providers," caregivers reported a strong desire for care coordination between pediatric care providers using the portal and included difficulties and lengthy intake processes with outside referrals as major barriers to care. Outside medical and behavioral health providers included Early On, applied behavior analysis therapy, behavioral therapy, community mental health, and other outside behavioral or developmental services. One caregiver wished there was a "universal" portal system:

> *Can we streamline this process and make life simple for everybody?*

Connections with outside medical and behavioral health providers were mentioned 6 times during the focus groups.

Inner Setting Themes

In the inner setting, the themes identified were "putting the 'human' in 'human-centered design'" and "virtual access to information." The "putting the 'human' in 'human-centered design'" theme refers to the various ways in which caregivers can use the portal as a tool for medical information, accessing pediatric care providers, and coordinating their children's care. This theme included statements about how the portal is an effective tool and ways in which it could be more tailored to meet families' needs. One caregiver even noted the following:

> *I do [use the portal], as much as possible. That's why I don't want to go see a doctor anywhere else because it makes my life easy.*

The theme of putting the "human" in "human-centered design" was identified 8 times throughout the focus groups. When 1 caregiver had difficulty getting ahold of someone to help them log into the portal, they mentioned missing behavioral health care visits. Virtual access to information refers to the overarching ways in which families seek information online to inform medical decisions. It was identified 12 times during the groups and included how caregivers access information about their children's health care, including information sent through the portal, such as websites with behavioral health information, and a desire for behavioral health providers to send behavioral health parent training videos. Without information provided through visits or the portal, parents stated that they would refer to social media.

Characteristics of Individuals Themes

Themes identified in the characteristics of individuals domain were "flexibility" and "personalization." Flexibility was conceptualized as the desire to have a responsive medical system that suits each unique family system and was mentioned 6 times during the focus groups. Some parents preferred visits to be in person, whereas others preferred them to be virtual. One caregiver mentioned that it was very challenging to bring her child to an in-person behavioral health visit, whereas another caregiver mentioned that it was difficult to get her child to sit still for a virtual behavioral health visit. Personalization was conceptualized as the caregiver's need for tailored and individualized care for their child and was mentioned 10 times during the focus groups. One caregiver noted the following:

> *Well, I know what's best 'cause I'm the parent. I'm the one dealing with it. But I want them [medical and behavioral health providers] to feel heard and I wanna feel heard. I wanna come to a good compromise.*

Whatever method of communication (in person, virtual, phone, or portal message), parents want personalized care that fits their children and families. Caregivers seek flexibility and personalization in their care, and the portal can either help facilitate these goals or hinder them depending on how it is designed and used.

Discussion

Principal Findings

To our knowledge, this is the first study of its kind to use the CFIR to better understand caregiver-reported facilitators and barriers surrounding accessing and using patient care portals in the context of pediatric IPC. The purpose of this investigation was to gather information for the development of a streamlined behavioral health toolkit that will guide institutional policies and procedures surrounding the use of patient-facing EHR tools to improve patient care. The current study is the first to our knowledge to examine caregiver perspectives on the use of a patient EHR portal for pediatric IPC, finding that caregivers believe it is a useful tool but there continue to be access issues to the portal.

Overall, the caregivers included in this study viewed the patient care portal as a positive space to participate in care for their children, in particular, helping meet needs within the context of the health system (inner setting). Structural barriers and inequities in caregiver access to electronic behavioral health records were also reported across participants, particularly surrounding care coordination and the need for more tailored and individualized care.

Using the family voice in our study design allowed for the identification of human-centered design principles to inform potential improvements in the patient and caregiver experience. Caregiver-reported positive interactions with the portal fell primarily within the inner setting domain of the CFIR, which

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suggests that, at the individual patient level, the portal aids in effective communication between caregivers and pediatric care providers. Specifically, the patient care portal was helpful in aiding caregivers' scheduling of appointments and their access to clinical care services such as video visits. Families also reported accessing health information on social media and through other open online sources, suggesting that future portal integration of health care information from trusted resources may be an area that families may find beneficial. Ultimately, families perceived the patient portal as an effective bridge to health care access. However, families often differed in their preference for virtual vs in-person care and communication of behavioral health needs.

A structural barrier commonly reported by participants was the problem of lengthy wait times to be able to schedule or reschedule behavioral health services when having to go through call centers. The patient portal, however, was perceived as something that helped increase access to care and reduce wait times. Prior work using time use diaries has found that low-income families are more likely to spend an additional 12 minutes per day waiting for services compared with their higher-income counterparts [26]. One potential mechanism might include a dearth of medical and behavioral health providers accepting Medicaid [27], which limits caregiver access to medical care overall. In this study, families indicated that the patient portal was one way to bypass long waits in the call center and that it was the more ideal way to reschedule care. Patient portals may be an important way to accommodate the time constraints of low-income families, whose employment may not have substantial flexibility to address scheduling and make phone calls during regular clinic hours.

Another area of potential future innovation that should be considered is developing capabilities to allow for communication across pediatric care providers and institutions. Families noted that systems-based communication between pediatric care providers and early intervention or community mental health was lacking, but a portal system that was universal and not institution specific could facilitate warm handoffs and referral monitoring between disparate systems. For example, the patient portal could display referral status across systems to create continuity and personalization of care, which families valued and desired.

Finally, an important barrier identified by caregivers was the lack of universal accessibility of the patient portal to foster parents. The number of children in foster care has increased from approximately 397,000 in 2012 to 442,000 in 2017 [28]. Children in foster care experience increased health problems compared to the general population and may require more extensive communication with their pediatric care providers [29]. For this population, there may be multiple encounters with the health care system in many settings and with many caregivers, leading to fragmented care [30] and complicating the communication of critical health information [31]. There is promise in leveraging the patient portal to create a more streamlined system to detangle health care delivery among children in foster care. Recognizing this gap in service delivery, Texas; Cincinnati, Ohio; and Allegheny County, Pennsylvania, have passed laws or created data systems that improve health care communication for children in foster care. Lessons learned from these regional efforts could be used to inform how health systems can incorporate more inclusive policies to allow foster parents to have portal access for services and features that can facilitate patient care while maintaining protection and privacy of patients in state custody.

Our study had several limitations. As a single-center study, our work may not be generalizable to other populations using different EHR portal systems or in other states with different regulations regarding foster care or privacy. In addition, data were qualitative and included a small number of participants. Patient perspectives may not reflect the views of other populations. Strengths of this study include the specificity of behavioral health information and inclusion of a low-income and racialized population, who experience greater barriers to health care and access. Future research should explore caregiver education on features and functions of the patient portal, as well as how policy changes can help caregivers better access behavioral health information, provide a more positive experience regarding scheduling appointments, and be more inclusive.

Conclusions

Using in-depth qualitative methods, we found that a patient portal is an effective and well-received tool for patients accessing behavioral health information. Despite positive perceptions, ways in which these tools can be personalized and reach beyond single institutions were identified as potential areas of improvement. It was also evident that disparities remain in health IT access that require systemic work to ensure that all populations have access to high-quality care, streamlined communication, and behavioral health information.

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Data Availability

Data are available from the corresponding author ETK on request (lizkoval@iu.edu).

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Authors' Contributions

Conceptualization: TGM, TPB, SH
Data curation: ETK, TGM, SH
Formal analysis: ETK, TGM, SH
Funding acquisition: SH
Investigation: ETK, TGM, TPB, SH
Methodology: TGM, TPB, SH
Project administration: ETK, TGM, SH
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Validation: ETK, SH
Visualization: ETK, TGM, TPB, SH
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Writing—review and editing: ETK, TGM, TPB, BMC, SH

Conflicts of Interest

None declared.

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Abbreviations

CFIR: Consolidated Framework for Implementation Research
COREQ: Consolidated Criteria for Reporting Qualitative Research

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DBP: developmental behavioral pediatrics
EHR: electronic health record
IPC: integrated primary care

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Original Paper

Human-Centered Baby Massage Mobile App for Low Birth Weight Infants: Usability Testing and a Pre-Post Pilot Intervention Study in Indonesia

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Abstract

Background: Low birth weight (LBW) is associated with increased risks of neonatal morbidity, developmental delays, and long-term health problems. Although baby massages have been shown to improve growth and neurodevelopmental outcomes in LBW infants, access to suitable training and adherence to massage protocols remain challenging, particularly in low-resource settings. Mobile health interventions may help address these gaps by providing scalable and standardized education on infant massage.

Objective: This study aimed to design and evaluate a human-centered baby massage mobile app to support the growth and development of LBW infants in Indonesia.

Methods: A human-centered iterative design approach was used to develop the mobile app. Usability was assessed using the System Usability Scale among 42 caregivers of LBW infants. Qualitative data were collected through semistructured interviews and analyzed thematically to understand user experience. A pilot pre-post intervention study was conducted to evaluate the impact of the app on caregivers' knowledge, confidence, adherence to baby massage practices, and infant growth outcomes. Pre- and postintervention measures were compared.

Results: The app demonstrated high usability, with a mean System Usability Scale score of 78.6 (SD 8.2), indicating good usability (≥68). Most participants rated the app as "excellent" or "good." Qualitative findings highlighted improved caregiver confidence and ease of learning massage techniques. Statistically significant improvements were observed in caregiver knowledge (mean difference 20.5 points; *P*=.002), confidence (21.6 points; *P*=.001), and adherence to recommended massage practices (20.3 points; *P*=.02). Infant outcomes also improved, including weight gain (mean increase 330 g; *P*=.003) and head circumference (mean increase 1.3 cm; *P*=.004).

Conclusions: The human-centered baby massage mobile app showed promising feasibility and effectiveness in improving caregiver knowledge, confidence, and adherence to infant massage practices. The app provides a culturally appropriate and user-friendly tool to support early interventions for LBW infants in resource-limited settings.

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KEYWORDS

low birth weight; baby massage; mobile health; human-centered design; infant growth

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Introduction

Low birth weight (LBW), defined by the World Health Organization as a birthweight less than 2500 g, remains a substantial global public health challenge [1]. LBW is a critical indicator of neonatal morbidity and mortality, with an estimated 15% to 20% of all births worldwide classified as LBW, representing more than 20 million births annually [2]. The burden of LBW is prevalent in South Asia and sub-Saharan Africa, with 44% and 28% of LBW cases globally, respectively [3]. In Indonesia, the prevalence of LBW ranges from approximately 6% to 10% of all live births, according to national health surveys and global estimates [4,5]. LBW can pose several health risks for infants, such as stunted growth, neurodevelopmental delays, and an increased risk of infections and chronic diseases [6,7]. Such challenges underscore the urgent need for effective interventions to mitigate the long-term sequelae associated with LBW.

Existing interventions for LBW infants can be divided into methods such as kangaroo mother care (KMC) [8,9] and those that use modern technology [10-12]. KMC refers to holding the infant in skin-to-skin contact with the caregiver and has been widely adopted in low- and middle-income countries because of its practicality and effectiveness [8]. However, its reliance on continuous physical contact can be impractical for caregivers, especially in resource-limited settings. Complementary nonpharmacological techniques, including baby massages, have potential benefits, but this procedure usually necessitates training and routine practice, which often remain inaccessible [13].

Baby massages, a form of touch intervention, have shown promise in promoting health outcomes for LBW infants. Research indicates that massage can enhance weight gain, support neurodevelopment, and strengthen the emotional bond between infants and caregivers [14-18]. Randomized controlled trials and systematic reviews further suggest that infant massage significantly improves weight gain and neurobehavioral development in LBW infants [19-22]. Despite these benefits, barriers such as a lack of trained health care providers and inconsistent app by caregivers limit its widespread adoption.

The therapeutic benefits of baby massages in neonatal care are well documented. As a nonpharmacological approach, it promotes vagal nerve stimulation and facilitates improved digestion and increased weight gain [23]. Moreover, it promotes neurodevelopment through enhanced sensory integration and modulation of stress hormones [18,20,24]. Baby massages promote emotional bonding, which is crucial for the psychological development of the infant [22]. Studies have demonstrated that it enhances digestive and immune functions and reduces levels of stress hormones in infants and parents alike [23,24]. It is also involved in critical motor and sensory development, especially in premature and term infants [16]. However, in low- and middle-income countries, structural challenges make it difficult to find and use baby massages, including health care infrastructure and sociocultural obstacles [25]. The diversity of massage techniques and cultural practices also creates challenges in its implementation, highlighting the importance of standardized training and evidence-based guidelines [26,27]. In Indonesia, the limited availability of relevant and culturally sensitive educational materials has been a major obstacle to its adoption.

The rise of mobile health (mHealth) has shown promise in improving parental knowledge and compliance with neonatal care practices [28,29]. Parents have been encouraged to practice KMC and monitor infant growth through some mobile apps [11,12]. Such tools have also been shown to support prenatal care, breastfeeding, and early childhood development, and to improve parental confidence, adherence to health recommendations, and child health outcomes [29-31]. Studies show that mobile apps with interactive and user-centered features can be associated with higher user satisfaction and improved maternal health behaviors [32]. However, despite the increasing use of mHealth technologies, there is a significant lack of literature describing mHealth for baby massage education, particularly in multiculturally diverse contexts [33].

In many cases, existing mHealth apps are unable to implement human-centered design principles vital for usability and engagement, particularly in the Indonesian context [34]. Additionally, few evidence-based, culturally appropriate interventions exist to address the specific needs of LBW infants and their caregivers [35,36]. Little is currently known about the factors influencing the digital classroom experience in this field, including opportunities for bias against visual assets, as most research around baby massage education and experience continues to rely on face-to-face instructional culture. This creates a major gap in knowledge concerning how effective mHealth apps can be in increasing the knowledge, skills, and confidence of parents to perform baby massages [33]. Evidence is limited regarding infant health outcomes or how usability features may influence user engagement, satisfaction, and long-term adherence [34].

Filling these gaps is essential for informing scalable, accessible, and effective interventions targeting diverse populations. To ensure the development of such clinically meaningful mobile apps, we need a user-centered design process, complemented with a solid evaluation framework [34]. This study aims to address these gaps by developing and evaluating a human-centered baby massage mobile app designed to enhance growth and development in LBW infants in Indonesia.

Methods

Study Design

This study used a mixed methods design consisting of (1) usability testing and (2) a single-arm pilot pre-post intervention study conducted over 4 weeks.

The usability phase evaluated user experience (UX) and system performance using the System Usability Scale (SUS) and qualitative interviews.

The pilot phase used a 1-group pretest-posttest design to assess changes in caregiver knowledge, confidence, adherence to baby massage practices, and infant growth parameters following exposure to the mobile app.

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No control group was included in this pilot study, as the primary objective was to assess the feasibility, usability, and preliminary effectiveness.

Participant Recruitment and Sample Size Rationale

Participants were recruited between January and March 2025 through community health centers, pediatric outpatient clinics, and online announcements distributed via maternal health networks in West Java, Indonesia.

Eligibility criteria included the following: being a primary caregiver (mother or father) of an infant with documented LBW (<2500 g), infant age between 0 and 12 months, ownership of an Android smartphone, and ability to read Bahasa Indonesia.

Caregivers of infants with congenital abnormalities or severe medical instability were excluded.

The sample size (N=42) was determined based on recommendations for pilot feasibility studies, which suggest 30 to 50 participants to estimate preliminary effect sizes and usability metrics. The sample was also considered adequate for detecting moderate pre-post effects using paired statistical testing.

Overview

A human-centered iterative design framework guided the development and evaluation of a mobile app designed to optimize growth and development in LBW infants through baby massages. The app design and development process was broken down into 6 clear steps, each contributing to the app definition and validation process.

Stages of App Design and Development

Overview

The development of the baby massage mobile app followed a systematic, human-centered design framework, resulting in a functional and user-friendly tool. The process was iterative, consisting of six development cycles that produced six progressively refined versions of the app. Each iteration incorporated user feedback to improve usability, content, and functionality. A brief description of each stage is presented in the subsections below.

Stage 1: Establishing the Study Team

A multidisciplinary team was established, comprising neonatologists, pediatricians, child development experts, mobile app developers, and UX designers. The team also included pediatric nurse specialists, nursing researchers, and software engineers.

Regular meetings were conducted to ensure alignment among team members, foster interdisciplinary collaboration, and integrate clinical insights with technical perspectives. These meetings also facilitated knowledge exchange across disciplines and supported systems thinking, which helped define the project's scope, objectives, and technical approach.

Stage 2: Defining a Set of App Design Requirements

The app design requirements were informed by a comprehensive literature review and expert consultations. Academic databases were systematically searched for peer-reviewed articles, systematic reviews, and clinical guidelines related to LBW infants, baby massages, and mHealth apps (PubMed and Google Scholar; publications up to October 2023). Records published since 2019 were emphasized to ensure relevance and alignment with current best practices. We extracted findings on effective interventions, user preferences, and technological features and identified gaps in the literature, specifically for culturally tailored digital solutions for LBW infants in low-resource settings. These efforts were further complemented by consultations with neonatologists, pediatricians, child development specialists, and UX designers to inform screen design requirements. Several key features emerged: step-by-step tutorials for baby massages, progress tracking, reminders, and culturally relevant content. These requirements were based on evidence-based practices and adapted to the specific needs of LBW infants and their caregivers [37].

Stage 3: Defining User Requirements

Focus group discussions (FGDs) were conducted with caregivers of LBW infants and health care providers to identify user requirements. The discussions explored users' preferences, challenges, and expectations regarding a baby massage app.

Participants emphasized the need for a simple and intuitive interface, clear visual guidance, and offline functionality, particularly to accommodate limited internet access in rural settings [38].

Stage 4: Creating the App Prototype

In addition to instructional videos, interactive guides were incorporated to enhance user engagement. These guides allowed caregivers to access additional information, such as diagrams and animations, to better understand massage techniques and their benefits. The design emphasized intuitive navigation and responsive feedback to support ease of use.

A growth tracker feature was also included to enable caregivers to monitor infants' development. The dashboard displayed key indicators such as weight and head circumference in an easy-to-read format, allowing users to visualize progress over time.

The prototype was developed as a set of wireframes representing the app's layout and structure. Design tools such as Figma (Figma, Inc), Adobe XD (Adobe Inc), and Sketch (Sketch BV) were used to visualize the interface, typography, and icons through semi-interactive mock-ups.

Stage 5: Expert UX Review

A panel of experts in neonatal care, digital health, and UX design conducted a comprehensive review of the prototype. The panel included neonatologists with expertise in LBW infant care, clinicians experienced in mHealth apps in low-resource settings, and UX designers specializing in usability and user engagement.

The review process was structured and began with an initial briefing session, during which the prototype's features, design principles, and intended user journey were presented. Experts then evaluated the prototype based on predefined criteria,

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including usability, functionality, visual design, sustainability, and cultural relevance.

Feedback from the experts led to refinements in several areas, including navigation clarity, instructional content, feature integration (eg, instructional videos and dashboard), and cultural appropriateness for the target Indonesian users.

Stage 6: Testing the Prototype

Usability testing and pilot testing were conducted to assess the refined prototype in real-world conditions.

Usability Testing

We conducted usability testing with 42 caregivers of LBW infants recruited from a tertiary care hospital in Indonesia. Respondents who were willing to download and evaluate the app were included in the study sample. To evaluate the app's usability, we used the SUS, which produces scores from 0 to 100. A higher score indicates improved usability. Furthermore, qualitative feedback on UX was collected via semistructured interviews [39]. We provided participants the app prototype and asked them to perform tasks such as finding a tutorial, setting reminders, and tracking their progress. Observations of users' interactions with the app, along with feedback collected through the SUS and interviews, were analyzed. Quantitative data from the SUS were analyzed using descriptive statistics, and thematic analysis was applied to the qualitative data.

Pilot Testing Phase

The pilot study used a single-arm pre-post design and was conducted among 42 caregivers of LBW infants from various socioeconomic backgrounds in Indonesia.

Knowledge, confidence, and adherence to baby massage practices were assessed using preintervention and postintervention questionnaires. The instrument, known as the Caregiver Baby Massage Knowledge, Confidence, and Adherence Questionnaire, was developed by the research team, comprising neonatologists, pediatricians, child development specialists, and nursing researchers.

The questionnaire development followed an iterative process, including a literature review on baby massage practices and caregiver self-efficacy, as well as expert consultation in neonatal care and digital health. The final instrument consisted of 30 items across three domains:

1. Knowledge (10 items)—assessing caregivers' understanding of baby massage techniques, benefits, and precautions
2. Confidence (10 items)—measuring caregivers' perceived ability to correctly and consistently perform baby massages
3. Adherence (10 items)—evaluating compliance with recommended baby massage routines

Items in the confidence and adherence domains were scored on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Knowledge items were scored as 1 (incorrect) or 5 (correct). Domain scores were calculated by summing item scores, with higher scores indicating better knowledge, confidence, or adherence.

The questionnaire was translated into Bahasa Indonesia and validated in a preliminary study involving 30 caregivers. Reliability testing demonstrated good internal consistency, with Cronbach α values of 0.88 (knowledge), 0.90 (confidence), and 0.86 (adherence).

Intervention Procedure

During the 4-week intervention period, caregivers were instructed to use the mobile app as their primary guidance tool for baby massage practice. Specifically, caregivers were asked to perform the following tasks:

- Watch instructional baby massage videos within the app at least 3 times per week
- Perform baby massage sessions at home at least once daily (minimum 5 sessions per week)
- Log massage completion in the app after each session
- Record infant weight weekly using digital baby scales available at community health centers
- Enter infant growth measurements, including weight and head circumference, into the in-app growth tracking feature

The app provided automated daily reminders to encourage adherence. All instructional materials were accessible offline after initial download.

No biochemical or laboratory biomarkers were assessed. Infant outcomes were limited to anthropometric measurements, specifically weight and head circumference.

Information regarding caregiver responses, app use patterns, and infant growth parameters was collected at baseline and after completion of the 4-week intervention. The mobile app for baby massages was developed as a functional prototype (Figure 1).

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Figure 1. Mobile app for baby massages.



Statistical Analysis

Paired *t* tests (2-tailed) were conducted to compare preintervention and postintervention outcomes for caregiver knowledge, confidence, adherence scores, and infant growth parameters. Statistical significance was set at $P<.05$.

Ethical Considerations

This study was approved by the institutional review board of STIKep PPNI Jawa Barat (III/045/KEPK/STIKep/PPNI/Jabar/XI/2024). All participants provided written informed consent prior to participation. Participants did not receive financial compensation for their participation in the study. Caregivers were informed of their right to withdraw at any time without consequences. All collected data were anonymized and stored securely in password-protected databases.

Results

Demographic Characteristics of Participants

The study included 42 caregivers of infants aged 0 to 12 months. The demographic characteristics of the participants are presented in Table 1. Most of the participants (n=35, 83.3%) were mothers with an average age of 29.5 (SD 5.2) years. Most participants had a university-level education (n=31, 73.8%) and were first-time caregivers (n=25, 59.5%). Nearly all participants (n=40, 95.2%) had no prior experience with baby massage.

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Table 1. Demographic characteristics of participants (N=42).

Characteristic	Values, n (%)
Gender	
Female	35 (83.3)
Male	7 (16.7)
Age (years)	
<25	10 (23.8)
25-34	27 (64.3)
≥35	5 (11.9)
Education level	
High School	8 (19)
University	31 (73.8)
Postgraduate	3 (7.1)
First-time caregiver	25 (59.5)
Prior baby massage experience	
Yes	2 (4.8)
No	40 (95.2)

Usability Testing Results

Table 2 presents the descriptive statistics for the SUS scores. The mean SUS score was 78.6 (SD 8.2), indicating a high level of usability. Most participants (85%) rated the app as "excellent" or "good" for ease of use and navigation. The highest-rated aspect was "ease of learning" (mean score 4.5; 5-point scale), while the lowest-rated aspect was "visual design appeal" (mean score 3.9; 5-point scale; Table 2).

Table 2. Descriptive statistics for usability testing using the System Usability Scale.

Usability metric	Value
Overall System Usability Scale score, mean (SD)	78.6 (8.2)
Ease of navigation, mean (SD)	4.3 (0.7)
Ease of learning, mean (SD)	4.5 (0.6)
Visual design appeal, mean (SD)	3.9 (0.8)
Task completion rate (%)	92
Error rate (%)	5.2

Qualitative Feedback From Users

Thematic analysis identified key themes related to usability, functionality, aesthetic design, user satisfaction, and cultural relevance. Table 3 summarizes the themes, categories, and example quotes.

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Table 3. Thematic analysis of user feedback.

Theme and category	Example quote
Usability	
Ease of use	"I found the app very easy to navigate, and I didn't need much time to learn how to use it."
Clarity of features	"The app's instructions are clear, but some icons could be more intuitive."
Intuitive navigation	"The app is very easy to use. I found the tutorials and reminders without any difficulty."
Functionality	
Reminder system	"The reminder feature is very helpful in ensuring I don't forget my baby's checkups."
Tracking progress	"I like how I can track my baby's weight and feeding schedule in one place."
Informative content	"The videos and interactive guides taught me how to massage my baby properly. I feel more confident now."
Aesthetic design	
Visual appeal	"The design is good, but a more colorful interface would make it more engaging."
User satisfaction	
Overall experience	"I would recommend this app to other parents; it makes managing my baby's health much easier."
Cultural relevance	
Local language support	"I appreciate that the app is in Bahasa Indonesia. It makes it easier for me to understand."
Culturally appropriate	"The massage techniques shown in the app are similar to what my mother taught me. It feels familiar and comfortable."

Pilot Testing

Caregivers demonstrated a significant increase in knowledge about baby massage techniques and their benefits, with a mean improvement of 20.5 points (P=.002). Confidence levels among caregivers improved significantly, with a mean increase of 21.6 points (P=.001). Caregivers reported feeling more capable of performing baby massage correctly and consistently. Adherence to baby massage practices improved by 20.3 points (P=.02), indicating that caregivers were more likely to follow the recommended massage routines after using the app. Infants showed significant improvements in weight (mean increase of 330 g; P=.003) and head circumference (mean increase of 1.3 cm; P=.004), suggesting positive effects of the intervention on infant growth and development (Table 4).

Table 4. Preintervention and postintervention outcomes for caregivers and infants.

Outcome measure	Preintervention, mean (SD)	Postintervention, mean (SD)	Mean difference (SD)	*P* value
Caregiver knowledge	65.2 (8.5)	85.7 (6.3)	20.5 (7.1)	.002
Caregiver confidence	60.8 (9.2)	82.4 (7.8)	21.6 (8.3)	.001
Adherence to practices	55.3 (10.1)	75.6 (8.9)	20.3 (9.5)	.02
Infant weight (grams)	2200 (150)	2530 (140)	330 (120)	.003
Infant head circumference (cm)	32.5 (1.2)	33.8 (1.1)	1.3 (0.9)	.004

Discussion

Principal Findings

This study assessed the effectiveness of a human-centered mobile app designed to support the growth and development of LBW infants in Indonesia through baby massages. The app achieved a high usability rating, reflecting its user-friendly design and ease of navigation.

Postintervention evaluations showed significant improvements in caregivers' knowledge (P=.002), confidence (P=.001), and adherence to baby massage practices (P=.02). Importantly, infants whose caregivers used the app demonstrated significant increases in weight (P=.003) and head circumference (P=.004), indicating positive effects on their growth.

The app's high usability and positive user feedback highlight its success in addressing the needs of its target audience. Caregivers praised its intuitive interface, clear instructions, and culturally relevant content, which were designed to reduce cognitive load and enhance engagement. Features such as the reminder system and progress tracking were particularly valued, as they supported consistent massage routines and enabled caregivers to monitor infant growth. These findings align with human-centered design principles, which emphasize tailoring digital health solutions to users' needs and contexts [33,34,40,41].

While the app's usability was generally high, minor concerns regarding visual design and icon intuitiveness suggest areas for future improvement. This study builds on these insights by introducing a culturally tailored, human-centered app

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specifically designed for Indonesian caregivers, addressing a gap in the literature.

The findings corroborate prior research on the benefits of baby massages and mHealth interventions for LBW infants. For instance, Vickers et al [16] reported that baby massages enhance weight gain and neurodevelopment in LBW infants, while Knop et al [28] highlighted the role of mHealth interventions in improving parental education and adherence to neonatal care practices. Similarly, Bangor et al [42] found that high usability scores in health apps are associated with increased user satisfaction and adherence to health recommendations.

Additionally, the app incorporates traditional massage techniques that align with local practices, making it more acceptable and practical for Indonesian caregivers, thus enhancing its relevance and effectiveness [36]. Furthermore, the app's offline functionality addresses the challenge of limited internet access in rural areas, where nearly 80% of the population lacks reliable connectivity. This approach aligns with global health strategies advocating for digital tools to improve maternal and child health outcomes, especially in resource-constrained settings.

This study, while demonstrating promising outcomes, is not without limitations. One notable constraint is the relatively small sample size, which may restrict the generalizability of the findings. Additionally, the research was conducted within a specific cultural and regional context in Indonesia, potentially limiting its applicability to other settings with different cultural norms and health care environments. To address these limitations, future studies should aim to include larger and more diverse participant groups, as well as evaluate the app's usability and effectiveness across varied cultural contexts. Another limitation is the short duration of the intervention, which prevents conclusions about the long-term impact of the app on infant growth and development. Extending the study period and incorporating follow-up assessments would provide deeper insights into the sustained benefits of the app. Furthermore, while qualitative feedback offered valuable perspectives on UXs, a more structured and comprehensive qualitative analysis could uncover additional insights into caregiver preferences and areas for improvement.

This pilot study used a single-arm pre-post design without a control group; therefore, causal inference cannot be established. Improvements in infant growth may have been influenced by natural growth progression or other unmeasured factors. Future randomized controlled trials are needed to confirm effectiveness.

Conclusions

This study highlights the effectiveness of a culturally tailored, human-centered baby massage mobile app in improving caregiver knowledge, confidence, and adherence to infant massage practices, while also positively influencing the growth and development of LBW infants in Indonesia. The app's high usability reflects its user-friendly design and intuitive navigation. The integration of such digital health tools into routine postnatal care offers a promising strategy for addressing the challenges faced by caregivers of LBW infants, particularly in low-resource settings. The app's culturally relevant content, local language support, and offline functionality make it accessible and practical for users in diverse contexts, including rural areas with limited internet access. Positive feedback from participants further emphasizes the app's value, with caregivers appreciating features such as step-by-step tutorials, progress tracking, and reminders. While minor usability concerns, such as the need for a more visually engaging interface, were noted, overall satisfaction with the app was high, indicating its potential as a reliable tool for supporting infant care. Looking ahead, future research should focus on scaling up the app, conducting longer-term evaluations to assess its sustained impact, and exploring its integration into existing neonatal care programs.

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Authors' Contributions

Conceptualization: SS, RIIID, HCH
Methodology: SS, RIIID, HCH
Investigation: SS
Data curation: SS
Formal analysis: HCH
Project administration: SS
Supervision: RIIID, HCH
Validation: RIIID, HCH
Resources: HCH
Writing – original draft: SS
Writing – review & editing: RIIID, HCH
All authors reviewed and approved the final manuscript.

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Conflicts of Interest

None declared.

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Abbreviations

KMC: kangaroo mother care
LBW: low birth weight
mHealth: mobile health
SUS: System Usability Scale
UX: user experience

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Parents' Experiences From Participating in an Online Peer Support Child Feeding Intervention: The "PICNIC Sweden" Explanatory Sequential Mixed Methods Feasibility Study

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Abstract

Background: Parents' feeding practices play a role in shaping children's dietary patterns, which influence chronic disease risk. Feeding children is challenging, so parents need guidance and support. Parents In Child Nutrition Informing Community (PICNIC) is an Australian program that promotes responsive child feeding using dietitian-led training and online communication, then facilitates peer-to-peer information sharing within parents' social networks.

Objective: This pilot study aimed to test the feasibility, acceptability, appropriateness, and perceived impact of PICNIC with Swedish parents.

Methods: This explanatory sequential mixed methods study involved 47 parents of children aged 0 to 24 months. Parents attended a 2-hour online dietitian-led workshop, followed by 2 months of child nutrition and feeding support in a moderated, closed Facebook group. Quantitative data from digital questionnaires (n=43) were analyzed and integrated with qualitative findings from thematic analysis of semistructured interviews (n=15).

Results: Parents attended 1 of 10 workshops, and 4 to 5 posts per week (of which 20% were participants' questions) were shared in the project's Facebook group. Both quantitative and qualitative data indicated parents' child feeding knowledge and parental self-efficacy increased after participation. Parents reported that the intervention filled a gap in the existing support from child health services, strengthening their confidence in child feeding, while providing a sense of recognition and community. PICNIC information was described as trustworthy, shareable, and something to "lean on." Parents valued the social interaction during the workshops but also suggested providing recorded content for easier access.

Conclusions: This pilot study demonstrated high acceptability and appropriateness of the PICNIC intervention model among parents in Sweden. This study will inform the design of an adapted version of PICNIC to be offered through child health services.

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KEYWORDS

child nutrition; child health; child feeding; responsive feeding; parent; primary prevention; feasibility studies; peer support; peer education; child health services

Introduction

Background

Promotion of healthy lifestyle habits in early childhood is of paramount importance [1], as eating behaviors and dietary patterns develop early in life [2] and often persist into adulthood [3]. Children's eating behaviors are influenced by their parents' food habits and feeding strategies [4,5]. Responsive feeding is an evidence-based approach in which parents recognize and respond appropriately to children's hunger and satiety cues, while also modeling healthy eating behaviors [6]. It emphasizes repeated, neutral (nonpressured) exposure to a variety of foods,

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which has been shown to shape children's preferences [7], such as increasing fruit and vegetable consumption [8].

Parents often describe child feeding issues as stressful and can find it difficult to translate available information into practice [9,10]. Qualitative research has shown that parents' child feeding practices are influenced more by peers (family and friends) than by dietary guidelines [10]. In addition, parents increasingly seek information and encounter advertising on social media and the internet, and may therefore be exposed to a confusing array of misinformation and conflicting advice as they strive to feed their children optimally [9]. Normal child eating behaviors, such as neophobia or "fussy or picky eating", also create concerns for parents [11,12] and can lead to nonresponsive parenting strategies such as pressure to eat or offering only accepted "safe foods," possibly impacting negatively on children's food preferences and development [13,14]. Higher perceived parenting competence, such as self-efficacy and satisfaction, has been reported to be positively associated with greater use of responsive food parenting practices [15].

In Sweden, the child health services (CHS) are responsible for offering parenting and child feeding support, aiming to empower parents through conversations during regular health visits and parent group sessions at the CHS center [16]. This health promotion work is particularly important, considering that less than 1 in 10 children and adolescents in Sweden meet the recommended fruit and vegetable intake [17,18] and approximately 10% of children have developed overweight by 4 years of age [19]. However, the national CHS program is multifaceted, leaving limited time for individualized, nutrition-related discussions [20]. CHS nurses frequently identify time constraints as a barrier to addressing family lifestyle habits, and these are complex topics that can be perceived as both sensitive and challenging to talk about [21,22]. Thus, there is a need for evidence-based resources to facilitate the support.

The "Parents In Child Nutrition Informing Community" (PICNIC) program is an ongoing population-level nutrition intervention in the Mid North Coast Local Health District, Australia, aimed at improving parental feeding practices and children's dietary quality [23]. PICNIC parents are trained in dietitian-led workshops and provided with ongoing, evidence-based plain-language child feeding information through online resources (website, Facebook, and Instagram; Meta Platforms, Inc). This peer education model was informed by formative research, which recommended early recruitment (<6 mo) and easy access to shareable online child feeding information to facilitate knowledge exchange and peer support between parents [10,24,25]. Parents co-designed the intervention, actively shared information with peers, contributed their experiences, and provided feedback to the research team through participatory action research [26]. Parents accessing PICNIC have shown improvement in child feeding practices and higher intake of vegetables in children compared to age-matched population data (Ball et al, manuscript submitted), and content analysis indicates that parents engage most with instructive ("how-to") content and messages on food restriction and fussy eating [27]. The online shareable format has shown potential to reach more than those directly engaged in the program [28]. For example, while a total of 1250 parents have been trained in a PICNIC workshop to date, PICNIC social media content reached almost 17,000 unique users on Facebook over the last month (as of January 2026; insights from Meta Business Suite).

The PICNIC project has attracted great interest from child and family health centers and is currently being scaled to other Australian health districts and new settings. This peer-to-peer education model may also be a suitable strategy to influence parents' feeding practices in Swedish CHS where no comparable programs currently exist. A feasibility trial is warranted to evaluate PICNIC transferability to the Swedish context and ensure that the program is tailored to meet end users' needs and expectations.

Aim

This pilot study aimed to assess the feasibility, acceptability, appropriateness, and perceived impact of the online peer education child feeding program PICNIC, developed in Australia, to be offered to parents of young children in Sweden.

Methods

Study Design

"PICNIC Sweden" was a mixed-methods single-group feasibility study designed to let parents in Sweden test an adapted version of the PICNIC child feeding peer education program, originally developed in Australia [23,26]. We used an explanatory sequential design integrating both quantitative and qualitative data to gain a comprehensive understanding of various feasibility aspects of the intervention in Sweden [29]. Data were collected concurrently between October 2023 and February 2024 and consisted of digital questionnaires, social media analytics, and semistructured interviews. This study is reported according to the COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist (qualitative interviews) [30] and the guidelines for Good Reporting of A Mixed Methods Study (GRAMMS) [31] (Checklist 1).

Participants and Recruitment

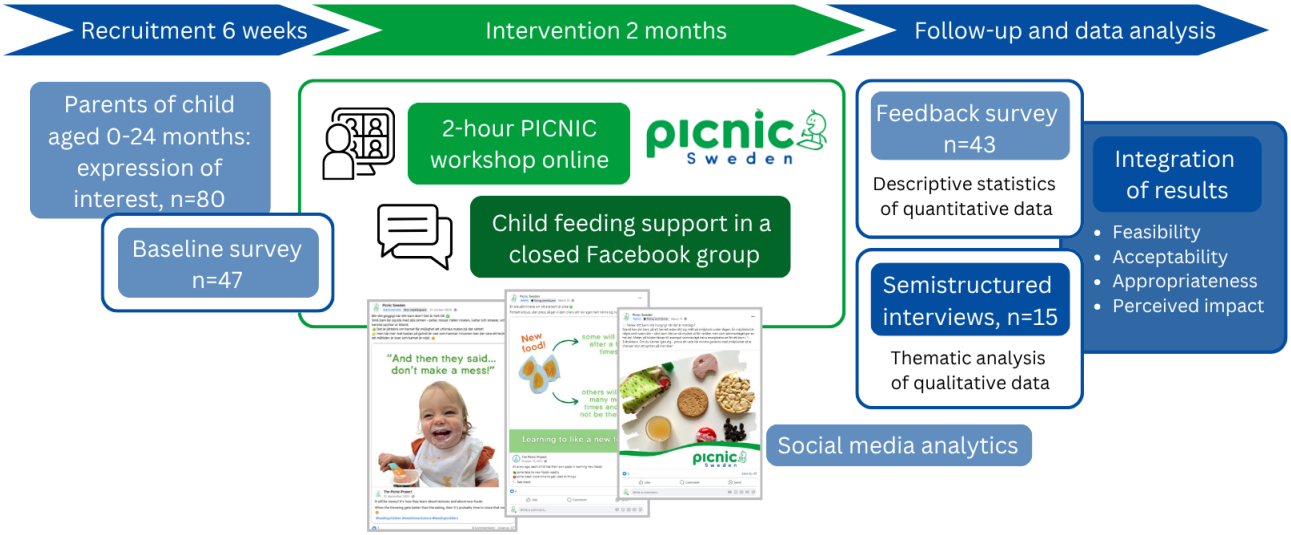
Participants in this study were parents or primary caregivers of a child aged 0 to 24 months. To participate, parents had to be aged at least 18 years, reside in Sweden, and understand written and spoken Swedish sufficiently well to participate in the workshop and answer the surveys. Recruitment took place between October 1 and November 15, 2023, using convenience sampling in the health care region of Sörmland, combined with snowball (peer-to-peer) sampling. All 26 child health centers located in the region were sent recruitment material, including posters and brochures, for display and distribution within their centers and social media post templates for online CHS pages and groups. A link referred to the recruitment webpage at ki.se and the expression of interest form. Interested parents were emailed full study information and offered the option to receive further information via phone before consenting to participate in the study.

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PICNIC Intervention

The intervention consisted of online training (a 2-hour virtual workshop on Zoom [Zoom Communications, Inc]) on food introduction and responsive feeding practices, as well as social network support resources (Figure 1). A registered dietitian (SA) with extensive experience working with families led the workshop, which was adapted from the Australian PICNIC project to a Swedish context. Thus, the same food introduction and responsive feeding concepts were covered, while the content was translated and adapted to Swedish dietary guidelines and the local food context. The only structural changes compared to the Australian original intervention included virtual workshops only (no face-to-face sessions) and no follow-up sessions, while the workshop duration remained unchanged (2 h). The participants were also invited to a closed Facebook group managed by the research team. In this forum, approximately 3 posts per week were shared to reinforce PICNIC messaging, either reshared from the Australian PICNIC page with Swedish captions or created by MHE and SA. The posts covered the same key concepts of responsive child feeding as those in the original Australian PICNIC and used a similar messaging tone. Parents could also submit child feeding questions through user-created posts, which were approved by the group administrator before being published and answered by the dietitian (SA) for the benefit of all group members. Group members could react ("like") and comment on all posts but could not share them outside the group due to Facebook privacy settings. As PICNIC used a peer education approach, participants were allowed to invite their partner, family, and parent friends to the Facebook group. However, entry required agreement to the group rules, which clearly outlined the group's purpose as part of a research project and explained that group-level engagement metrics would be collected. For this pilot study, no public resources were developed; only the closed Facebook group was used. Participants were, however, encouraged to visit the Australian PICNIC project website and social media pages (Facebook and Instagram) for additional resources.

Figure 1. Study design with flow of participants, data collection and analysis, and the "PICNIC Sweden" intervention with examples of Facebook content.



Data Collection

Questionnaires

A secure digital platform (REDCap, hosted at Karolinska Institutet) was used to distribute consent forms and digital questionnaires. A baseline questionnaire that included background parent or family and child characteristics and questions about previous experience of parent groups, perceived self-efficacy, and information-seeking behavior about healthy food and child feeding was distributed by email before participants attended the workshop. Two months after workshop participation, each of the 47 parents was approached via email and asked to fill in a follow-up questionnaire evaluating their program experience and providing feedback with regard to the research questions (feasibility, acceptability, appropriateness, and perceived impact). The questions were developed based on previous feasibility and intervention studies [24,32,33] and single items in validated questionnaires [34,35], modified to fit the current intervention, setting, and research aims. The questionnaires were pilot tested within the research team to ensure usability prior to data collection.

Social Media Analytics

Basic metrics, including the number of members as well as "active" engagement such as reactions or "likes" and comments, were exported from the Facebook group to Microsoft Excel by the administrator MHE. The data were then manually verified and supplemented with additional details, including post views (a type of "silent" engagement) by AJ after the study period. Only post reactions made by study participants were counted and included in the summary.

Semistructured Interviews

Semistructured individual interviews were conducted 2 to 3 months after the workshop (January to February 2024). The aim was to gain a deeper understanding of parents' views and experiences of the intervention, including perceived barriers to and facilitators of engaging in it, and potential impact. Using maximum variation sampling, 20 participants were invited in

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the first round. The study sample was subdivided by education level, country of birth, gender, number of children, and age or gender of child for random selection by characteristic groupings. Nine parents consented to interviews (the reasons for nonparticipation were unknown). To reach the target of 15 interviews, which was considered adequate for acquiring rich and sufficiently detailed data, another 2 rounds of invitations were sent out to 6 and 3 additional participants, respectively, of whom 6 consented and completed an interview. Subsequent rounds on invitations were selected from those with the same combination of characteristics to increase the likelihood of capturing diverse perspectives and experiences. We intentionally sought to interview both mothers and fathers with varying educational levels and country of birth, as well as parents with one or multiple children, including both girls and boys across the age range represented in our study. Interviews were conducted via phone in Swedish by AJ, a female registered dietitian with clinical experience in counseling families with children and employed as a part-time research assistant in this project. The interviews were attended by AJ, the interviewee, and, in 2 cases, the interviewee's partner. The interviewees were aware that AJ was a research assistant, but no other prior relationship existed. The interview followed a semistructured format with a preset interview guide (Multimedia Appendix 1) developed by AJ and MHE (project leader, nutritionist, and assistant professor experienced in early intervention). The interview guide was pilot tested with a mother of a 6-month-old girl (not included in the study), resulting in minor revisions. All interviews were audio recorded and transcribed verbatim using a professional transcribing service, with final transcripts not reviewed by participants. Interviews lasted a mean of 41 (SD 8, range 28-60) minutes.

Data Analyses

Quantitative Analysis

The quantitative data in questionnaires as well as social media analytics were summarized with descriptive statistics using R (version 4.3.0; R Foundation for Statistical Computing) in RStudio (version 2023.3.0.386). A question on parental self-efficacy (PSE) for promoting healthy eating behaviors in their children, from the validated PSEPAD (Parental Self-Efficacy for Promoting Healthy Physical Activity and Dietary Behaviors in Children) instrument [35], was included in the questionnaires to enable comparison with previous studies and explore its distribution and change in this study population. The item response was a Likert-type scale, ranging from 0 (*not at all*) to 10 (*to a very high degree*). Although PSE change scores deviated from normality (Shapiro-Wilk test: W=0.90; P=.002), a 2-tailed paired t test was used as the primary analysis because of its robustness in samples of this size. A Wilcoxon signed-rank test was also conducted as a sensitivity analysis.

Qualitative Analysis

The 15 interview transcripts were analyzed using thematic analysis with an inductive approach [36,37]. First, data familiarization was performed through a read-through of all transcripts and initial discussions between AJ (registered dietitian), MHE, MH, and EBV, all female. Initial notes were taken to capture first impressions and emerging patterns in the data. MH and EBV were final-year bachelor's students in nutrition at the time, working on the data as part of their degree project. Supervised by MHE, systematic coding was performed independently by AJ and MH using meaning units and codes in Microsoft Excel 2023 (version 16.78.3). To achieve a shared understanding, the individual coding results and preliminary themes were discussed between AJ, MH, MHE, and KD in an iterative process. The themes were also refined by MHE through a revisiting of transcripts, coded data, and notes from the initial discussions. Final theme names and their scope were reviewed by all authors to reach consensus. The preliminary analysis was carried out in Swedish, with themes and quotations translated into English for co-analysis by English-speaking authors and for publication.

Data Integration

Quantitative and qualitative data in this sequential mixed methods study [29] were integrated using side-by-side comparison within framework analysis to interpret findings. Framework domains reflected the aims of understanding feasibility, acceptability, appropriateness, and perceived impact of the PICNIC program.

Ethical Considerations

All participants provided informed consent before participating in the study. To enter the closed Facebook group, members were required to accept the "group rules," which clearly described the purpose of the Facebook group and that group-level engagement metrics would be collected and reported in scientific communications. For the interviewees, additional informed consent was obtained after they had received individual invitations and study information related to the interview. No compensation was given to participants. The study was conducted in accordance with the Declaration of Helsinki, and the Swedish Ethical Review Authority approved this study (Dnr 2023-04381-01).

Results

Characteristics of Participating Parents at Baseline

Over a 6-week period, 80 parents submitted an expression of interest (Figure 1). Of these, 47 (59%) parents gave formal study consent, filled in the baseline questionnaire, and were able to attend 1 of the 10 workshops held during the trial period. Twenty (43%) participants resided in Sörmland, and 27 (57%) were from 6 other neighboring health care regions across central Sweden. They reported being recruited through their child health center or nurse (n=15, 32%), a social media post (n=8, 17%), or a friend or family member (n=24, 51%). Table 1 presents descriptive characteristics of the participating parents. The majority were mothers (46/47, 98%) born in Sweden (44/47, 94%) and aged approximately 33.8 (SD 4.8; range 22 - 44) years, and 43 (91%) participants had a university degree. Most participants had a child aged 6 to 12 months (22/47, 47%) or 0 to 6 months (17/47, 36%). While 25 (53%) parents had attended CHS parent groups, 20 (43%) reported not being invited to one at their child health center. The PSE was, on average, 7.8 (SD 1.5; range 5 - 10). Before engaging in the PICNIC intervention, more than half (27/47, 58%) of participants replied they *quite*

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often or *very often* had questions on children's food or feeding, and one-third (14/47, 30%) felt they had not received sufficient child feeding support from CHS. The most common sources of information were the internet, the Swedish Food Agency website, family, friends, or other peers. The 15 interviewed parents were comparable to the study population in terms of demographic and baseline characteristics.

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Table . Characteristics of parents participating in the PICNIC[a] Sweden pilot study.

Characteristics	All (n=47)	Interviewed (n=15)
Gender, n (%)		
Female	46 (98)	14 (93)
Male	1 (2)	1 (7)
Age (years), mean (SD)	33.8 (4.8)	32.8 (3.5)
Country of birth[b], n (%)		
Sweden	44 (94)	13 (87)
Other	3 (6)	2 (13)
Education, n (%)		
University	43 (91)	13 (87)
No university	4 (9)	2 (13)
Number of children[c], n (%)		
One child	41 (87)	11 (73)
Two children	4 (9)	3 (20)
Three children	2 (4)	1 (7)
Age of youngest child (months), mean (SD)	7.9 (4.2)	8.1 (4.9)
0 - 6 months, n (%)	17 (36)	6 (40)
6 - 12 months, n (%)	22 (47)	6 (40)
>12 months, n (%)	8 (17)	3 (20)
Gender of youngest child, n (%)		
Girl	10 (21)	4 (27)
Boy	30 (64)	10 (67)
One boy and one girl[c]	1 (2)	1 (6)
NA[d]	6 (13)	—[e]
How did you find out about the “PICNIC Sweden” project?, n (%)		
Child health center or nurse	15 (32)	8 (53)
A friend or family	24 (51)	6 (40)
Social media	8 (17)	1 (7)
Internet, Googled, or other	0 (0)	0 (0)
Have you participated in a CHS[f] parent group with your child?, n (%)		
Yes, several times	16 (34)	3 (20)
Yes, one session	9 (19)	3 (20)
No, but the other parent has	0 (0)	0 (0)
No, didn’t want to/couldn’t	2 (4)	1 (7)
No, have not been invited	20 (43)	8 (53)
Do you usually take part in other parent groups outside of the child health center?[g], n (%)		
Open preschools (*swe* öppen förskola)	30 (64)	10 (67)
Maternal health parent group	0 (0)	0 (0)
Friends	26 (55)	7 (47)
Social media (eg, groups)	22 (47)	4 (27)

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Characteristics	All (n=47)	Interviewed (n=15)
Other	2 (4)	1 (7)
No, I only participate in parent groups at the child health center	4 (9)	1 (7)
No, I do not participate in parent groups (at child health center or outside it)	4 (9)	1 (7)
How confident are you that you can promote healthy eating habits for your child?		
Average PSE[h] score (scale 0 - 10), mean (SD)	7.8 (1.5)[i]	8.1 (1.4)
Do not know, n (%)	1 (0)	0 (0)
Do you tend to have questions or wonder about children's food/feeding?, n (%)		
Very often (every day)	4 (9)	1 (7)
Quite often	23 (49)	6 (40)
Sometimes	17 (36)	7 (47)
Seldom	3 (6)	1 (7)
Never	0 (0)	0 (0)
Where do you turn to for information or answers to questions about children and food/feeding? *Answers coded as 1 (never), 2 (rarely), 3 (sometimes), 4 (often), and 5 (very often*), mean (SD)		
Internet (eg, Googling)	3.9 (1.0)	3.5 (1.1)
Social media	3.0 (1.3)	3.0 (1.0)
Friend and social contacts	3.3 (1.0)	3.3 (1.0)
Family	3.0 (1.1)	3.1 (1.0)
Child health center or nurse	3.2 (1.0)	3.3 (1.1)
Swedish Food Agency (website)	3.4 (1.0)	3.5 (1.1)
1177.se (national health care service)	3.1 (1.0)	3.2 (0.8)
Registered dietitian (eg, in health care)	1.4 (1.0)	1.5 (1.1)
Media (newspapers, radio, and TV)	1.6 (0.7)[i]	1.7 (0.7)[j]
If you get information or advice about children and food on social media, which platforms do you usually get it from?, n (%)		
Facebook	22 (47)	7 (47)
Instagram	31 (66)	12 (80)
TikTok	3 (6)	0 (0)
YouTube	1 (2)	1 (7)
Other platform	1 (2)	0 (0)
Do not get info from social media	3 (6)	0 (0)
Do not use social media	3 (6)	0 (0)
How much do you trust information about children and food that you find online? *Scale answers coded from 1 (do not trust at all) to 5 (have a lot of trust*), mean (SD)		
Trust score	3.1 (0.7)	3.2 (0.7)
Do you feel you have received sufficient information and support from CHS on child feeding?, n (%)		
Yes	21 (45)	8 (53)
No	14 (30)	4 (27)

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Characteristics	All (n=47)	Interviewed (n=15)
Do not know	12 (25)	3 (20)

[a]PICNIC: Parents In Child Nutrition Informing Community.

[b]All participants understood written and spoken Swedish and English (OK or well).

[c]One participant who had 3 children was a mother of twins (a girl and a boy).

[d]NA: Not applicable (missing data).

[e]Missing data are reported as not applicable (NA).

[f]CHS: child health services.

[g]Multiple answers could be chosen; % may add up to more than 100%.

[h]PSE: parental self-efficacy.

[i]n=46.

[j]n=14.

Process Evaluation and Social Media Engagement Metrics

Ten online workshops were held over a period of 5 weeks (October 10 to November 17, 2023), with an average of 4 to 5 participants per workshop, totaling 47 parents. An additional 3 fathers (not included in data collection) were present and listened in together with their participating partner. After the workshops, the closed Facebook group had grown to 60 members, including PICNIC team members or administrators, study participants, and peer-invited partners or friends. During the 4 months of Facebook group activities (October to January), a total of 52 intervention posts (including 9 video posts) were shared by the PICNIC Sweden team, and 17 user-created posts from parents were published and answered in the group. Regarding feeding-related messages, posts focused on children's learning to eat process (n=10), division of responsibility, including pressure to eat and feeding cues (n=9), meal environment and role modeling (n=8), what or how to serve (n=8), fussy eating (n=7), food exposure (n=6), and other or mixed topics (n=4). Most videos (5/9) addressed learning to eat. Notably, many posts were multimessaged, reflecting the intertwined nature of responsive child feeding practices. A variety of communication techniques were used, such as "how-to" content, storytelling, rhetorical questions, relatable and realistic photos and videos, and real-world tie-ins (eg, Christmas or Easter food) [27]. In general, the active engagement in the group was low; posts received an average of 2 "likes" (minimum to maximum: 0 - 7) from parents participating in the project. User-created posts always received some comments (3 on average, including the PICNIC dietitians' answers to questions), whereas 8 (15%) of 52 PICNIC-created posts received comments from parents. However, silent engagement, that is, viewing or reading posts, was overall higher, and while PICNIC-shared posts received 39 views on average, user-created posts received 47 views, suggesting higher "silent" engagement from parents with these question-and-answer type of posts. The most viewed PICNIC Facebook content (>55 views) included posts on what foods to serve, when and how to serve water, family meals (eating together), and the concept of "parents provide, children decide." The most engaging user-created post (58 views, 10 comments) was a parent's question on the use of taste buttons to introduce babies to new flavors.

Quantitative Survey Data—Follow-Up After PICNIC

Participants' responses to the follow-up questionnaire are presented in Table 2 (n=43, 91.5% response rate). Overall, the parents reported high satisfaction with the intervention and seemed to find the workshop especially useful. They also reported gained knowledge or insights, especially around how to practically manage different mealtime situations with their children. The mean PSE scores increased from 7.69 (SD 1.52) at baseline to 8.17 (SD 1.40) at follow-up among participants with data at both time points (n=42). A paired *t* test showed that PSE scores were significantly higher at follow-up than at baseline, with a mean increase of 0.48 points (95% CI 0.11-0.84; t_{41}=2.63; *P*=.01). A Wilcoxon signed-rank test yielded the same conclusion (*V*=601.5; *P*=.02). Furthermore, Facebook and Instagram were considered appropriate platforms for PICNIC, where open-ended answers (16/43, 37% chose to add a comment) explained that these were the most used platforms in this group today and the group function that Facebook provides was suitable for sharing in PICNIC; however, considering younger generations are not using Facebook as much, other platforms should be considered. Moreover, online engagement varied; while one-third (14/43, 33%) had actively viewed group posts 2 to 3 times per week and another third (15/43, 35%) more often than that, the remaining 32% (14/43) had viewed posts only once a week or more seldom (Table 2). Parents had shared information or advice from PICNIC primarily with the child's other parent (33/43, 77%), friends (25/43, 58%), and/or family (24/43, 56%), and most (30/43, 70%) considered it appropriate to be invited to PICNIC when the child was 3 to 4 months of age. Parents' opinions on the preferred format of the PICNIC workshop varied; most favored the online workshop as it was (41/43, 95%), but in-person meetings (14/43, 33%) and prerecorded information (17/43, 40%) were also suggested. Open answers to this question (28/43, 65% chose to comment) identified both pros and cons with different modes of delivery. Live workshops were considered valuable as questions could be asked directly to the dietitian. Parents commented that in-person meetings could be more socially enjoyable and boost discussions; however, getting there with the child may be challenging and time-consuming. Attending from home or from "anywhere" was considered more feasible. Prerecorded or self-directed options were commented upon as a good option for those who could not attend at a specific time or who wanted

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to relisten but were suggested as a complement combined with interactive sessions or workshops to gain the benefits from both.

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Table . Participants' response to the follow-up survey after 2 months of engagement with the PICNIC[a] Sweden child feeding support (n=43).

Question or statement and response	Values
Part 1. The dietitian-led online PICNIC workshop, n (%)	
To what extent do you agree with these statements?	
The workshop gave me useful tips/advice/information	
Strongly disagree	—[b]
Disagree	—
Neither agree nor disagree	—
Agree	12 (28)
Strongly agree	31 (72)
Participating online (on Zoom) worked well	
Strongly disagree	—
Disagree	—
Neither agree nor disagree	—
Agree	9 (21)
Strongly agree	34 (79)
I liked participating in the PICNIC workshop	
Strongly disagree	—
Disagree	—
Neither agree nor disagree	1 (2)
Agree	8 (19)
Strongly agree	34 (79)
I would recommend the workshop to other parents	
Strongly disagree	—
Disagree	—
Neither agree nor disagree	1 (2)
Agree	9 (21)
Strongly agree	33 (77)
In what format do you think the PICNIC workshop should be?[c,d] *Multiple responses allowed.*	
Online workshop (like we had)	41 (95)
In person (at the child health center or other venue)	14 (33)
Prerecorded (to watch at your own convenience)	17 (40)
Other way	—
Do not know	—
What do you consider a suitable duration for the workshop?	
Not more than 1 hour	1 (2)
1 - 1.5 h	15 (35)
2 h (like we had)	23 (53)
2.5 - 3 h	3 (7)
More than 3 h	—
Do not know	1
If you had been offered additional workshops, such as follow-up Q&A[e] sessions online, would you have wanted to participate?	

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Question or statement and response	Values
Yes	34 (79)
No	—
Do not know	9
Part 2. Other parts of PICNIC, n (%)	
Other than the workshop, what other parts of PICNIC have you engaged with?[c]	
The closed Facebook group “PICNIC Sweden”	41 (95)
The Australian PICNIC website (picnicproject.com.au)	6 (14)
The Australian Facebook page (“The PICNIC Project”)	8 (19)
The Australian PICNIC Instagram (@picnic_nsw)	10 (23)
None of these (participated in the workshop only)	2 (5)
What do you think about the closed Facebook group “PICNIC Sweden” and the information shared there?	
The Facebook group gave me useful tips/advice/information	
Strongly disagree	—
Disagree	—
Neither agree nor disagree	5 (12)
Agree	19 (44)
Strongly agree	19 (44)
Social media is an appropriate channel for sharing child feeding information in PICNIC	
Strongly disagree	1 (2)
Disagree	—
Neither agree nor disagree	3 (7)
Agree	16 (37)
Strongly agree	23 (53)
I enjoyed being part of the Facebook group	
Strongly disagree	—
Disagree	—
Neither agree nor disagree	4 (9)
Agree	18 (42)
Strongly agree	21 (49)
I would recommend the closed Facebook group to other parents	
Strongly disagree	—
Disagree	2 (5)
Neither agree nor disagree	7 (16)
Agree	15 (35)
Strongly agree	19 (44)
How often have you read posts shared in the Facebook group? Think about a usual week during the period between joining the group and now (last 2 months).	
Several times per day	—
Once a day	5 (12)
More than 3 times per week	10 (23)
2 - 3 times per week	14 (33)

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Question or statement and response	Values
Once a week	12 (28)
2 - 3 times per month	1 (2)
Once a month or less	—
Never	1 (2)
Have you experienced any negative comments from others in the Facebook group?	
No	40 (93)
Yes	—
Do not know	3
Which social media platforms do you think PICNIC should be present on?[c,d]	
Facebook	40 (93)
Instagram	33 (77)
TikTok	3 (7)
Snapchat	1 (2)
X (formerly Twitter)	1 (2)
Other social media platform	1 (2)
None	1 (2)
Do not know	1
Would you like to continue being part of the closed Facebook group (PICNIC Sweden)?	
Yes	40 (93)
No	—
Do not know	3
Part 3. Experiences and perceptions of the PICNIC Sweden intervention as a whole	
What is your overall impression of PICNIC?, n (%)	
PICNIC is suitable for sharing information and support on child feeding	
Strongly disagree	—
Disagree	—
Neither agree nor disagree	—
Agree	8 (19)
Strongly agree	35 (81)
I perceive the information provided in PICNIC as factually correct	
Strongly disagree	—
Disagree	—
Neither agree nor disagree	—
Agree	7 (16)
Strongly agree	36 (84)
PICNIC answers questions that are common among parents of young children	
Strongly disagree	—
Disagree	—
Neither agree nor disagree	—
Agree	7 (16)
Strongly agree	36 (84)

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Question or statement and response	Values
I believe there is a need among parents in Sweden to have access to a project like PICNIC	
Strongly disagree	—
Disagree	—
Neither agree nor disagree	1 (2)
Agree	4 (9)
Strongly agree	38 (88)
How has your participation in PICNIC affected you? I have gained more knowledge/insights around:, n (%)	
what type of foods are healthy for my child	
Strongly disagree	—
Disagree	—
Neither agree nor disagree	5 (12)
Agree	19 (44)
Strongly agree	19 (44)
what amount of food is appropriate for my child	
Strongly disagree	—
Disagree	—
Neither agree nor disagree	7 (16)
Agree	18 (42)
Strongly agree	18 (42)
how I introduce new foods to my child	
Strongly disagree	—
Disagree	—
Neither agree nor disagree	3 (7)
Agree	11 (26)
Strongly agree	29 (67)
how I can practically manage different mealtime situations with my child	
Strongly disagree	—
Disagree	—
Neither agree nor disagree	1 (2)
Agree	13 (30)
Strongly agree	29 (67)
how I can respond to a child who doesn’t want to eat what is served	
Strongly disagree	—
Disagree	—
Neither agree nor disagree	1 (2)
Agree	14 (33)
Strongly agree	28 (65)
How confident are you that you can promote healthy eating habits for your child?, mean (SD)	
PSE score (scale 0 - 10; n=43)	8.1 (1.4)
Have you shared information/tips/advice from PICNIC to others?[1] Verbally/in writing/digitally/on social media, n (%)	
The child’s other parent(s)	33 (77)
Friends	25 (58)

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Question or statement and response	Values
Family	24 (56)
Parent group/early childhood center	14 (33)
CHS nurse	6 (14)
Others	1 (2)
I have not shared information with others	2 (5)
Did you recommend others to participate in the "PICNIC Sweden" project?[c], n (%)	
The child's other parent(s)	10 (23)
Friends	28 (65)
Family	5 (12)
Parent group/early childhood center	15 (35)
Others	1 (2)
I have not actively recommended anyone	5 (12)
From what age of the child do you think one should be invited to PICNIC?, n (%)	
Already before birth (through maternal health clinic)	5 (12)
1 month/2 months	—
3 months	13 (30)
4 months	17 (40)
5 months	5 (12)
6 months	3 (7)
7/8/9/10/11/12 months or older[f]	—

[a]PICNIC: Parents In Child Nutrition Informing Community.

[b]No responses.

[c]Multiple responses allowed; percentages may exceed 100%.

[d]Respondents could also comment on their answers to these questions (optional).

[e]Q&A: question and answer.

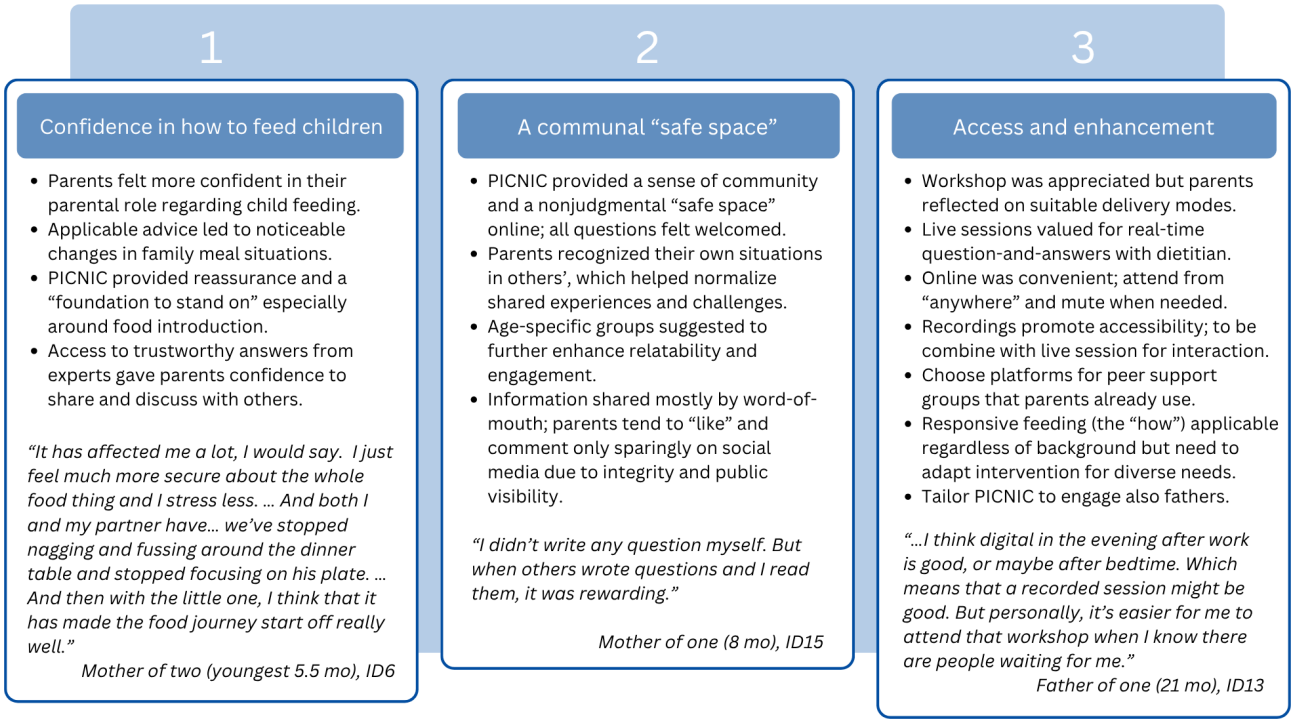
[f]Response options with no answers from participants were grouped in this table.

Qualitative Insights From Interviews

Thematic analysis of transcripts from the 15 interviews (descriptive characteristics in Table 1) resulted in 3 themes. These are presented in Figure 2 and described below. Selected quotes have been labeled with an identifying number, *mother* or *father*, total number of children, as well as age of their youngest child when enrolling in the project.

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Figure 2. Themes in data from semistructured interviews with PICNIC (Parents In Child Nutrition Informing Community) participants.



Theme 1: Confidence in How to Feed Children

The parents described the intervention as pedagogic and useful. They reported increased understanding of how children learn to eat and perceived the information and advice as easy to absorb and apply in practice. This feeding efficacy led to increased self-confidence and greater trust in their child's own ability during mealtimes. For instance, parents reported feeling less anxious about offering new foods and textures for their young children to explore:

> *Not to get stuck with purées and ready-made baby food jars, but rather to cut up pieces of something easy to grip and gnaw on—and well, to dare a bit more.* [Mother of one (6 mo), ID8]

It was evident during the interviews that parents had learned about responsive feeding; they spoke about the importance of creating curiosity and joy for food, being a role model, and maintaining a neutral expression toward the child's eating behaviors and amount eaten. Many parents had become more aware of their own behaviors at mealtimes, and they shared stories on how they had changed practices and approach at home, resulting in a more positive atmosphere at the table:

> *I don't run around tidying up in the kitchen while he's eating—instead, I sit with him.* [Mother of two (youngest 6 mo), ID11]

Most participants emphasized that questions and concerns tend to arise when solid food is introduced and would be the ideal time to invite parents to PICNIC. Participating parents who had just entered their "food journey" also described the workshop as particularly reassuring, giving them "a foundation to stand on":

> *We were just at the beginning of our food journey with our daughter, and there was a sense of reassurance when hearing about, well, how to think about it, what needs to be considered, and what to stress over and not to stress over. I thought that felt super comforting.* [Mother of one (7.5 mo), ID2]

Parents with previous feeding experience with older children also found the intervention useful. Some felt reassured knowing that their feeding approach aligned with current evidence, while others reported reflecting on their past practices and now adopted new feeding strategies when introducing food to their second child. This was described as motivated by encouragement rather than blame or judgment:

> *But then when this project came along and everything...well, suddenly things just made sense. And became easier, I would say. I'd say that the food journey now with our second child has started off much better—easier.* [Mother of two (youngest 5.5 mo), ID6]

Participants' increased confidence and self-efficacy were partly attributable to their perception of the PICNIC content as trustworthy. Parents felt comfortable sharing PICNIC content because the advice was evidence-based and delivered and moderated by dietitians and nutritionists. Most had shared the information with partners, friends, or extended family members, who generally responded with interest and curiosity. Some also felt more comfortable discussing child feeding with their own parents:

> *Then my mom said, "Can't you just feed him, isn't he too young to eat by himself?" That's when I could use this information and explain that it's evidence-based—there are benefits to letting him squeeze and feel the food, look at it, and learn to put it in his mouth.* [Mother of one (5.5 mo), ID3]

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Access to child feeding and nutrition expertise was recognized and highly valued by participants and also saved them time and effort relative to trying to access credible information online:

> *It was really nice to be able to ask so many questions and have someone who is an expert answer them every time. I felt like there's nowhere else you get that opportunity in the same way...I can search for as much information as I want, but to ask specific questions...felt very luxurious and...good.* [Mother of one (7.5 mo), ID2]

At the same time, participants emphasized the importance of experts being relatable and nonjudgmental:

> *She really seems very competent and good at talking to...people in an understandable way.* [Mother of one (7 mo), ID12]

Overall, participation in PICNIC provided parents with the type of information and strategies they needed to transition toward responsive child feeding. This was evidenced by apparent, constructive change in the feeding dynamic with their child, and in parents' reported feelings of reassurance and confidence, which motivated further engagement with the PICNIC online community and sharing of PICNIC principles with peers.

Theme 2: A Communal "Safe Space"

Being able to witness other parents' questions was highly appreciated by the participants, both during the workshop and in the Facebook group. Parents described how they could recognize their own situation in others, which created a reassuring feeling and a sense of not being the only one feeling "a bit lost":

> *Sometimes there are things you haven't even thought about yourself that other people bring up. And things you feel so alone in and think you're the only one who has...those issues. But then you realize that others experience the same.* [Mother of two (youngest 5.5 mo), ID6]

Several parents reported that participating in the project and being part of the supportive online group supported a sense of community, where hearing from other parents helped counter feelings of loneliness in their parental role. Thus, PICNIC filled a gap, particularly for those who had not attended parent groups at their child health center:

> *At the child health centre I go to, there are no parent groups or anything. And food is a really big thing, especially in the beginning [of parenthood]. So, I have appreciated being able to get advice from other parents and, well, having the opportunity to engage in that way.* [Mother of one (3.5 mo), ID4]

Some parents suggested additional workshops, with content tailored to the child's age, including ages beyond 0 to 2 years, and with online parent groups organized accordingly. This was perceived as a way to enhance the relevance and engagement of the content, as it would be even easier for parents to relate to. However, one parent pointed out that it could also be beneficial for first-time parents to hear about the experiences of those with older children:

> *At the same time, I think it can be helpful for first-time parents to hear from those who have more than one child, because as a first-time parent, you're often more worried, cautious, and maybe a bit nervous about it.* [Mother of two (youngest 4 mo), ID10]

Integral to the sense of community was the closed Facebook group being seen as a "safe space" to share. Parents appreciated its nonjudgmental tone and felt that all questions were welcomed, making it easier to engage:

> *It's a very friendly tone. Even I, who don't usually ask or comment much, have done so. Just because I've felt that the environment has been very, well, pleasant.* [Mother of three (youngest twins 8 mo), ID5]

While some parents actively engaged with PICNIC content or posted questions in the Facebook group, others preferred to observe. Although they found the content interesting and useful, they tended to comment or "like" only sparingly. Parents explained that this reflected personal considerations of privacy and a concern about being publicly visible and potentially judged, both within the group and on social media more broadly:

> *It's like...when you ask a question or post something, it's as if you're stepping out onto a stage...and in a way, exposing yourself.* [Mother of one (7 mo), ID7]

Participants perceived that having attended the online workshop encouraged them to feel comfortable to share or comment on posts. Keeping the groups relatively small and local, as well as meeting each other in person, was believed to further enhance engagement:

> *I think it also gives a sense of security, like, "Okay, I know who's going to read this, I know them a little."* [Mother of one (16 mo), ID1]

Notably, while most content was consumed online, on-sharing was done primarily through word-of-mouth:

> *I haven't done it [shared content] on social media. But I've talked a lot about it.* [Mother of one (7.5 mo), ID2]

Overall, parents responded positively to the peer education model, explaining that one typically perceives information as more trustworthy when obtained from someone with personal experience and that you know. Some parents described how friends who became parents found food introduction overwhelming and feared making mistakes, and PICNIC was seen as an opportunity to share a reassuring resource that friends could rely on.

> *When mentioning this project, everyone has been really curious and kind of like, "We would've wanted this too." So I think many people...well, sometimes you don't realize you're missing something until you have it, and it's been a bit like that with PICNIC.* [Mother of two (youngest 5.5 mo), ID6]

Participants emphasized the importance of involving fathers, recognizing their significant role in child feeding. The predominance of mothers in parent groups at child health centers and in child feeding groups on social media was reflected upon.

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Some participants attributed this to the common practice in Sweden of mothers staying home during the child's first year, leading to a greater involvement in feeding. Others suggested that differences in information-seeking behavior and peer support needs between men and women may play a role:

> *...men maybe don't talk to each other in the same way, like "Hey, I heard about this," as we women do.* [Mother of one (5.5 mo), ID3]

The effectiveness of the PICNIC peer model hinged around engendering a feeling of safety for participants. The combination of shared life stage (parenting) and exposure (PICNIC) meant participants were willing to share vulnerabilities, which then perpetuated deeper connection and a more meaningful experience. The model could require adaptation to be as effective for men and for different cultural groups.

Theme 3: Access and Enhancement

The theme of access and enhancement related to the suitability of accessing the PICNIC content for participants and other parents. They reflected on and compared their experience of accessing PICNIC content with previous experiences and considered other parents who may have more challenges accessing and engaging with PICNIC.

The live, online format was considered convenient, as parents enjoyed the social interaction while also easily participating from their home environment, with the capability to "mute themselves" when needing to care for their children. However, it was also posed that in-person workshops would be more "fun," with the child health center suggested as a venue. Physical meetings were thought to boost discussions among parents and may also help increase engagement in the online Facebook group afterward:

> *Of course, it helps if you can do it digitally,...you open the door for more people to participate. At the same time, I do feel that when you meet in person, it's a bit easier to really be present in the moment and take in all the information. So there's a bit of ambivalence in my answer, but in any case, some form of real-time workshop.* [Mother of one (6 mo), ID8]

Recorded workshops or material were also discussed, and several parents highlighted the benefits of this approach, such as the ability to view it anytime, pause, and relisten, and to share it with their partner. Some also acknowledged the efficiency and potential for wider reach compared to live meetings. On the other hand, it would limit social interaction and viewing material may not be prioritized when it is not scheduled:

> *If it's a lecture you can watch anytime, it's easy to say, "Yeah, we don't have time tonight, we'll do it tomorrow," and then forget about it.* [Mother of one (7 mo), ID7]

Overall, parents identified both advantages and disadvantages of different workshop delivery modalities, primarily related to ease of access. Some suggested having a range of options to accommodate differing needs, while others suggested a hybrid format. Parents also emphasized that the quality of a workshop largely depends on who leads it, regardless of the delivery method.

The accessibility of simple Facebook posts that reinforced workshop content was appreciated. Posts appeared in parents' feeds and functioned as friendly reminders reinforcing PICNIC feeding messages. To boost engagement, creative content ideas and the combined use of multiple social media platforms were proposed:

> *To have it appear in your daily scrolling, and then very simple things like "Think about this" or "Good things to know" or something. I think it's a format that's incredibly helpful, and especially for parents with small children, it can be so easily accessible.* [Mother of one (7.5 mo), ID2]

As a hosting platform, Facebook was perceived by most parents as accessible and appropriate because of its closed group format with moderated content. However, some parents noted that Facebook use is lower among younger parents and therefore suggested other options be explored. Some also emphasized that because not everyone uses social media, emails with the same content should be included as a complementary feature.

Interviewees felt PICNIC's focus on *how* to feed children was relevant across diverse cultures and family situations, and integrating it into standard CHS care was seen as a way to enhance credibility and accessibility. However, reaching and engaging different parents could be a challenge, and adaptations would be needed. Suggestions included translating and culturally adapting content for non-Swedish-speaking parents, and addressing other potential barriers such as low education, intellectual disabilities, and limited social media use:

> *I think the content itself...it's not too difficult for someone with only an upper secondary education, I think, or with a different cultural background. But the question is how you reach people.* [Mother of two (youngest 6 mo), ID11]

To improve comprehension and engagement, alternative communication channels and tailored content, such as topic-specific workshops or question-and-answer sessions, were proposed. Parents expressed a desire for more practical meal tips, and one asked specifically for advice for a child with multiple allergies, noting limited guidance from CHS:

> *Our son is allergic to pretty much everything—milk, eggs, nuts...and it's really hard to find information and recipes and such, food-wise.* [Mother of one (12 mo), ID9]

One mother described herself as the "food encyclopedia" at home and said she would have appreciated it if her partner had received the information directly. However, while many wished fathers would be more engaged in learning about responsive child feeding, they also recognized that it may be challenging to reach them with an intervention like PICNIC. They emphasized that the intervention probably needs to be "dad focused," with information tailored specifically to fathers and their role. Some suggested more active recruitment through CHS but also at places where fathers tend to meet during parental leave:

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> *Maybe information from CHS—even if the mother goes [to CHS visits], she can bring the information home to the father—or open preschools [a free drop-in centre for parents and young children], where more fathers might be when children are a bit older...* [Mother of one (12 mo), ID9]

A father who participated in the project highlighted the underrepresentation of fathers in such interventions and also suggested open preschools could be a way to engage them. During his parental leave, when his daughter was aged 10 to 18 months, he felt strongly responsible for her eating. However, he reported a lack of guidance and that other fathers would sometimes choose convenient "safe" options to avoid making mistakes:

> *I've also noticed with other dads, yeah, it's not so easy to find information...and if you want to be sure, you just grab a baby food pouch—then it can't go wrong. Or things like that.* [Father of one (21 mo), ID13]

Accessibility of accurate, relatable information, facilitators, and peer support was considered a key success factor in this pilot intervention. To enhance access, parents suggested using hybrid (in-person and online) delivery options or simulating characteristics of in-person participation as much as possible in the online environment. To effectively facilitate on-sharing of PICNIC content, social media platforms need to have suitable functionality and popularity with participants and prospective participant cohorts.

Synthesized Data

In Table 3, key results from the quantitative and qualitative data are compared side-by-side based on framework domains reflected by the aims of the study: to understand feasibility, acceptability, appropriateness, and perceived impact of the PICNIC program.

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Table . Quantitative and qualitative data integrated and compared based on the sequential mixed method study aims.

Domain	Quantitative	Qualitative	For further exploration
Feasibility (logistics)	• Use of online and social media communications • High workshop interest, enrollment, and participation • High retention to follow-up • Social media content feasible	• All aspects highly feasible for mothers • Peer education model feasible with PICNIC[a] structure and format (workshop, closed social media group, and supporting resources)	• PICNIC peer-to-peer education and support model would benefit from further exploration • PICNIC scope requires clear boundaries explained (behavioral focus, can triage but not treat sensory and complex child feeding issues) • Scalability of face-to-face model may limit feasibility
Acceptability (subjective, a good social fit)	• High acceptability for parents of first child or with more than one child • Relatively high "silent" engagement in the closed Facebook group, with a higher number of post views in user-created posts (47 views per post) than PICNIC social media posts (38 views per post) • 93% would have continued in Facebook group • 77% had shared with partner • >50% had shared with friend or family • Content easy to absorb and apply in practice	• Highly acceptable to mothers, potentially acceptable to fathers, with modification • Facebook group and website highly acceptable alternative to current information-seeking approaches • Sense of solidarity and community • Nonjudgmental tone supported engagement • Social media platform acceptable to active sharers and observers, especially with known contributors (other PICNIC parents) and expert moderators • Acceptability of PICNIC participation, engagement for fathers and culturally diverse groups requires further exploration • Facilitator's approach and demeanor valued	• To optimize social media closed group engagement and access, parents need to feel secure (in platform and group) • Adaptations needed to be feasible for culturally diverse groups • Need for "dad focused" arm of PICNIC—they may have different ways of consuming and engaging with content and different mindsets about feeding
Appropriateness (suitable, fit for context, objective)	• Complemented or supplemented child feeding support from child health services • Appropriate to promote peer and family sharing of child feeding information or content • 3 - 4 months most appropriate child age for parent to commence PICNIC	• Expertise of facilitator • Application of responsive feeding practices • Invitation to PICNIC around the time of introducing infant to solid food considered most appropriate • Responsive feeding principles appropriate across cultural and gender contexts, but different approaches needed to reach different target groups	• Consider separate groups for first-time parents and those with more than one child (or shared groups for peer learning)? • Adaptations needed to be appropriate for fathers and culturally diverse groups
Perceived impact (outcomes, what happened as a result of involvement)	• Significant increase in parental self-efficacy score from baseline to follow-up • Self-reported increased practical skills for managing mealtimes	• Increased feeding efficacy reported • "Safe space" to share decreased stress and burden of child feeding • Information from someone with lived experience perceived as trustworthy and impactful	• Further research should measure child feeding, child diet quality, parental efficacy, and parenting-related anxiety outcomes over more than 12 months

[a]PICNIC: Parents In Child Nutrition Informing Community.

Discussion

Principal Findings

This study confirmed that the PICNIC program is feasible, acceptable, and appropriate and has potential for high impact in Sweden. Overall, parents participating in this pilot study reported improved confidence in their parental role regarding child feeding from participating in the project, and PSE also improved significantly from baseline to follow-up. In interviews, parents described how the advice shared in PICNIC had made

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a difference in their family meal situations. This, together with the evidence-based content and inclusive facilitation, encouraged parents to want to share the information with others. The focus on responsive feeding was considered applicable for "everyone." Interviewed parents also identified the need and opportunities to improve reach to specific, underserved groups of parents and ways to optimize PICNIC program delivery. The intervention filled a gap complementing the support received from CHS and providing a sense of community and opportunity to share and recognize oneself in others.

Comparison With Prior Work

This mixed methods pilot study indicated that the PICNIC program format is feasible and scalable, with adaptations needed for it to be acceptable and appropriate for fathers and culturally diverse groups. Consistent with qualitative analysis of the culturally adapted Healthy Beginnings program, feasibility and acceptability for culturally diverse groups depend on the availability of in-language resources and access to bicultural health professionals or support workers [38]. Language barriers between parents and health professionals can pose communication challenges [39], and Swedish CHS nurses have described a need for more cultural competence training and knowledge [40]. In the digital space, learnings from cultural adaptations of the MINISTOP mobile app in Sweden also showed that translation alone is not sufficient; literacy needs must also be addressed, for instance by providing video or audio formats [41].

Although this pilot study was not powered to assess intervention effectiveness, we observed a statistically significant improvement in PSE from baseline to follow-up. Both the baseline PSE level (mean 7.7, SD 1.5, among 42 complete cases) and the observed increase (0.48 points on a 0 - 10 scale) were comparable to findings from the Swedish MINISTOP 2.0 trial, which used the same PSE item [32]. These findings suggest that the PSE item showed sufficient variability in our target population, with no indication of a ceiling effect, and was sensitive to change. This warrants further investigation in a well-powered interventional randomized controlled trial using validated PSE instrument(s).

The principles of responsive feeding form the basis of the PICNIC program and were considered feasible, acceptable, appropriate, and impactful in this pilot study. Participants expressed that responsive feeding is powerful and applicable across child ages and stages and across diverse cultural and gender contexts [6,42]. Although fathers' feeding practices have been reported as modifiable when their partner participates in a child feeding intervention [43], direct involvement is likely to enhance engagement and peer sharing with other fathers. However, different approaches were considered necessary to reach fathers and other underserved groups, and examples of responsive feeding practices may need adaptation to pique interest and identification with the concepts [42]. For example, fathers may have a need for more organizational and practical support [44] or may engage more if they understand how influential their feeding practices are on their child's health outcomes [45]. Individual peer-to-peer support from a "father mentor" trained in the PICNIC model could also be explored as an approach to specifically engage and support fathers. Similarly, concepts such as food security may resonate with parents from different cultural contexts [6].

The PICNIC program requires a highly developed and specific facilitation skill set, including expertise in both responsive feeding and the ability to apply the principles to meet the needs of a wide range of prospective participants. It was clear in this pilot study that this needs to be balanced with an empathic and approachable facilitation style. This finding is consistent with previous research, with a systematic review highlighting the importance of practitioners being nonjudgmental [46].

This pilot study showed that parents engage with PICNIC to meet their own needs in feeding children and that their altruistic intentions to support and educate other parents evolve as their own confidence grows and they want to share their learnings and experiences. This phenomenon mirrors the qualitative findings from PICNIC implementation in Australia, with delineation between peer educators' and education recipients' roles considered unrealistic because a high proportion of peer education recipients subsequently became peer educators. As a result, the "educator" role was therefore reframed toward a "champion" model, in which all parents exposed to the PICNIC intervention became "PICNIC parents" [26]. The impact of peer-to-peer support on recipients' child feeding, along with the concept of a dual parent-peer role and the value of peer education versus peer support, requires further exploration in a larger trial.

To be sustainable and impactful, the PICNIC peer education model needs clear boundaries and referral pathways. The initial workshop provides an opportunity to discuss scenarios where PICNIC content is adequate and what to do if parents inquire about topics that are out of scope for parent-to-parent peer support, for example, sensory and complex child feeding issues. For enduring feasibility, PICNIC needs to optimize reach without overstretching resources, be clear about scope, and ensure facilitators are well trained with a combination of expertise and empathy, and that social media content and the website or other online information platforms are maintained.

The acceptability and appropriateness of the PICNIC pilot program were evidenced by high interest and uptake, high engagement, and enthusiastic quantitative and qualitative feedback. The format of involving an educational workshop to "meet and greet" and be "on the same page," followed by ongoing incremental "drip feeding" of content, served a dual purpose. This format is also consistent with the educational concept of balancing reinforcement and extension of learning, without information overload or message fatigue [47]. In parallel, familiarity and trust were built between participants and with the facilitator, which served to create the "safe space" for sharing. Meanwhile, participants in the present study identified pros and cons with in-person versus online and suggested recorded or self-directed learning in addition to interactive live sessions. Thus, alternative modes of delivery should be explored when PICNIC is further adapted for the Swedish context to optimize reach to a diverse group of parents while using resources effectively.

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It was notable that participants felt more comfortable sharing in person or with close peers, whereas sharing through liking or on-sharing social media posts was less common. This reluctance among some parents to like and share content may reflect their insecurity about feeling vulnerable in their parenting role in a wider, less familiar forum or a limited awareness that liking and sharing could be a way to on-share the information that resonated with them. Previous research has shown that "nonclickers" on social media can still be active content viewers and that personality and perceived attitudes toward clicking and on-sharing can influence decisions to do so [48]. Finding a balance between broader peer sharing while maintaining the sense of a "safe space" is a challenge for the PICNIC program as it expands to more parent groups [49].

Anticipatory guidance is a strategy used effectively in the original Australian PICNIC program to match content to the learning needs of participants. As children's eating behaviors evolve rapidly with their stage of development, anticipating what they will likely experience in the next stage is both a science and an art [50]. The age of the children was described as a key factor for how well the parents related to the content in PICNIC, with early intervention around the time of introducing solids considered ideal. Relatable content that they could recognize themselves in was most valued, and some parents therefore suggested making the intervention more age specific. This suggestion was counterbalanced by feedback highlighting the value of input from parents who had more than one child or had already experienced situations relevant to a child transitioning through that particular stage. To increase the acceptability and appropriateness of content across child ages and stages, while remaining logistically feasible, PICNIC programming needs to consider and incorporate these concepts and expectations into planning, implementation, and continuous evaluation.

Strengths and Limitations

The strengths of this study included the mixed methods approach in which qualitative data corroborated and contextualized the quantitative results. Maximum variation sampling was used for the interviews to capture a broad range of participant perspectives and experiences, where 15 interviews were considered sufficient for ensuring data richness and saturation. The trustworthiness of the study was also strengthened by investigator triangulation, in which 2 investigators at different professional levels independently coded the qualitative data. The other coauthors then discussed and provided feedback on the results in an iterative process, revisiting the original data when needed. As this was a pilot study, baseline recruitment continued until at least 40 participants had enrolled and were scheduled for 1 of the 10 PICNIC workshops offered. This was considered adequate and feasible for the nature of the study, but not large enough to measure objective outcomes. Nevertheless, despite the small sample size, we observed a statistically significant improvement in PSE from baseline to follow-up. We did not quantitatively measure intervention effectiveness, such as parents' child feeding practices or children's eating behaviors; this should be investigated further in a well-powered randomized controlled trial.

Furthermore, most parents who participated in this study were female and highly educated. This pattern is commonly seen in this field of research and is a limitation that may influence the transferability of findings to other parent groups. However, it also indicates which parents are most likely to engage voluntarily in PICNIC, suggesting that others may require more active outreach. At the same time, it was surprising that as many as 43% (20/47) of our study participants had not been invited to a parent support group at their child health center. Such groups should be offered as universal CHS support [16], but national statistics from 2023 to 2025 show that only 20% to 30% of children have parents attending [51]. This indicates that further efforts are needed to expand group health care in Sweden and address barriers to parent participation. Previous qualitative research shows that mothers often feel isolated during the first year of parenthood and express a need to share their experiences and to feel supported, reassured, and understood [44]. Parents who cannot attend physical CHS group meetings may therefore benefit from PICNIC's online peer support. Meanwhile, Swedish CHS follows the principle of proportionate universalism, aiming to provide equitable care by offering targeted support to families with greater needs. This should guide prioritization of target groups, especially if resources are limited.

Conclusions

This pilot study indicated that Swedish parents of young children found the PICNIC peer education model feasible, acceptable, and appropriate for supporting parents in responsive child feeding. Engaging with the intervention resulted in parents feeling more confident in their parental role and in the child feeding process. Recognizing their own experiences in other parents' questions within a nonjudgmental "safe space" felt reassuring. The parents highly valued the direct access to expert advice and opportunities to interact with other parents, while also seeing value in recorded content. A large-scale effectiveness-implementation trial will evaluate whether "PICNIC Sweden" can improve feeding practices and children's eating behaviors. The planned study will also determine how the program can be realistically scaled within available resources, CHS settings, and conditions.

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manuscript, Microsoft Copilot was used to improve clarity and grammar. All content was reviewed and edited by the authors, who take full responsibility for the final version.

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Data Availability

The interview transcripts generated and analyzed in this study are not openly available to maintain participant confidentiality. However, supporting information such as analysis documentation is available from the corresponding author upon reasonable request.

Authors' Contributions

MHE, KD, RB, and SA conceptualized the pilot study, and MHE acquired the funding; MHE and AJ collected the data and delivered the intervention together with SA; AJ and MH coded the qualitative data, followed by thematic analysis supervised by MHE; MHE, EBV, and AJ summarized the quantitative data; data were merged by KD and MHE, who led the manuscript writing with contributions from AJ. All authors critically reviewed the manuscript and approved the final version. While MHE is principal investigator for "PICNIC Sweden," RB is principal investigator, and KD is co-investigator of the original PICNIC program running in Australia, on which the intervention in this study is based.

Conflicts of Interest

None of the authors have a conflict of interest. Coauthor SA, a registered dietitian, who previously worked clinically, is currently self-employed as a writer and educator on the topic of nutrition.

Multimedia Appendix 1
Interview guide.
[PDF File, 109 KB - pediatrics_v9i1e93565_app1.pdf]

Checklist 1
COREQ and GRAMMS checklists.
[PDF File, 183 KB - pediatrics_v9i1e93565_app2.pdf]

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Abbreviations

CHS: child health services
COREQ: Consolidated Criteria for Reporting Qualitative Research
GRAMMS: Good Reporting of a Mixed Methods Study
PICNIC: Parents in Child Nutrition Informing Community
PSE: parental self-efficacy
PSEPAD: Parental Self-Efficacy for Promoting Healthy Physical Activity and Dietary Behaviors in Children

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Generative AI Engagement and Perceived Nutrition-Oriented Feeding Practices Among Urban Indonesian Mothers: Mixed Methods Study

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Abstract

Background: The Asia-Pacific region faces an escalating double burden of malnutrition, with childhood obesity now affecting more than 113 million children aged 0 - 19 years. A demographic of highly educated, digitally literate urban mothers—referred to in this study using the descriptive label “Alpha Mother”—increasingly draws on generative AI as a source of toddler nutrition information. Yet, whether this shift empowers or undermines quality feeding practices remains empirically untested.

Objective: This study examined how generative artificial intelligence (AI) engagement is associated with perceived nutrition-oriented feeding practices among urban Alpha Mothers in Indonesia, with cognitive empowerment and parental self-compassion as intervening variables, and eHealth self-efficacy as a moderator. The study contextually refined 5 AI engagement dimensions, organized through an AI parenting nutrition alignment approach.

Methods: An exploratory sequential mixed methods design was used. Phase 1 comprised semistructured interviews with 10 Alpha Mothers and used hybrid deductive-inductive thematic analysis to contextually refine 5 literature-informed AI engagement constructs: AI algorithmic trust, AI health information quality, AI personalization fit perception, AI information-seeking intensity, and AI social proof sensitivity. These informed a survey instrument developed through the qualitative phase and refined against previously validated scales in phase 2, recruiting 442 respondents across 4 Indonesian urban centers. A 14-hypothesis structural model was tested using PLS-SEM (partial least squares–structural equation modeling)

Results: Twelve of 14 hypotheses were supported. The model demonstrated substantial explanatory power for cognitive empowerment (R^2=0.661) and parental self-compassion (R^2=0.719), while perceived nutrition-oriented feeding practices yielded a more modest value (R^2=0.280). This result reflects the multifactorial nature of self-reported nutrition-oriented feeding practices, which is shaped by numerous personal, cultural, and situational factors beyond AI engagement. AI algorithmic trust showed the strongest association with parental self-compassion (β=.479; P<.001), while AI personalization fit perception most strongly predicted cognitive empowerment (β=.275; P<.001). Both intervening variables were significantly associated with nutrition-oriented feeding practices, with cognitive empowerment (β=.232; P=.003) outperforming parental self-compassion (β=.165; P=.009). eHealth self-efficacy moderated the cognitive empowerment pathway (β=.124; P=.02) but not the self-compassion pathway.

Conclusions: The findings suggest that generative AI engagement is associated with perceived nutrition-oriented feeding practices via 2 distinct indirect associations examined in this study: cognitive empowerment and parental self-compassion. These associations were strongest when mothers trusted the AI system and perceived its recommendations as fitting their child and household realities, indicating that the perceived value of AI in toddler feeding may lie less in algorithmic sophistication than in its capacity to build trust, fit context, and support maternal judgment. Because the outcome reflects maternal perception rather than observed feeding behavior or child nutrition outcomes, these findings should be interpreted as associational. They may nonetheless inform future research on AI-assisted feeding support that complements, rather than replaces, professional nutrition counseling.

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KEYWORDS

generative artificial intelligence; mothers; feeding behavior; parenting; parental self-compassion; cognitive empowerment; self-efficacy; health literacy; Indonesia

Introduction

Southeast Asia continues to face a double burden of malnutrition, with persistent undernutrition coexisting alongside rapidly increasing childhood overweight and obesity [1]. In East Asia and the Pacific, more than 113 million children aged 0 - 19 years are overweight or obese, with Indonesia among the countries substantially affected [2,3]. Early dietary patterns established during the toddler period play an important role in shaping lifelong eating behaviors and health outcomes, making caregiver feeding practices an important target for public health intervention [4]. The quality of these early feeding practices, rather than obesity as a measured outcome, is the focus of this study. Accordingly, the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) identify responsive feeding as a cornerstone of optimal infant and young child nutrition, emphasizing reciprocal caregiver-child interactions that encourage autonomous eating, healthy food preferences, and appropriate responses to hunger and satiety cues [5]. Consistent with this principle, the WHO Guideline for Complementary Feeding of Infants and Young Children aged 6 - 23 months recommends responsive feeding alongside continued breastfeeding, age-appropriate complementary feeding, dietary diversity, and limiting unhealthy foods and beverages [6]. These recommendations provide an important benchmark for evaluating how emerging digital technologies may support or potentially undermine maternal feeding decisions.

Despite these recommendations, maintaining responsive feeding has become increasingly challenging for many Indonesian mothers who simultaneously balance employment, caregiving responsibilities, and growing exposure to digital nutrition information and commercial food marketing [7-10]. Social media further amplifies conflicting dietary advice, increasing cognitive demands and making it more difficult to distinguish evidence-based recommendations from misinformation [11,12]. Contemporary motherhood literature describes an emerging demographic of highly educated urban mothers who combine professional identities with intensive parenting practices centered on optimizing children's development [13,14]. To characterize this population, this study adopts the descriptive label "Alpha Mother," a term previously used in motherhood literature to describe technologically engaged mothers who actively seek expert guidance for child-rearing decisions [15]. Related scholarship further suggests that online parenting environments reinforce intensive mothering ideals through social comparison and curated self-presentation [16,17]. In this study, the term refers specifically to urban Indonesian mothers with tertiary education, relative economic stability, and active use of generative artificial intelligence (AI) for toddler nutrition information. It is used solely as an analytical descriptor of the study population rather than as a normative ideal of motherhood.

As digital health technologies become increasingly integrated into parenting, Alpha Mothers are also adopting generative AI platforms as convenient sources of personalized nutrition information [18-24]. Unlike conventional search engines, conversational AI can provide interactive, context-sensitive responses that may help mothers navigate complex feeding decisions while managing substantial cognitive demands. However, these potential benefits remain accompanied by important limitations. AI-generated health information is highly dependent on user prompting and remains susceptible to hallucinations, inaccurate recommendations, and embedded biases [25-27]. Furthermore, although AI may complement evidence-based resources such as the WHO and UNICEF Community Infant and Young Child Feeding (C-IYCF) Counselling Package, its role in supporting maternal decision-making has not yet been sufficiently established.

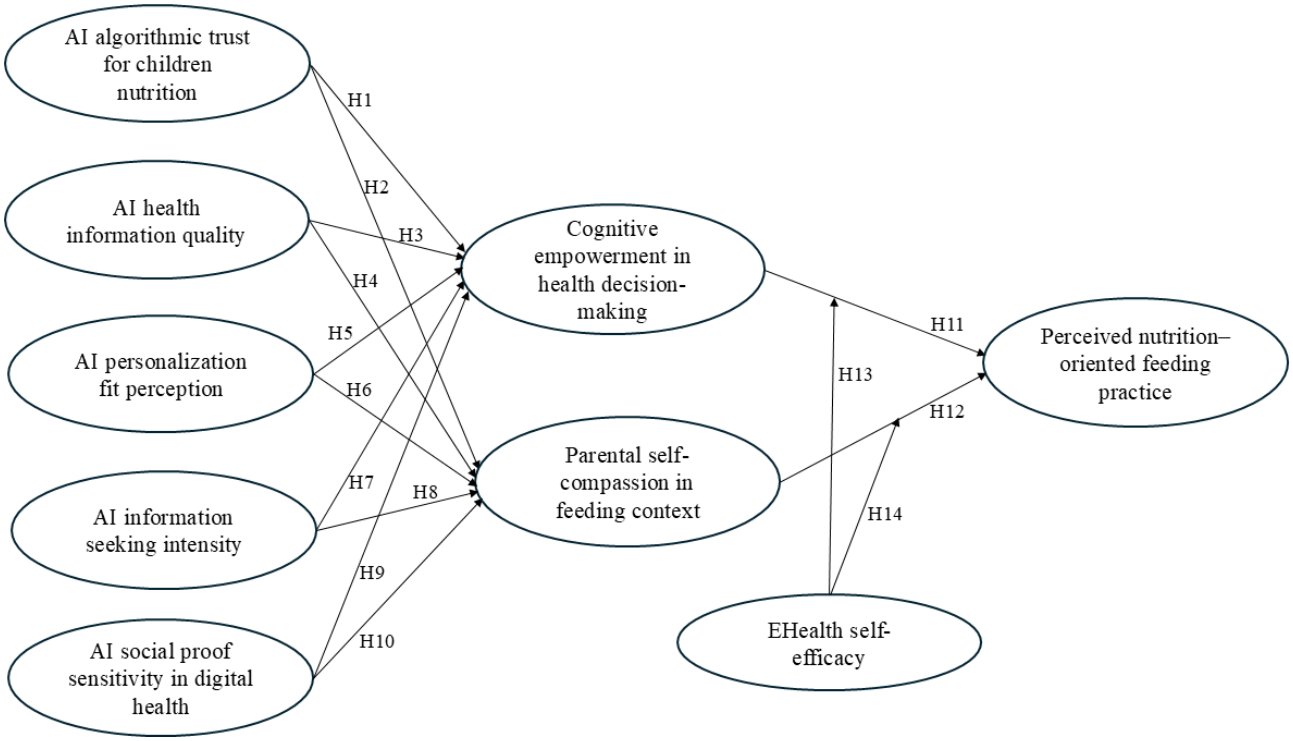
Beyond information quality, the conversational nature of generative AI introduces additional psychological considerations. Human-like responses may encourage users to attribute credibility, empathy, and emotional understanding to AI systems despite their lack of genuine interpersonal awareness—a phenomenon referred to as pseudoempathy [28,29]. Such interactions may foster algorithmic authority, whereby users increasingly defer health-related decisions to algorithmic recommendations rather than their own judgment or professional advice [30-34]. While traditional maternal feeding research has largely relied on knowledge-attitude-practice frameworks [35], these models do not fully capture AI-mediated parenting decisions in which trust, cognitive burden, and perceived personalization influence how caregivers interpret health information [27,36-39]. Consequently, understanding maternal engagement with generative AI requires conceptual approaches that extend beyond conventional behavioral models.

Although digital motherhood, AI-assisted health communication, and parenting technologies have received increasing scholarly attention, little empirical research has examined how maternal engagement with generative AI relates specifically to perceived nutrition-oriented feeding practices within real-world parenting contexts. To address this gap, this study proposes the AI Parenting Nutrition Alignment Approach, a conceptual framework informed by prior literature and contextually refined through the qualitative phase of this mixed methods study. Drawing on Sánchez-Vera's [40] 3 dimensions of algorithmic agency—structural, operational, and symbolic—the approach describes how AI-generated nutrition advice aligns with mothers' child characteristics, cultural context, household circumstances, and parenting values. Rather than introducing entirely new behavioral theories, this framework organizes the 5 AI engagement dimensions refined through a hybrid deductive-inductive thematic analysis conducted during phase 1 into a coherent structure for subsequent quantitative evaluation. The study's primary contribution therefore lies not in proposing new theoretical constructs but in operationalizing these dimensions and demonstrating their convergence with established constructs within this specific parenting context.

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Building upon the AI Parenting Nutrition Alignment Approach, this exploratory sequential mixed methods study investigates how generative AI engagement is associated with perceived nutrition-oriented feeding practices among urban Indonesian Alpha Mothers. Specifically, the study examines whether these relationships are indirectly associated via the complementary constructs of cognitive empowerment and parental self-compassion, while evaluating eHealth self-efficacy as a potential moderator. Guided by these objectives, 2 research questions were formulated. Research question 1: To what extent is generative AI engagement associated with the 2 intervening constructs—cognitive empowerment and parental self-compassion—and, in turn, with perceived nutrition-oriented feeding practices? Research question 2: Does eHealth self-efficacy serve as a boundary condition in the indirect associations involving these constructs to perceived nutrition-oriented feeding practices? To address these questions, 14 hypotheses were developed. The 5 AI engagement dimensions refined through the qualitative phase—AI algorithmic trust, AI health information quality, AI personalization fit perception, AI information-seeking intensity, and AI social proof sensitivity—were hypothesized to be positively associated with cognitive empowerment and parental self-compassion (hypothesis [H]1 to H10). Both intervening constructs were further hypothesized to be associated with perceived nutrition-oriented feeding practices (H11 to H12), while eHealth self-efficacy was hypothesized to moderate both construct–outcome relationships (H13 to H14). The resulting conceptual framework is presented in Figure 1.

Figure 1. Conceptual framework. AI: artificial intelligence.



Methods

Study Design

This study used a mixed methods exploratory sequential design [41]. The initial qualitative phase explored Alpha Mothers' interactions with AI to understand maternal emotional dynamics and to refine and contextualize key constructs. These findings directly informed the subsequent quantitative phase by guiding item development, refining definitions, and contextualizing scale wording to reflect actual feeding experiences. Finally, the second phase empirically tested the derived structural model and research hypotheses within a larger population sample. The resulting conceptual framework, which maps the 14 proposed hypotheses and structural pathways, is illustrated in Figure 1.

Mixed Methods Integration: From Qualitative Themes to Quantitative Constructs

Consistent with the exploratory sequential design, the 2 phases were connected at an explicit point of interface: the 5 literature-informed domains were contextually refined in phase 1, and the resulting subthemes and indicators informed the constructs measured in phase 2. Each of the 5 AI engagement dimensions—algorithmic trust, health information quality, personalization fit perception, information-seeking intensity, and social proof sensitivity—was operationalized into a measurable construct with a corresponding conceptual definition and a dedicated set of survey items.

The quantitative instrument was developed in several stages. Items were developed from the context-specific subthemes and indicators identified in phase 1 and refined with reference to previously validated instruments measuring related constructs. Before data collection, all items underwent face validity review by 2 subject-matter experts to assess clarity and relevance. The

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instrument was then pilot-tested with 30 respondents meeting the study eligibility criteria to evaluate item readability and preliminary internal consistency (Cronbach α). Based on the pilot results, several items were reworded for clarity and 1 item was removed before finalizing the instrument. These 30 pilot respondents were not included in the main analytic sample (N=442). All measurement items used a 5-point Likert response format.

Recruitment and Participant Demographics

The target population, referred to using the descriptive label "Alpha Mothers" as defined in the Introduction section, comprised urban mothers actively engaging with generative AI for child-related information. Eligibility was determined through a 2-stage process: a brief prescreening confirmed current parenting of a child aged 6 - 59 months and prior AI use, while remaining criteria (duration and frequency of AI use, urban residence, and exclusion of health care professionals) were verified through the main survey and manual confirmation by the first author during recruitment. The complete screening and verification items are presented in Multimedia Appendix 1. The geographic scope covered Greater Jakarta, Bandung, Surabaya, and Medan.

For the qualitative phase, recruitment was conducted using purposive and snowball sampling techniques across diverse urban domiciles. The targeted sample size was established at 10-20 key informants, with interviews continuing until theoretical data saturation was achieved and no new themes emerged. In the quantitative phase, participants were recruited via a nonprobability purposive sampling approach.

Outreach efforts strategically used digital parenting communities, pediatric clinic networks, and school communities, channels deliberately selected for their alignment with the digitally literate profile of the target population with implications of this approach for sample composition discussed in the Limitations section. Sample size was determined a priori using G*Power (version 3.1.9.7; Heinrich Heine University Düsseldorf) [42]. Following a recommendation by Hair et al [43], the minimum sample size for PLS-SEM (partial least squares–structural equation modeling) was estimated based on the maximum number of predictors converging on a single endogenous construct in the structural model. The most complex regression equation in the model corresponded to the cognitive empowerment and parental self-compassion constructs, each receiving 5 direct paths from exogenous variables (AI Algorithmic Trust, AI Health Information Quality, AI Personalization Fit, AI Information-Seeking Intensity, and AI Social Proof Sensitivity). With f^2=0.15 (medium effect size), α=.05, and statistical power=0.90, the minimum required sample size was 116 respondents. To ensure proportional geographic representation across the designated urban centers, stratified purposive sampling with regional quotas was applied.

Inclusion criteria stipulated that participants must (1) be mothers residing in the designated urban areas; (2) have at least 1 child aged 6-59 months; (3) actively use generative AI platforms (eg, ChatGPT, Gemini, Grok, etc) for at least 6 months, with a minimum frequency of 3 times per week, to seek childcare and nutritional information; and (4) provide voluntary informed consent to participate in the study. Mothers employed as health care professionals (eg, physicians, nurses, or nutritionists) were excluded from the study. This was a deliberate purposive sampling decision rather than a convenience-based one. Because the study examines how nonexpert mothers perceive, trust, and appraise AI-generated nutrition information, the inclusion of clinically trained mothers would have introduced a systematic confound: such participants evaluate health information through specialized professional knowledge and established clinical standards that differ fundamentally from the lay appraisal processes this study sought to capture [44,45]. Excluding them preserved the conceptual homogeneity of the target population and ensured that the measured constructs reflected lay maternal perception rather than professional clinical judgment. This exclusion was verified manually by the first author (LNA) during recruitment through direct confirmation of occupational status with each potential participant, in addition to the occupation question captured in the main survey. The complete eligibility screening and verification procedure is presented in Multimedia Appendix 1.

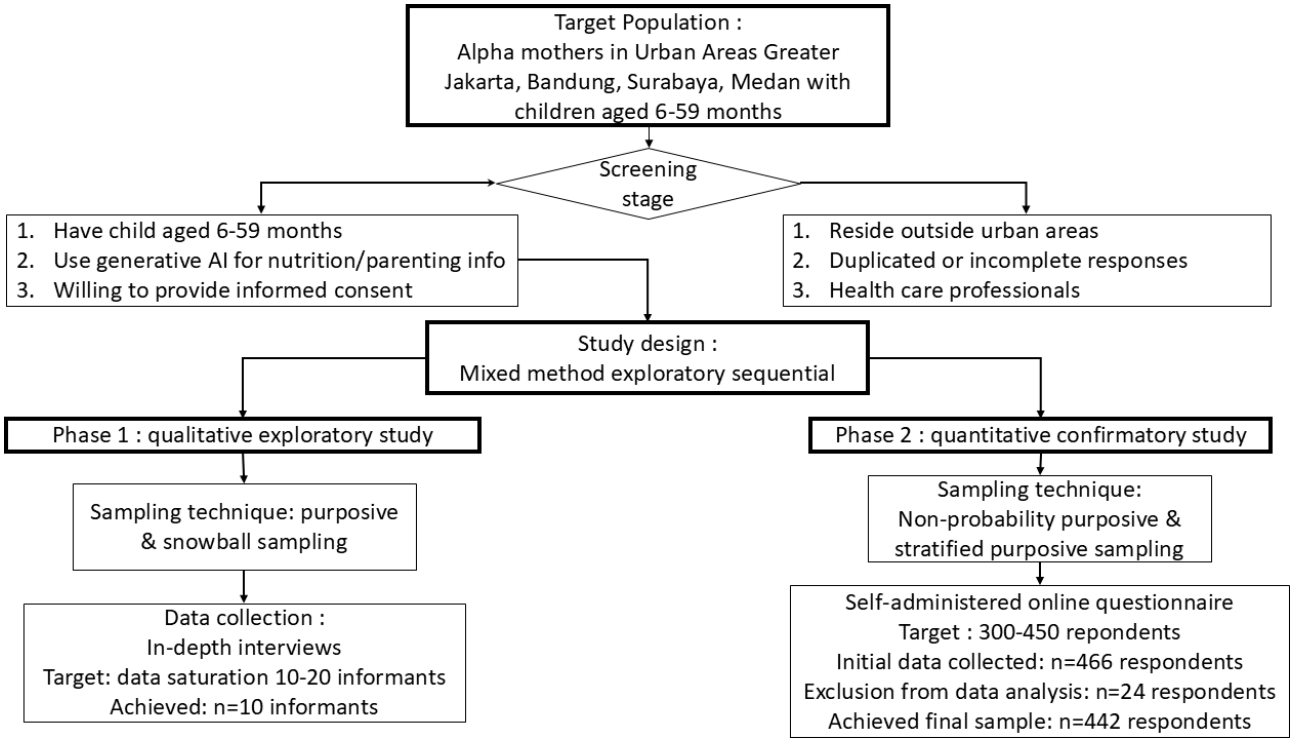
Data Collection Procedures

Data collection was conducted sequentially across 2 distinct phases. During the qualitative phase, the first author (LNA) conducted all semistructured in-depth interviews face-to-face over a 3-week period in December 2025. All study materials were administered in Bahasa Indonesia. Interview quotations were translated into English using AI-based tools and verified for meaning equivalence by 2 bilingual team members (FA and SA) against the original transcripts. AI tools were used only for translation and language editing; all coding and thematic analyses were conducted manually. As the quantitative instrument was administered in Bahasa Indonesia, the English wording of the measurement items is for reporting only and did not affect measurement validity. A semistructured guide comprising 16 open-ended questions across 5 core domains (AI trust formation, information quality evaluation, personalization expectations, information-seeking behaviors, and social validation) directed each session, with flexible probing questions to elicit deeper reflection. With participant consent, all sessions were audio-recorded and transcribed verbatim, each lasting 30-45 minutes. To enhance credibility, synthesized member checking following the approach by Birt et al [46] was conducted, returning summarized thematic findings to participants for confirmation.

The quantitative phase data were collected using a self-administered online questionnaire. This survey commenced with a brief screening section to verify that respondents met the designated "Alpha Mother" criteria. Several procedural remedies were implemented to mitigate common method bias (CMB), including randomization of item order within construct blocks, use of psychological separation between predictor and criterion measures, and ensuring respondent anonymity to reduce social desirability concerns [47,48]. Finally, rigorous data-cleaning protocols, including IP address tracking to identify and remove duplicate entries, were implemented prior to statistical analysis. An overview of the data collection process can be seen in Figure 2.

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Figure 2. Sampling framework flowchart. AI: artificial intelligence.



Statistical Analysis

Qualitative data from the phase 1 interviews were analyzed using Braun and Clarke's [49] 6-phase thematic analysis framework [50]. Because the interview guide was informed by 5 predefined conceptual domains from prior literature, the analysis followed a hybrid deductive-inductive approach. The predefined domains provided an initial structure for organizing the data, while open coding was used to identify context-specific meanings, indicators, and subthemes within and across those domains. Initial coding was conducted manually by the third author (SA), generating 29 initial codes that were collaboratively grouped into 13 subthemes and consolidated into 5 overarching themes. The coding framework and thematic structure were subsequently reviewed and refined through consensus discussion with LNA and FA to ensure conceptual coherence and that the themes remained grounded in participants' accounts. A complete audit trail linking the predefined domains, interview questions, initial codes, subthemes, final themes, construct definitions, and survey items is provided in Multimedia Appendix 2. Data saturation was assessed iteratively rather than assumed. After each interview, the research team evaluated whether new codes, themes, or subthemes were emerging. No substantive new themes or subthemes were identified across the final 3 consecutive interviews (interviews 8 - 10), indicating that thematic saturation had been reached by the 10th interview. This sample size is consistent with empirical guidance indicating that thematic saturation is typically achieved within 9-17 interviews in studies involving relatively homogeneous populations and narrowly defined research objectives [51], conditions that characterize this study's focus on urban Alpha Mothers.

The first author (LNA), who conducted all interviews, is a mother with personal experience using AI for parenting decisions. This shared identity not only facilitated rapport and nuanced understanding of participants' experiences but also introduced potential for overidentification. To mitigate this risk, initial coding was conducted by the third author (SA), who was not involved in conducting the interviews. The coding framework, subthemes, and final themes were subsequently reviewed and refined through consensus discussions with LNA and FA, helping ensure that interpretations remained grounded in participants' accounts.

Quantitative data from phase 2 were analyzed using PLS-SEM via SmartPLS 4 software (SmartPLS GmbH), following the evaluation guidelines by Hair et al [43]. The evaluation was conducted in 2 primary stages: the measurement model (outer model) and the structural model (inner model). For the measurement model, indicator reliability was assessed using outer loadings. Construct reliability was established using both Cronbach α and composite reliability (CR), while convergent validity was evaluated through the average variance extracted. Discriminant validity was assessed using the Heterotrait-Monotrait (HTMT) ratio of correlations, with thresholds and interpretation criteria following the guidelines of Hair et al [43,52].

Following a satisfactory measurement model, the structural model was evaluated. The overall quality and predictive relevance of the inner model were assessed by examining the inner variance inflation factor (VIF) for collinearity issues, the coefficient of determination (R^2), $Q^2_{predict}$ values, and Cross-Validated Predictive Ability Test (CVPAT) [53,54]. Subsequently, a bootstrapping procedure was applied to test the significance of the 14 proposed research hypotheses, including the moderation effects. Following the a priori structural model, the 5 AI engagement constructs were linked to perceived nutrition-oriented feeding practices only via cognitive

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empowerment and parental self-compassion; direct AI engagement-to-outcome paths were not estimated. Consequently, the present analysis does not distinguish direct from indirect associations, and results are interpreted solely as indirect associations rather than as evidence of mediation. Indirect effects were tested using bias-corrected bootstrap confidence intervals, and an effect was considered supported when its 95% CI excluded zero. Finally, an Importance-Performance Map Analysis (IPMA) was conducted to generate actionable insights regarding priority areas for digital health interventions. To assess whether the modeled relationships were consistent across child developmental stages, a bootstrap-based multigroup analysis (MGA) was additionally conducted, comparing mothers of children aged 6 - 24 months with those of children aged 25 - 59 months (Multimedia Appendix 3) [43,55].

Ethical Considerations

All research procedures were conducted in accordance with strict ethical principles for medical and social research. The study protocol was reviewed and approved by the Research Ethics Committee (KEP FEB), Faculty of Economics and Business, Universitas Pelita Harapan, under approval number 047/MARS/EC/XI/2025, issued on November 26, 2025. All recruitment and data collection commenced after this approval was granted. Prior to participation, all individuals were provided with a comprehensive participant information sheet detailing the study's objectives, guarantees of data anonymity and confidentiality, and their right to withdraw at any time without penalty. Explicit informed consent obtained either in writing for the interviews or electronically for the survey was mandatory before any data collection occurred.

Results

Phase 1: Qualitative Exploratory Study

Participant Characteristics

In the first phase of this qualitative study, 10 informants were selected through in-depth interviews until data saturation was reached. All informants were Alpha Mothers with children aged 6 - 59 months, residing in Indonesia's urban centers, including Greater Jakarta, Bandung, Surabaya, and Medan, and frequently using AI as their health care assistant. The informants' characteristics indicated a middle-to-upper socioeconomic profile with a high level of education.

All 10 participants subsequently engaged in the synthesized member-checking process and confirmed that the thematic interpretations accurately reflected their experiences as urban Indonesian mothers navigating AI-assisted child nutrition decisions. No substantive disagreements emerged, and the thematic structure was carried forward to operationalization for the phase 2 quantitative instrument. The participants' employment dynamics were quite diverse, consisting of housewives (n=3), full-time workers (n=3), freelancers (n=2), and professionals (n=2). Most informants had 2 children (n=5), while the remainder had 1 child (n=5), providing a broad perspective from both new and more experienced mothers. Regarding digital literacy, all informants had extensive experience using generative AI (all had more than 6 months of AI use). ChatGPT was the primary platform universally used by all informants, with some participants using additional platforms such as Gemini (n=4), Claude (n=1), and Grok (n=1) to validate children's nutritional information.

Thematic Findings

Hybrid deductive-inductive thematic analysis organized the findings across 5 predefined domains and identified 13 context-specific subthemes (Table 1). These themes explore how Alpha Mothers evaluate, validate, and integrate AI-generated information into their toddler-feeding routines, directly establishing the foundation for the quantitative structural model in phase 2. The first major theme, AI Algorithmic Trust, highlights that maternal trust in AI does not emerge automatically; rather, it is contingent upon perceived technical competence (T1) and moral integrity (T2). Mothers position AI not merely as a search engine but as a stable "thinking partner" expected to provide objective advice free from commercial bias. As one mother emphasized, "I need honest advice...solely focused on my child's health, no commercial bias" (I1). Furthermore, mothers expect the algorithm to align with their core parenting values (T3), seeking an AI that "has the same values and goals" (I8) while maintaining a "strong scientific basis" (I3).

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Table . Thematic exploratory.

Theme	Respondent quotes	Conceptual interpretation
AI[a] Algorithmic Trust		
T1: Competency and Reliability	"I need a thinking partner who is stable, unchanging, and this AI is competent...has a strong scientific basis." [I3]	The perception that AI is a competent and stable expert provides a sense of security, such as technical trust for users.
T2: Moral Integrity and Objectivity	"I need honest advice...solely focused on my child's health, no commercial bias." [I1]	The perception that AI provides honest, genuine advice free from commercial advertising bias.
T3: Value Alignment	"Must have the same values and goals as me...just like chatting with friends on the same wavelength." [I8]	The degree of conformity between AI logic and the parenting principles held by the mother.
AI Health Information Quality		
T4: Accuracy and Completeness	"The data must be accurate...really look for accuracy. It must be complete and thorough...from measurements to allergy risks." [I8]	Information must be proven to be medically accurate and presented in a complete manner.
T5: Relevance	"It's useless if it's not relevant to my child's current condition." [I3]	The accuracy of information in answering specific questions with the user's current conditions.
T6: Understandability	"Don't use complicated language...medical jargons or (seemingly) otherworldly language." [I2]	Use simple language and do not contain complicated medical language.
AI Personalization Fit		
T7: Biological Fit	"I really don't like it when I am given a menu that doesn't suit my little brother's situation... he has allergies...I was even given risky ingredients." [I2]	AI's ability to adapt suggestions to a child's physical limitations for child safety.
T8: Culture and Taste Fit	"Our palate is local...if the food tastes too foreign or too western, children will definitely be turned off." [I2]	Align menu suggestions with local tastes and family eating habits
T9: Practical Fit (Time and Budget)	"It fits the kitchen budget...It fits our time and daily eating habits." [I7]	The level of realism of suggestions regarding the availability of time, energy, and mother's shopping budget.
AI Information-Seeking Intensity		
T10: Search Frequency and Immediate Response	"Going back and forth opening the application, asking again, and again...I have to act quickly, I need an emergency solution right away." [I10]	A behavioral pattern of asking questions repeatedly in a short period of time with the demand for an immediate response.
T11: In-Deep Exploration and Verification Effort	"Keep checking and comparing the answers to be sure. Dig deeper, not just about the menu...but also psychological tricks." [I5]	Efforts to dig deep into the root of the problem while still actively verifying the accuracy of the data.
AI Social Proof Sensitivity		
T12: Mass Acceptance and Herd Safety	"Knowing that this AI is already widely accepted...thousands of other mothers are already using it. I don't want my child to be a guinea pig...there's a sense of security in being in the same group." [I4]	The sense of security that arises from knowing that this technology is already used by the majority of people or mass acceptance.
T13: Validation And Consensus Reliance	"Very necessary for social validation...honest reviews, testimonials...need confirmation from the majority of other users confirming the safety." [I3]	The need for confirmation from a third party in the form of personal testimony or expert opinion before finally being able to trust AI input.

[a]AI: artificial intelligence.

This reliability must be substantiated through rigorous AI Health Information Quality. Mothers demand comprehensive clinical accuracy (T4) and direct relevance to their specific situation (T5), coupled with high understandability (T6). They require thorough data, "from measurements to allergy risks" (I8), while strictly noting that any advice is "useless if it's not relevant to my child's current condition" (I3). Furthermore, to ensure that the information is easily comprehensible, the AI must avoid "medical jargon or (seemingly) otherworldly language" (I2).

Furthermore, objective medical quality must be complemented by AI personalization fit. AI recommendations must be adaptable to the user's specific biological (T7), cultural (T8), and practical realities (T9). Biologically, mothers express strong dissatisfaction when AI fails to account for a child's physical

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limitations, such as suggesting “risky ingredients” for a child with allergies (I2). Culturally, suggestions must align with local palates to avoid children being “turned off” by overly Westernized foods (I2). Finally, on a practical level, these recommendations must strictly conform to the mother’s “kitchen budget,” available time, and established daily eating habits (I7).

Interestingly, despite their high digital literacy, Alpha Mothers exhibit pronounced AI Social Proof Sensitivity. There is a distinct reluctance to adopt algorithmic advice without mass acceptance or third-party validation (T12, T13). The psychological safety of adopting AI relies heavily on herd consensus, driven by the fear of making their child a “guinea pig,” thus requiring “honest reviews, testimonials...need confirmation from the majority of other users confirming the safety” (I3, I4).

Finally, this comprehensive evaluation of trust, quality, and social validation drives AI Information Seeking Intensity (T10, T11). During critical situations, such as sudden toddler-feeding strikes, mothers demand immediate, “emergency solutions” (I10). However, they do not accept these answers passively; instead, they engage in intense, repetitive probing to “dig deeper, not just about the menu...but also psychological tricks,” while continuously cross-checking the data for accuracy (I5).

While participants valued AI as a feeding-support tool, their accounts also surfaced consistent negative and critical experiences. The most consequential concerned safety: several mothers reported that AI recommended ingredients unsuitable for their child’s specific medical condition. One mother described that for her allergic child, the AI “even offered risky ingredients” (I2), and another recounted that it suggested a menu whose ingredients “could actually risk making my child sick” (I10). Beyond safety, mothers expressed frustration when AI acted as if it “knew best” yet remained insensitive to their real situation at home (I1, I8), produced culturally mismatched menus that children refused so that the food “ended up wasted” (I3), or kept slipping in hard-to-find ingredients even after being explicitly prompted to avoid them (I6). These experiences indicate that mothers did not engage with AI uncritically; rather, they actively detected, questioned, and worked around its limitations.

These qualitative findings directly informed the quantitative phase of the study. The contextually refined themes and subthemes regarding mothers’ interactions with AI were systematically operationalized into measurable constructs. Table 2 outlines the conceptual definitions of these constructs, which served as the foundation for the survey instrument and structural model testing in phase 2.

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Table . Construct definition.

Constructs	Conceptualized definition
AI[a] Algorithmic Trust for Children Nutrition	This construct represents the mother's psychological belief in AI technology for child nutrition which, within the AI parenting nutrition alignment approach, emerges from both a rational assessment of the system's technical reliability and an emotional conviction regarding its integrity and its capacity to provide reassurance consistent with her parenting values [56].
AI Health Information Quality	This construct captures the mother's evaluation of AI-generated nutritional information, focusing specifically on how she perceives its accuracy, completeness, and understandability [21,27].
AI Personalization Fit Perception	AI Personalization Fit Perception reflects the mother's evaluation of how effectively the AI tailors its nutritional guidance to her specific reality. This encompasses her child's biological health status, her own psychological preferences, and her immediate environmental or situational context [57].
AI Information-Seeking Intensity	AI Information-Seeking Intensity represents the frequency, duration, and depth of mother's engagement with AI to obtain and verify nutritional information [58,59]. Within this study, a high intensity of use reflects the mother's active alignment efforts to navigate and resolve digital uncertainty.
AI Social Proof Sensitivity	AI Social Proof Sensitivity characterizes a mother's responsiveness to collective validation signals, such as app reviews, ratings, and overall popularity [60,61]. Within the AI parenting nutrition alignment approach, this reflects a herd—safety tendency, illustrating how mothers seek safety in numbers as a form of collective validation before adopting new health technologies.
Cognitive Empowerment in Health Decision-Making	Cognitive Empowerment in Health Decision-Making refers to a mother's psychological and cognitive capacity to understand, evaluate, and use AI-generated information for practical toddler nutrition decisions. This construct is heavily dependent on her language comprehension and critical appraisal skills [36,62].
Parental Self-Compassion in Feeding Context	Adapted from Hasyyati and Abidin [63], this construct captures a mother's ability to approach toddler-feeding challenges with self-compassion, which operationally involves practicing self-kindness, viewing feeding setbacks through the lens of common humanity, and sustaining mindfulness to preserve emotional balance.
eHealth Self-Efficacy	eHealth Self-Efficacy refers to a mother's perceived confidence in her ability to effectively find, evaluate, and resolve toddler-feeding challenges using AI and other digital technologies [22,26].
Perceived Nutrition-Oriented Feeding Practices	Perceived Nutrition-Oriented Feeding Practices reflects a mother's subjective evaluation of the nutrition-focused feeding strategies she implements for her child, distinct from observed feeding behavior or objective child nutrition outcomes. Operationally, this encompasses meal schedule consistency, deliberate nutritional appraisal of foods offered, limitation of low-nutrient foods, and attentiveness to the child's satiety signals. Within the food parenting practices content map, these correspond primarily to the structure domain and, in part, to nutrition education within autonomy support; the construct does not operationalize coercive control practices or child autonomy support in full and therefore does not represent the complete responsive feeding construct as defined by WHO[b] and UNICEF[c] [64-66].

[a]AI: artificial intelligence.

[b]WHO: World Health Organization.

[c]UNICEF: United Nations Children's Fund.

Phase 2: Quantitative Explanatory Predictive Study

The second phase of this study used a quantitative survey to empirically validate the structural model derived from the qualitative findings. Specifically, this phase evaluated perceived nutrition-oriented feeding practices, operationalized as maternal self-report, not observed feeding behavior or objective child nutrition outcomes. The model then tested how nutrition-oriented feeding practices are associated with 5 AI-related predictors via 2 intervening constructs, cognitive empowerment (CE), and parental self-compassion (PSC), with eHealth self-efficacy (ESE) as a moderator.

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Participant Characteristics

A total of 442 respondents completed the survey and met all inclusion criteria, substantially exceeding the minimum sample size of 116 derived from the a priori power analysis. This sample size provided robust statistical power for testing the proposed structural model. Geographic distribution was concentrated in the Greater Jakarta area (255/442, 57.7%). Demographically, the largest segment of mothers was aged 31-35 years (184/442, 41.6%).

Reflecting the “Alpha Mother” profile, over half held a bachelor’s degree (227/442, 51.4%), with a substantial proportion possessing postgraduate degrees (155/442, 35.1%). Socioeconomically, the predominant employment status was full-time office worker (139/442, 31.4%), followed closely by professionals (111/442, 25.1%). Routine monthly household expenditure primarily fell between US $292.18 and US $584.36 (217/442, 49.1%). Regarding family dynamics, nearly half of the participants had 2-3 children (217/442, 49.1%), and the target toddlers were most commonly aged between 37 and 59 months (169/442, 38.2%). ChatGPT emerged as the most frequently used AI platform for health information (259/442, 58.6%), followed by Gemini (125/442, 28.3%). A comprehensive breakdown of these participant demographics and characteristics is presented in Table 3.

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Table . Participant demographics and characteristics (N=442).

Characteristics	Participants
City of residence, n (%)	
Greater Jakarta	255 (57.7)
Surabaya	64 (14.5)
Bandung	63 (14.3)
Medan	60 (13.6)
Mother's age (years), n (%)	
18 - 25	15 (3.4)
26 - 30	148 (33.5)
31 - 35	184 (41.6)
36 - 40	95 (21.5)
Education level, n (%)	
Diploma (D3/D4)	60 (13.6)
Bachelor's degree (S1)	227 (51.4)
Postgraduate degree (S2/S3)	155 (35.1)
Employment status, n (%)	
Full-time worker (office/WFO)	139 (31.4)
Professional	111 (25.1)
Housewife	99 (22.4)
Entrepreneur	53 (12)
Part-time/freelance	40 (9)
Monthly household expenditure, n (%)	
$292.18 to $584.36	217 (49.1)
$584.36 to $1168.73	92 (20,8)
>$1168.73	133 (30.1)
Number of children, n (%)	
1	202 (45.7)
2 - 3	217 (49.1)
>3	23 (5.2)
Target child's age (months), n (%)	
6 - 24	136 (30.8)
25 - 36	137 (31)
37 - 59	169 (38.2)
Most frequently used AI[a] platform, n (%)	
ChatGPT	259 (58.6)
Gemini	125 (28.3)
Claude	25 (5.7)
Grok	14 (3.2)
Copilot	10 (2.3)
Bing	9 (2)

[a]AI: artificial intelligence.

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AI Usage for Child Nutrition

To understand exactly how these mothers relied on AI for toddler feeding, we asked them to identify their most frequent search topics. Respondents could select multiple options, so percentages total more than 100%. The data show that they primarily turned to AI for day-to-day nutritional optimization. More than half of the mothers searched for information on child growth supplements (237/442, 53.6%) and the nutritional value of various foods (235/442, 53.2%). A full breakdown of these search topics is available in Multimedia Appendix 4.

Measurement Model Evaluation

The measurement model was evaluated by examining indicator reliability, construct reliability, convergent validity, and discriminant validity. Indicator reliability was assessed through outer loadings, which ranged from 0.739 to 0.918, indicating that the majority of indicators adequately represent their respective constructs. Construct reliability was examined using Cronbach α and CR (rho_c). Cronbach α values ranged from 0.833 to 0.916, and rho_c values ranged from 0.882 to 0.941, all exceeding the recommended threshold of 0.70, demonstrating acceptable internal consistency. Convergent validity was evaluated through the average variance extracted, which ranged from 0.600 to 0.800, suggesting that more than half of the variance of each indicator was explained by the corresponding construct. These results indicate that the instrument demonstrates sufficient reliability and validity. Detailed values for each construct are presented in Table 4.

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Table . Construct validity and reliability results. Indicator codes NFP1–NFP5 correspond to FPQ1-FPQ5 in the SmartPLS output (Figure 3), which retains the original instrument coding.

Variable and code	Indicator	OL[a]
AI[b] Algorithmic Trust (AT)[c]		
AT1	I feel this AI provides pretty consistent nutritional advice for my child.	0.844
AT2	I believe this AI algorithm has accurate processing capabilities, thus minimizing errors in child nutrition recommendations.	0.875
AT3	I believe this algorithm was designed objectively without bias.	0.802
AT4	I know that the AI I use is not directed towards hidden commercial interests (eg, promotion of a particular brand).	0.764
AT5	I feel that this AI's advice aligns with my needs as a mother in managing my child's nutrition.	0.827
AI Health Information Quality (IQ)[d]		
IQ1	I consider the nutritional information provided by this AI to be accurate according to credible health references.	0.743
IQ2	The answers given by AI regarding children's nutrition are complete and comprehensive.	0.763
IQ3	The menu suggestions provided by AI are appropriate to my child's age and specific needs.	0.845
IQ4	Information from AI is presented in language that is easy for mothers like me to understand.	0.825
IQ5	I think the information from this AI is not contaminated by certain political interests.	0.825
AI Personalization Fit (PF**)** Perception[e]		
PF1	I feel that the food recommendations from AI are appropriate for my child's growth stage.	0.805
PF2	I feel that the food suggestions from AI are quite in line with my child's appetite.	0.802
PF3	I feel that the AI's grocery suggestions are still within my family's spending power.	0.789
PF4	I feel that I can implement the AI's suggestions in the midst of my daily activities.	0.761
PF5	I feel that the AI's suggestions are in line with my child's physical needs.	0.861
AI Information-Seeking Intensity (ISI)[f]		
ISI1	I often use AI applications to get the information I need.	0.836
ISI2	I often use AI to check information from other sources.	0.846
ISI3	I often ask AI if I need ideas for doing something.	0.850
ISI4	I usually ask questions over and over again so that I really understand the information I need.	0.758
AI Social Proof (SP) Sensitivity[g]		
SP1	I felt more confident in AI when I learned that many other mothers were using it too.	0.878

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Variable and code	Indicator	OL[a]
SP2	Knowing that this app is used by so many people makes me even more confident in the accuracy of this AI.	0.918
SP3	I tend to choose AI that is popular among mothers because I believe that "the more users, the less error in the AI."	0.893
SP4	If the majority of mothers share positive stories about an AI, then I will be more likely to believe in this AI.	0.887
Cognitive Empowerment (CE) in Health Decision-Making[h]		
CE1	This AI encouraged me to learn to understand the nutritional terms needed in child nutrition planning.	0.812
CE2	Using AI has made me understand better how to measure children's nutritional content.	0.880
CE3	It became easier for me to conclude the information provided by this AI through the explanations given in a coherent manner.	0.846
CE4	I have become better able to sort out information from AI that is useful for addressing my child's nutritional issues.	0.861
CE5	I was taught by AI to be more independent when making decisions about managing my child's nutrition.	0.808
Parental Self-Compassion (PSC) in Feeding Context[i]		
PSC1	I can stay calm when my child's meal plan doesn't go as expected.	0.808
PSC2	I feel more at ease knowing that toddler food refusal behavior is a common experience among mothers, not a reflection of my own parenting failure.	0.820
PSC3	I don't blame myself when my child refuses to eat the healthy food I have prepared.	0.817
PSC4	I have learned to manage my stress response when my child refuses to eat during mealtimes.	0.750
PSC5	I don't beat myself up too much when my kids' food choices don't always go according to plan.	0.783
eHealth Self-Efficacy (ESE)[j]		
ESE1	I am confident using AI to help me solve my child's eating problems.	0.797
ESE2	I am confident that I can find other reliable sources of information if the AI's advice on children's diet does not suit my child's condition.	0.844
ESE3	I am confident that I can find a variety of menus that suit my child's nutritional needs through appropriate AI prompting (giving instructions or questions).	0.813
ESE4	I am confident that I can ask or give orders to the AI myself without the help of others.	0.842
Perceived Nutrition-Oriented Feeding Practices (NFP)[k]		
NFP1	I can usually recognize the signs of fullness in my child correctly.	0.752

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Variable and code	Indicator	OL[a]
NFP2	Generally, I have consistently implemented a regular schedule for main meals and snacks.	0.790
NFP3	I am able to limit giving my child less nutritious food.	0.753
NFP4	I usually think about what kind of food is healthy enough for my child every day.	0.835
NFP5	I always read the nutritional content on the packaging of food prepared for my child.	0.739

[a]OL: Outer loading.

[b]AI: artificial intelligence.

[c]Mean=3.7873, Cronbach α=0.881, Rho_a=0.884, Rho_c=0.913, and average variance extracted=0.678.

[d]Mean=3.9090, Cronbach α=0.860, Rho_a=0.860, Rho_c=0.899, and average variance extracted =0.642

[e]Mean=3.7805, Cronbach α=0.863, Rho_a=0.868, Rho_c=0.901, and average variance extracted=0.647

[f]Mean=3.9745, Cronbach α=0.841, Rho_a=0.842, Rho_c=0.894, and average variance extracted=0.678

[g]Mean=3.5249, Cronbach α=0.916, Rho_a=0.918, Rho_c=0.941, and average variance extracted=0.800

[h]Mean=3.8181, Cronbach α=0.897, Rho_a=0.898, Rho_c=0.924, and average variance extracted=0.709

[i]Mean=3.8443, Cronbach α=0.855, Rho_a=0.855, Rho_c=0.896, and average variance extracted=0.633

[j]Mean=3.7755, Cronbach α=0.843, Rho_a=0.846, Rho_c=0.894, and average variance extracted=0.679

[k]Mean=4.0443, Cronbach α=0.833, Rho_a=0.835, Rho_c=0.882, and average variance extracted=0.600

Discriminant validity was rigorously evaluated using the HTMT ratio criteria, which can be seen in the Multimedia Appendix 5. The analysis results indicate that all constructs have adequately met the discriminant validity criteria. The research data recorded the highest HTMT ratio of 0.922 in the relationship between the AI Algorithmic Trust (AT) construct and Parental Self-Compassion in Feeding Context (PSC). This study then applied further testing in the form of an HTMT inference test to evaluate the high ratio in this relationship. The test results proved that the upper limit of the 90% confidence interval (bias-corrected) was at 0.955. This result supports the empirical distinctiveness between constructs, as the upper confidence bound falls below the absolute threshold of 1.000, indicating that all constructs in this study meet the discriminant validity criteria.

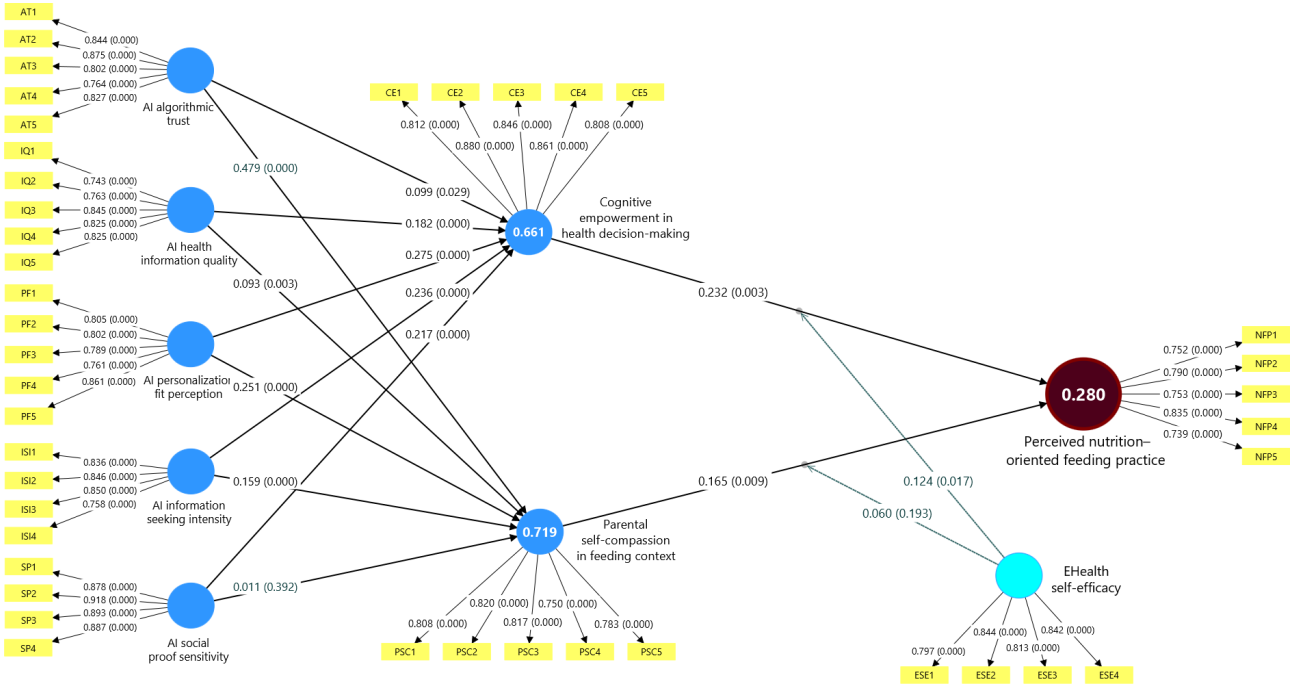
Structural Model and Hypothesis Testing

Before evaluating the structural paths, the model was assessed for multicollinearity and potential CMB. Following the full collinearity assessment approach proposed by Kock [67], the inner VIF was examined for all predictor constructs. As shown in Multimedia Appendix 6, all inner VIF values ranged from 1.376 to 2.785. Since these values fall below the conservative threshold of 3.3, the predictor constructs can be considered empirically independent, and CMB is unlikely to be a serious concern in this dataset

Based on the out-of-sample predictive power evaluation using PLSpredict, all latent variables yielded $Q^2_{predict}$ values greater than zero: Cognitive Empowerment in Health Decision-Making (0.992), Parental Self-Compassion in Feeding Context (0.994), and Perceived Nutrition-Oriented Feeding Practices (0.989)—indicating low descriptive prediction error at the construct level. These values, while notably high, are consistent with the strong construct reliability observed in the measurement model (Cronbach α 0.833 - 0.916, CR 0.882 - 0.941) and the large sample size (N=442), both of which enhance out-of-sample predictive stability [68]. Because $Q^2_{predict}$ is a descriptive metric based on error reduction, predictive validity was further examined through the CVPAT, which compares model performance against 2 benchmarks of increasing stringency: the naive indicator average (IA) and the stricter linear model (LM). Against IA, the model produced significant improvements across all constructs (P<.001). Against LM, only the overall row simultaneously produced a negative average loss difference and a significant P value of .024—a combination that under CVPAT constitutes formal predictive validity at the aggregate model level. Future replications should interpret construct-level predictive advantages with caution. Following this validation, the complete structural model, detailing the path coefficients and variance explained, is illustrated in Figure 3.

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Figure 3. Structural (inner) model estimated with PLS-SEM. Circles represent latent constructs and yellow rectangles their measured indicators. Light blue circles denote the exogenous predictors and the 2 mediators; the cyan circle denotes eHealth self-efficacy, modeled as a moderator (interaction effects shown as dashed teal arrows); and the dark red circle denotes the endogenous target construct. Arrow values are path coefficients with P values within parentheses, and values within the endogenous circles are R^2 values. AI: artificial intelligence; PLS-SEM: partial least squares–structural equation modeling.



The CVPAT was used to evaluate the model's out-of-sample predictive capabilities. As shown in Table 5, the PLS-SEM produced significantly lower prediction errors than the naive IA benchmark across all constructs and the overall model (P<.001). When compared against the more conservative LM benchmark, the overall model demonstrated a significantly negative average loss difference (P=.02), although individual constructs (CE and PSC) did not reach statistical significance against this benchmark. Based on the overall model's significantly lower prediction errors relative to both the IA and LM benchmarks, the model demonstrates adequate predictive validity at the aggregate level.

Table . Cross-Validated Predictive Ability Test.

Variable	PLS-SEM[a] versus IA[b]				PLS-SEM versus LM[c]			
	PLS loss	IA loss	Average loss difference	*P* value	PLS loss	LM loss	Average loss difference	*P* value
CE[d]	0.280	0.515	−0.235	<.001	0.280	0.287	−0.007	.30
PSC[e]	0.273	0.496	−0.223	<.001	0.273	0.276	−0.002	.62
NFP[f]	0.364	0.430	−0.066	<.001	0.364	0.384	−0.020	.05
Overall	0.305	0.480	−0.175	<.001	0.305	0.315	−0.010	.02

[a]PLS-SEM: partial least squares–structural equation modeling.

[b]IA: indicator average.

[c]LM: linear model.

[d]CE: cognitive empowerment in health decision-making.

[e]PSC: parental self-compassion in feeding context.

[f]NFP: perceived nutrition-oriented feeding practices.

Of the 14 hypotheses tested, 12 were supported, while 2 (H10 and H14) were not supported as zero fell within their confidence interval ranges. This indicates insufficient evidence that AI Social Proof Sensitivity is associated with Parental Self-Compassion (H10), or that eHealth Self-Efficacy significantly moderates the relationship between Parental Self-Compassion and Perceived Nutrition-Oriented Feeding Practices (H14). Among the independent variables, AI Algorithmic Trust showed the strongest association with Parental Self-Compassion (β=.479; P<.001), while AI Personalization Fit Perception showed the strongest association with Cognitive Empowerment (β=.275; P<.001). Cognitive Empowerment demonstrated a stronger association with Perceived Nutrition-Oriented Feeding Practices (β=.232; P=.003) than

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did Parental Self-Compassion (β=.165; *P*=.009). For the moderation analysis, eHealth Self-Efficacy significantly strengthened the pathway from Cognitive Empowerment to Perceived Nutrition-Oriented Feeding Practices (β=.124; *P*=.02). The predominance of small f^2 values reflects the model's indirect association architecture rather than weak associations. Because 5 correlated AI engagement predictors converge on each intervening construct, the incremental variance of any single path is necessarily diluted, even as the collective R^2 remains substantial (0.661; 0.719). The negligible effects (H1, f^2=0.011; H12, f^2=0.017; and H13, f^2=0.018) operate reliably in the hypothesized direction while adding little unique variance once stronger predictors are accounted for; this pattern also applies to H13, given that interaction terms are typically smaller than main effects in behavioral models [69]. The single medium effect, AI Algorithmic Trust → Parental Self-Compassion (H2, f^2=0.293), identifies the emotional trust pathway as the model's most prominent association, consistent with the difficulty of explaining feeding outcomes from psychosocial predictors alone. A bootstrap MGA comparing mothers of children aged 6 - 24 months (n=136) and 25 - 59 months (n=306) found no statistically significant differences across any of the structural paths (all *P*>.05; smallest difference *P*=.13), indicating that the modeled associations were stable across this age range (Multimedia Appendix 3). The complete hypothesis testing results are presented in Table 6.

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Table . Hypothesis testing results.

Hypotheses	β [a]	*P* value	Confidence interval		f^2 value	Decision
			5.0%	95.0%		
H1: AI Algorithmic Trust → Cognitive Empowerment in Health Decision-Making	.099	.03	0.014	0.186	0.011	Hypothesis supported
H2: AI Algorithmic Trust → Parental Self-Compassion in Feeding Context	.479	<.001	0.397	0.558	0.293	Hypothesis supported
H3: AI Health Information Quality → Cognitive Empowerment in Health Decision-Making	.182	<.001	0.108	0.256	0.071	Hypothesis supported
H4: AI Health Information Quality → Parental Self-Compassion in Feeding Context	.093	.003	0.036	0.146	0.023	Hypothesis supported
H5: AI Personalization Fit Perception → Cognitive Empowerment in Health Decision-Making	.275	<.001	0.189	0.361	0.083	Hypothesis supported
H6: AI Personalization Fit Perception → Parental Self-Compassion in Feeding Context	.251	<.001	0.176	0.326	0.084	Hypothesis supported
H7: AI Information Seeking Intensity → Cognitive Empowerment in Health Decision-Making	.236	<.001	0.17	0.301	0.099	Hypothesis supported
H8: AI Information-Seeking Intensity → Parental Self-Compassion in Feeding Context	.159	<.001	0.093	0.226	0.054	Hypothesis supported
H9: AI Social Proof Sensitivity → Cognitive Empowerment in Health Decision-Making	.217	<.001	0.123	0.309	0.057	Hypothesis supported
H10: AI Social Proof Sensitivity → Parental Self-Compassion in Feeding Context	.011	.39	−0.057	0.073	0	Hypothesis not supported
H11: Cognitive Empowerment in Health Decision-Making → Perceived Nutrition-Oriented Feeding Practices	.232	.003	0.097	0.367	0.028	Hypothesis supported

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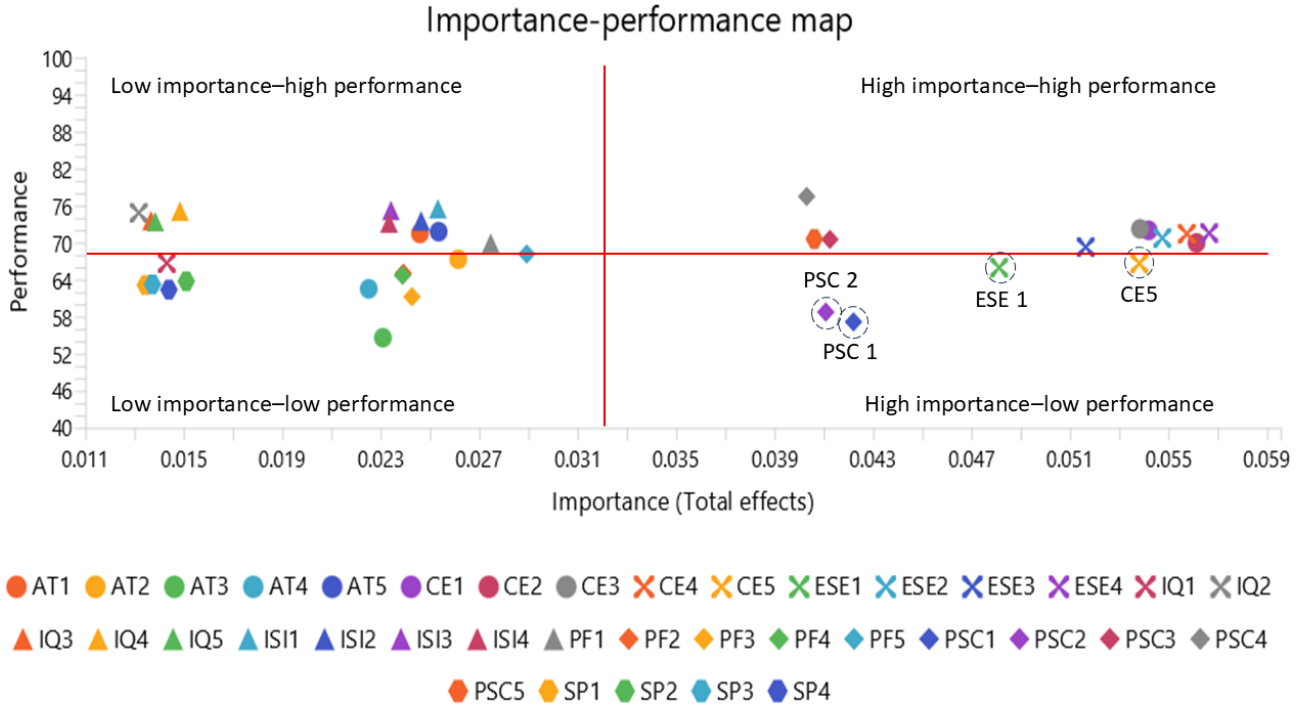
Hypotheses	β [a]	*P* value	Confidence interval		f^2 value	Decision
			5.0%	95.0%		
H12: Parental Self-Compassion in Feeding Context → Perceived Nutrition-Oriented Feeding Practices	.165	.009	0.044	0.275	0.017	Hypothesis supported
H13: eHealth Self-Efficacy × Cognitive Empowerment in Health Decision-Making → Perceived Nutrition-Oriented Feeding Practices	.124	.02	0.029	0.216	0.018	Hypothesis supported
H14: eHealth Self-Efficacy × Parental Self-Compassion in Feeding Context → Perceived Nutrition-Oriented Feeding Practices	.06	.19	−0.052	0.174	0.003	Hypothesis not supported

[a]β: path coefficient.

Advanced Analytics

AI engagement constructs were related to perceived nutrition-oriented feeding practices via both intervening constructs. Nine of 10 specific indirect effects and all 5 total indirect effects were supported, with the strongest indirect association via cognitive empowerment. The pathway from AI social proof sensitivity through parental self-compassion was not supported, consistent with H10. As the model included no direct paths, these are reported as indirect associations; because no direct paths were estimated, mediation is not inferred. Full results are reported in Multimedia Appendix 7. In addition, this study also applies IPMA to evaluate intervention priorities practically (Figure 4).

Figure 4. Importance-Performance Map Analysis indicators. CE: cognitive empowerment; ESE: eHealth self-efficacy; PSC: parental self-compassion.



The IPMA identified 4 indicators positioned in the high-importance, low-performance quadrant, signaling priority areas for future intervention development. PSC1 (staying calm when meal plans do not go as expected) and PSC2 (feeling at ease knowing toddler food refusal is a common experience) both reflect the emotional regulation dimension of parental

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self-compassion—suggesting that AI-assisted feeding tools may need to incorporate emotional support and normalization features rather than focusing solely on informational content. ESE1 (confidence in using AI to solve child eating problems) indicates that user confidence in AI-based feeding solutions is a key gap, pointing to the need for progressive skill-building and user onboarding features. CE5 (learning to be independent in nutrition decisions through AI) suggests that AI platforms should scaffold—rather than replace—maternal decision-making autonomy. Together, these indicators suggest that future AI-assisted feeding tools should prioritize emotional support, confidence-building, and decision autonomy alongside informational accuracy. The mapping results showed that the data distribution placed indicators of parental self-compassion (PSC1 and PSC2), eHealth self-efficacy (ESE1), and cognitive empowerment (CE5) in areas of high importance with low performance. These findings may help identify potential priorities for future intervention development.

Discussion

Principal Findings

This mixed methods study investigated how urban Indonesian Alpha Mothers, a digitally literate, highly educated, and evidence-driven caregiver profile, had an increasing engagement with generative AI as a decision support partner in toddler feeding. Beyond the structural model, the qualitative phase contextually refined 5 literature-informed AI engagement dimensions relevant to maternal AI-mediated toddler feeding—algorithmic trust, health information quality, personalization fit perception, information-seeking intensity, and social proof sensitivity. Although these dimensions align with existing constructs in the literature, their context-specific refinement through mothers' lived experiences and their integration into a single framework for this specific context represent the study's principal qualitative contribution. The quantitative outcome examined was maternal perception of nutrition-oriented feeding practices and not observed feeding behavior or child nutrition outcomes. The findings suggest that associations between AI engagement and perceived nutrition-oriented feeding practices may involve 2 distinct indirect associations: 1 cognitive and 1 emotional. Mothers who trusted AI and found its recommendations relevant to their child's feeding context were better able to evaluate and adapt its suggestions on their own terms. Mothers who perceived AI as nonjudgmental and objective reported lower maternal guilt. In this study, it is captured as parental self-compassion. Both pathways were independently associated with better perceived nutrition-oriented feeding practices, although the cognitive pathway carried greater weight.

Four findings warrant closer attention. AI algorithmic trust was the strongest predictor of parental self-compassion, suggesting that lower emotional burden may be more closely associated with trust in the AI system rather than with its popularity. AI personalization fit perception was the strongest predictor of cognitive empowerment, more so than algorithmic trust, information quality, or information-seeking intensity. Alpha Mothers do not appear to value accurate AI content alone. The findings suggest that they also value advice tailored to their child, daily routines, and cultural feeding practices. Beyond personalization, AI social proof sensitivity predicted cognitive empowerment but had no bearing on parental self-compassion. Community support, whether in the form of ratings, peer recommendations, or popularity signals, may shape a mother's opinion about AI. Yet, it will not affect her inner convictions as a parent. Self-compassion in this context comes from personal experience and not from external reassurance.

Finally, eHealth self-efficacy strengthened the pathway from cognitive empowerment to nutrition-oriented feeding practices. However, it played no moderating role in the self-compassion pathway. Digital confidence and emotional self-regulation appear to be separate capacities that call for separate intervention approaches. The findings suggest that AI may serve as a supportive tool that complements, rather than replaces, maternal judgment and professional nutrition counseling.

Comparison With Prior Work

Algorithmic trust emerged as the strongest predictor of parental self-compassion in this study. In the digital health literature, trust in AI has largely been treated as a functional matter, assessed through criteria of technical performance, accuracy, and system credibility [70]. Less attention has been paid, however, to whether trust in AI also carries an emotional function. Recent empirical work suggests that patients' experiences with AI health systems extend well beyond rational cost-benefit evaluation, with emotional responses such as anxiety, cognitive overload, and resistance playing a significant role in how users actually engage with these tools [71,72]. The concept of algorithmic authority provides a framework for interpreting this emotional dimension.

The present findings add a maternal caregiving dimension to this picture. For these urban Indonesian mothers, trusting an AI system was not simply a matter of judging whether its nutritional advice was clinically sound. It also determined whether that trust could absorb some of the guilt and cognitive load that accompanies daily toddler-feeding decisions. AI-driven pediatric tools may benefit from being designed with this emotional function in mind, not only to improve informational output but also to offer meaningful psychological relief to the caregivers who rely on them.

Trust in health AI has been shown to rest less on technical performance than on the degree to which a system reflects the user's own values and ways of knowing [73]. For the Alpha Mothers in this study, factual accuracy was merely a baseline. Qualitative findings suggest that trust was closely tied to perceptions of commercial neutrality and value alignment.

The result indicated that AI personalization fit perception was the strongest predictor of cognitive empowerment compared with the other 4 variables. The dominance of AI personalization as a predictor of cognitive empowerment in these findings aligns with existing literature on parental digital behavior. This pattern is consistent with findings that parents of preschool children prioritize family-adapted technology over standardized content [57,74,75]. The findings suggest that mothers in this study preferred highly contextualized nutritional guidance. This

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finding is consistent with the interpretation that for this demographic, personalization is the strongest predictor associated with cognitive empowerment.

However, this study structural model also reveals that this technology-driven empowerment has distinct boundaries, particularly concerning the emotional complexities of parenting. Specifically, the rejection of the hypotheses regarding AI Social Proof Sensitivity (H10) and the moderating role of eHealth Self-Efficacy (H14) indicates that while AI can cognitively empower mothers, technical and social features were not associated with higher levels of Parental Self-Compassion in this study. Knowing that other mothers use AI (social proof) or possessing high technical skills to navigate health information (eHealth self-efficacy) does not organically translate into reduced maternal guilt or enhanced emotional grace when facing feeding challenges.

The nonsignificant relationship between AI social proof sensitivity and parental self-compassion may reflect a dynamic specific to digital parenting environments. When mothers evaluate AI guidance through the lens of social proof, they are simultaneously exposed to a wide and often contradictory range of parenting standards. Far from offering reassurance, this collective validation tends to fuel upward social comparison and maternal competition. Recent empirical research indicates that exposure to heterogeneous parenting norms in digital spaces intensifies the internalization of an unrealistic “good mother” ideology [18,76]. True self-compassion requires self-kindness and the acceptance that all parents struggle. However, this mindset is incredibly hard to maintain in digital spaces that constantly push idealized standards, leaving mothers feeling like they fall short. High sensitivity to social proof, in this reading, does not appear to soften self-judgment and may instead be associated with greater self-criticism.

eHealth self-efficacy moderated the cognitive empowerment pathway but not the pathway from parental self-compassion to nutrition-oriented feeding practices. Digital self-efficacy has been shown to associate positively with health self-management behaviors through chain mediation in general population samples [77]. The divergence in these findings reflects the nature of self-compassion itself. Cognitive empowerment involves active information processing and responds to greater digital confidence. Self-compassion, by contrast, is an affective response rooted in self-acceptance. A mother’s ability to navigate health platforms does not make her more forgiving of herself when feeding goes wrong. These 2 observed patterns may reflect differences in the underlying psychological constructs and require different intervention approaches. Ultimately, these different paths lead to the question: what can a model focused on AI engagement realistically explain?

Taken together, these findings can be interpreted through the algorithmic authority lens introduced earlier [32]. This interpretation is offered as a theoretical reading of the cross-sectional associations observed in this study rather than as a directly tested causal account. The strongest pathway, from AI algorithmic trust to parental self-compassion, may be consistent with early-stage algorithmic authority formation, in which higher trust is associated with reliance on AI not only for information but also for emotional reassurance. Within this theoretical framing, such reliance could mark the point at which AI begins to substitute for, rather than support, maternal judgment, although the present data cannot establish whether this substitution actually occurs. The nonsignificant association for H10 refines this picture: in maternal caregiving, awareness that other mothers use AI was not associated with parental self-compassion, a pattern interpreted here as peer signals inviting social comparison rather than reassurance [18,76]. The moderation finding adds further insight: eHealth self-efficacy strengthened only the cognitive pathway, suggesting that digital literacy helps mothers think critically about AI advice but does not protect them from becoming emotionally dependent on it.

Together, these patterns may suggest, at a theoretical level, that conditions for algorithmic authority are most pronounced when high trust in AI coexists with low emotional resilience, the pattern the AI parenting nutrition alignment approach is intended to address. This raises a conceptual concern about potential algorithmic dependency: if high trust in AI and emotional relief through its use were to develop together, mothers might progressively reduce consultations with health care professionals, perceiving clinical guidance as less necessary [32,42]. Consequently, AI-generated inaccuracies may remain undetected, potentially delaying appropriate referral when a child presents with genuine nutritional concerns. In the toddler-feeding domain specifically, these risks take concrete forms: AI-generated advice may recommend age-inappropriate foods, overlook individual allergies, or suggest incorrect nutrient dosages [28], concerns corroborated by qualitative participants who reported receiving recommendations containing potentially harmful ingredients for their child’s condition. Because detecting such errors depended on the mother’s own vigilance, the risk was unevenly distributed—least for mothers with stronger nutritional knowledge and critical appraisal skills, and greatest for those most reliant on AI. This remains a hypothesized risk that the cross-sectional design cannot confirm and that warrants longitudinal investigation.

The effect size pattern warrants careful interpretation. AI Algorithmic Trust showed the strongest contribution to Parental Self-Compassion, while the other supported pathways showed smaller contributions. Some pathways, although statistically significant, contributed only modestly to the outcome. Two factors help explain this pattern. First, nutrition-oriented feeding practices are shaped by many caregiving factors, such as economic, cultural, situational, and child-specific factors that fall outside any AI engagement model. Second, moderation effects are typically smaller than main effects in behavioral models [69]. The findings should therefore be read as statistically robust but practically modest contributions of AI engagement to perceived nutrition-oriented feeding practices, rather than as evidence that AI engagement is the dominant driver of nutrition-oriented feeding practices. The same reality is reflected in the modest overall explanatory power for nutrition-oriented feeding practices. This suggests that AI engagement, together with the 2 intervening constructs, captures only part of what shapes feeding practices, with substantial remaining variance attributable to factors outside the model, such as socioeconomic conditions, family food culture, child

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temperament, maternal mental health, and situational demands. Furthermore, perceived measures of caregiving behavior—as opposed to directly observed practices—are known to be shaped by momentary contextual influences and subjective interpretation, which further constrains the variance explainable by any structural predictor set. Structural models targeting behavioral outcomes rarely explain more than a small proportion of variance, even when theory-driven and methodologically robust. The identification of algorithmic trust and parental self-compassion as significant psychosocial pathways therefore represents a meaningful contribution within this explanatory context. The perceived nutrition-oriented feeding practices construct in this model captures the nutritional and structural dimensions of infant and young child feeding guidance, namely, schedule consistency, nutritional appraisal, and limitation of low-nutrient foods, together with attentiveness to satiety signals. It does not operationalize the reciprocal responsiveness components central to the WHO or UNICEF definition of responsive feeding, which additionally require assessment of coercive feeding pressure and child autonomy support [5,6]. While the findings suggest that AI engagement may reinforce these nutrition-oriented practices via its association with cognitive empowerment, current AI platforms remain unbenchmarked against WHO or UNICEF responsive feeding frameworks or the structured competencies delivered through the UNICEF C-IYCF Counselling Package [25]. AI-assisted feeding support should therefore complement, not replace, established C-IYCF counseling models.

Implications

The following implications should be interpreted as preliminary directions derived from cross-sectional associations rather than as established prescriptions. The policy, clinical practice, and system development levels outlined in this section each warrant validation through longitudinal investigation, intervention trials, and contextual adaptation prior to large-scale implementation. At the policy level, these findings highlight the growing importance of governance frameworks for AI-assisted parenting and nutrition support. As generative AI becomes increasingly integrated into health care, international guidance has emphasized transparency, accountability, safety, and human oversight in AI-enabled health systems [78,79]. Indonesia has similarly established foundational principles for responsible AI development through Ministerial Circular No. 9/2023 [80]. However, no dedicated framework currently addresses AI-generated child nutrition advice or clearly defines accountability when such advice is associated with harm. Future policy efforts may therefore benefit from establishing standards for transparency, evidence attribution, and alignment with WHO and UNICEF responsive feeding guidance, while ensuring that AI-assisted nutrition support complements rather than replaces professional nutrition counseling.

At the clinical practice level, the findings suggest that pediatricians, nutritionists, and public health practitioners may increasingly serve as facilitators who help mothers critically evaluate AI-generated nutrition advice and integrate it with professional guidance and their child's individual circumstances. Within the Indonesian context, future research may explore whether AI literacy and nutrition counseling can be incorporated into existing maternal and child health services, including Posyandu and routine well-child care. Such approaches should position AI as a complement to, and not a substitute for, professional nutrition counseling while strengthening maternal cognitive empowerment and critical appraisal skills.

At the system development level, the findings provide preliminary insights that may inform future AI-assisted feeding support tools. The AI Parenting Nutrition Alignment Approach highlights the potential value of contextualized guidance, transparent explanations, and support for critical evaluation of AI-generated recommendations. Future systems may also benefit from benchmarking against WHO and UNICEF responsive feeding guidance to improve consistency with evidence-based nutrition recommendations. Development and implementation of such tools would likely require collaboration among pediatricians, nutritionists, public health practitioners, AI developers, and policymakers to ensure appropriate clinical oversight, safety, and governance. However, these implications remain conceptual and require evaluation through longitudinal and intervention-based research before broader implementation.

Limitations

Several limitations should be acknowledged. First, the sample was drawn from a specific demographic profile—urban, digitally active mothers who actively use generative AI—referred to in this study using the descriptive label "Alpha Mother." This label functions as a recruitment descriptor rather than a validated theoretical construct, and findings should not be generalized beyond this defined demographic profile. Whether the patterns observed here apply to mothers from different socioeconomic, educational, or digital engagement profiles remains an open empirical question. Second, recruitment through digital parenting communities likely introduced self-selection bias toward mothers already favorably disposed toward generative AI. Findings should therefore be interpreted as reflecting the experiences of digitally active, AI-engaged urban mothers rather than urban Indonesian mothers more broadly.

Third, all data relied on self-report. Mothers may have overstated their trust in AI or their sense of self-compassion to align with perceived parenting ideals, particularly given the social pressures that surround toddler feeding in urban Indonesian contexts. Furthermore, perceived nutrition-oriented feeding practices capture maternal self-assessment, not observed feeding behavior or objective child nutrition outcomes. The instrument assesses nutrition-focused and structural aspects of feeding; coercive feeding pressure, caregiver responsiveness to the full range of hunger and satiety cues, and child autonomy support were not measured. Findings therefore speak to the nutritional and structural dimensions of feeding rather than to caregiver-child interactional quality and should not be read as evidence regarding responsive feeding as defined by WHO and UNICEF. Future work should triangulate this construct against behavioral instruments such as the Comprehensive Feeding Practices Questionnaire and against anthropometric indicators.

Fourth, the cross-sectional design and the modest variance explained limit interpretation. The associations identified through PLS-SEM are statistically robust but cannot establish whether AI engagement changes maternal behavior over time,

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and the low explained variance indicates that AI engagement is only one of several factors shaping feeding practices. The design also permits alternative explanations the present data cannot adjudicate: the trust-outcome relationship may be reversed or reciprocal, as mothers who already possess greater feeding confidence, knowledge, or emotional resilience may be more predisposed to trust AI and report favorable feeding experiences. An unmeasured third variable, such as general health literacy or socioeconomic advantage, could likewise elevate both, and such confounding is difficult to exclude given the self-selected sample. The reported associations should therefore be read as compatible with, but not confirmatory of, the mechanistic interpretation advanced in the Principal Findings section. Improvements in perceived nutrition-oriented feeding practices should therefore not be interpreted as evidence of improved child nutritional or developmental outcomes. In addition, although the sample spanned a broad age range (6‐59 months), an MGA confirmed that the structural estimates did not differ significantly between younger and older children (Multimedia Appendix 3); the younger stratum nonetheless follows the survey's 6‐ to 24-month category, 1 month wider than the WHO 6‐ to 23-month cutoff, and its smaller size warrants caution in interpreting subgroup estimates.

Fifth, social desirability and CMB cannot be fully excluded, as all constructs were self-reported through a single instrument at one time point. Although procedural remedies and a full collinearity assessment (all inner VIF <3.3) indicate that CMB is unlikely to be severe, these safeguards reduce rather than eliminate the risk. In addition, the 5 AI engagement dimensions were newly developed here and have not been externally validated, and the AI parenting nutrition alignment approach that organizes them adapts an existing framework [44] not yet validated in this domain. Findings involving them should be regarded as preliminary.

Finally, this study did not independently audit the clinical accuracy of AI-generated nutritional advice received by participants; the constructs measured reflect mothers' perceptions of AI quality rather than objective evaluation of AI output. Future research should systematically benchmark AI-generated feeding advice against WHO or UNICEF responsive feeding recommendations and the C-IYCF counseling competency framework, a critical step toward developing clinically validated AI-assisted feeding platforms.

Conclusions

This mixed methods study suggests that generative AI is not independently associated with perceived nutrition-oriented feeding practices. Associations between AI engagement and perceived nutrition-oriented feeding practices were strongest when mothers trusted the system and perceived its recommendations as fitting their child and household realities. Two distinct indirect associations may help describe these associations. Algorithmic trust was associated with parental self-compassion, which was linked to lower emotional burden during feeding challenges, whereas personalization fit was associated with cognitive empowerment, which in turn was associated with mothers' self-reported capacity to critically evaluate and adapt AI advice.

These indirect associations may reflect potentially important constructs by which AI engagement is associated with perceived nutrition-oriented feeding practices. Within the data, the perceived value of AI in toddler feeding appeared to relate less to algorithmic sophistication than to perceived trust, contextual fit, and support for maternal judgment. Beyond these associations, and extending past what the present cross-sectional data can establish, the findings may hold tentative implications for clinicians, policymakers, and developers. They may inform future research on, and the eventual design and evaluation of, AI-assisted feeding support, provided such tools are positioned to complement rather than supplant professional nutrition counseling. These implications remain hypotheses for future longitudinal and intervention research rather than evidence-based recommendations. In addition to these quantitative pathways, this study contributes a qualitative typology of AI engagement constructs specific to the toddler-feeding context, providing a conceptual foundation for future research at the intersection of AI, maternal cognition, and child nutrition.

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Data Availability

The datasets generated and/or analyzed during this study are not publicly available to protect the privacy and confidentiality of the participants, particularly regarding the qualitative interview transcripts and personal experiences shared. However, the data are available from the corresponding author on reasonable request.

Authors' Contributions

Conceptualization: LNA (lead), FA (supporting), DW (supporting)

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Formal analysis: LNA, SA
Investigation: LNA
Methodology: LNA (lead), FA (supporting)
Supervision: FA
Validation: LNA, SA, FA
Writing – original draft: LNA
Writing – review & editing: LNA, SA, FA, DW, RGM.
All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Eligibility screening and verification procedures.
[DOCX File, 17 KB - pediatrics_v9i1e100061_app1.docx]

Multimedia Appendix 2
Audit trail phase 1.
[XLSX File, 33 KB - pediatrics_v9i1e100061_app2.xlsx]

Multimedia Appendix 3
Age-based multigroup analysis.
[DOCX File, 17 KB - pediatrics_v9i1e100061_app3.docx]

Multimedia Appendix 4
Table frequencies of artificial intelligence search topics.
[DOCX File, 14 KB - pediatrics_v9i1e100061_app4.docx]

Multimedia Appendix 5
Table discriminant validity (Heterotrait-Monotrait ratio).
[DOCX File, 17 KB - pediatrics_v9i1e100061_app5.docx]

Multimedia Appendix 6
Collinearity statistics (inner variance inflation factor values).
[DOCX File, 15 KB - pediatrics_v9i1e100061_app6.docx]

Multimedia Appendix 7
Indirect effects table.
[DOCX File, 17 KB - pediatrics_v9i1e100061_app7.docx]

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Abbreviations

C-IYCF: Community Infant and Young Child Feeding
CMB: common method bias
CR: composite reliability
CVPAT: Cross-Validated Predictive Ability Test

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H: hypothesis
HTMT: Heterotrait-Monotrait
IA: indicator average
IPMA: Importance-Performance Map Analysis
LM: linear model
MGA: multigroup analysis
PLS-SEM: partial least squares–structural equation modeling
UNICEF: United Nations Children's Fund
VIF: variance inflation factor
WHO: World Health Organization

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Usability and Acceptability of a Digital Health App to Support Infant Feeding and Lifestyle Behaviors: Mixed Methods Pilot Study

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Abstract

Background: Childhood obesity is a global health concern with long-term cardiometabolic and psychosocial consequences. Establishing healthy feeding and lifestyle behaviors from infancy is critical to population health efforts with a life course perspective. Recently, digital health applications have gained traction in reaching out to parents and promoting healthy feeding behaviors.

Objective: The aim of this study was to evaluate the usability and acceptability of the Feeding, Lifestyle, Activity Goals app in providing parents with evidence-based guidance and tailored advice to promote healthier eating behaviors and lifestyle habits among infants.

Methods: We conducted a mixed methods pilot study among parents of infants aged 0 to 24 months recruited from a tertiary maternity and children's hospital in Singapore. Participants used the digital health app for 7 days. Usability was assessed using the validated System Usability Scale (score range 0 - 100, with ≥70 indicating acceptable usability). Acceptability was explored via open-ended questionnaires on satisfaction, relevance, and user experience, with qualitative data analyzed thematically by 2 independent coders to ensure rigor.

Results: A total of 26 parents of infants aged 3 weeks to 23 months completed the study. The app demonstrated good usability, with a mean System Usability Scale score of 71.3 (SD 11.0). Parents valued its role in organizing infant care; promoting self-reflection on parenting practices; and providing personalized, evidence-based recommendations. These benefits were particularly appreciated by first-time parents and those with multiple caregiving responsibilities. Challenges included an unintuitive user interface, high manual data entry burden, and advisory content that was occasionally overly general or text heavy. These insights highlight clear priorities for onward efforts in optimization.

Conclusions: Results of our mixed methods evaluation indicate that our digital health app demonstrated good usability and acceptability among parents of infants. Targeted refinements to the interface, data entry processes, and content delivery are warranted before large-scale evaluation to determine its impact on early-life health behaviors and obesity prevention.

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KEYWORDS

mobile health; mHealth; childhood obesity; obesity prevention; infant feeding; early-life behaviors; usability; acceptability; mobile apps

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Introduction

Childhood obesity is rising at an alarming rate worldwide. According to the World Health Organization [1], an estimated 35 million children under the age of 5 years are overweight, and the prevalence of children and adolescents with overweight aged 5 to 19 years has risen significantly from 8% in 1990 to 20% in 2022. This surge in childhood obesity not only results in health-related comorbidities such as metabolic syndrome and orthopedic issues but also significantly affects children's psychological well-being, body image, and overall quality of life [2]. In the long term, these children also have a moderate risk of obesity persisting into adulthood [3], along with its cardiovascular complications.

Numerous studies have shown that children's eating habits [4] and food preferences [5] are strongly linked to their body composition, with unhealthy diets and poor feeding practices increasing the risk of childhood obesity. Importantly, these dietary patterns often persist into adulthood as feeding practices established in early life influence future dietary and taste preferences [6,7]. Therefore, timely interventions during early childhood, particularly those aimed at shaping healthy feeding behaviors, are critical for long-term obesity prevention and for promoting sustainable, healthy growth trajectories [8]. Parents play a central role in this process [9]. From infancy, they influence not only the types and amounts of food offered to children but also the emotional and environmental context in which meals take place [10]. As a result, many public health initiatives encourage parents to act as "health promoters" shaping their child's feeding behaviors and long-term food preferences through informed and consistent modeling and support [11,12].

However, providing parents with consistent, evidence-based support remains challenging. Traditional interventions targeting feeding behaviors, such as in-person counseling and motivational interviewing, have shown benefit but are often labor-intensive, time-consuming, and difficult to scale [13]. With the advent of technological advancements, digital interventions such as mobile health (mHealth) apps have gained traction as a means of expanding outreach to parents and providing accessible, around-the-clock support for improving dietary choices and feeding behaviors [11]. For instance, a recent pilot study evaluating a parent-focused mHealth app designed to promote healthy eating behaviors in children found that parents perceived the app as helpful in increasing their nutritional knowledge and awareness of their children's diet [12]. Similar digital interventions in adult populations have also shown promise, with meta-analyses highlighting their effectiveness in managing and preventing obesity [14]. However, despite these benefits, commercially available mHealth apps still lack medical oversight, are not co-designed by stakeholders including health care professionals and end users, and often fall short in providing evidence-based or culturally tailored content [15,16]. These drawbacks limit their effectiveness and credibility, particularly when used as stand-alone tools for behavior change. In addition, given that cultural influences strongly shape feeding practices [17], there is a clear need for digital solutions that are evidence based, medically guided, and culturally sensitive, with the eventual aim of reinforcing good dietary practices and habits in the pediatric population.

To this end, our study team involving a diverse panel of domain experts, including neonatologists, pediatricians, dietitians, speech therapists, physiotherapists, and nurses, developed a digital health app named Feeding, Lifestyle, Activity Goals (FLAGs) to promote healthier eating behaviors and lifestyle habits in infants from birth to the age of 2 years. Its development involved a meticulous process for which the questionnaires and advisory content underwent extensive curation [18]. The tool is grounded in theoretical frameworks such as the capability, opportunity, and motivation–behavior framework, which emphasizes enhancing parents' capabilities through skill-building, while providing opportunities and motivation via a user-friendly app to support behavioral change and promote healthy feeding habits. Overall, FLAGs serves as both an assessment tool and a provider of tailored advice for parents on their infants' feeding practices, sedentary behavior, and physical activity. In this study, we specifically aimed to perform a mixed methods evaluation of the app's usability and acceptability among end users. These findings will inform iterative refinements and subsequent large-scale trials to examine the app's efficacy in effecting behavior change and on anthropometric outcomes.

Methods

Study Design and Setting

We conducted a mixed methods pilot study at KK Women's and Children's Hospital, Singapore, to evaluate the app's usability and acceptability among parents of infants. The study period was from September 2024 to November 2024.

Participants and Recruitment

A purposive sampling strategy was used to recruit eligible parents or primary caregivers of infants aged 0 to 24 months during outpatient clinic visits. Sampling sought to capture diversity in parental age, ethnicity, and caregiving experience to obtain a broad range of perspectives on usability and acceptability.

Our inclusion criteria were infants aged 0 to 24 months as well as parents' ability to understand a basic level of English in view of the fact that all the content within the app and the feedback instruments used was in English. Meanwhile, our exclusion criteria were any infants with congenital abnormalities and physical or neurodevelopmental disabilities that may interfere with app use or who may have unique feeding requirements.

Ethical Considerations

Ethics approval was obtained from the SingHealth Centralised Institutional Review Board, Singapore (reference 2024/3224). The study was conducted in accordance with the principles of the Declaration of Helsinki and adhered to all applicable local regulatory requirements. All participants received a verbal and written explanation of the study and provided written informed consent before enrollment. Upon successful completion of the study, participants received reimbursement of SG $20 (approximately US $15). Each participant was assigned an

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anonymized study ID; all collected data were encrypted and stored on a secure, password-protected server accessible only to the study team.

Study Procedures

At baseline, we collected parental and infant demographic data, including age, sex, ethnicity, and gestational age at birth. Infant anthropometry was measured using the Seca 210 mobile measuring mat for recumbent length and Seca 334 weighing scale for weight, and BMI-for-age was calculated as weight divided by height squared (kg/m^2). After recruitment, participants underwent a cognitive walk-through via both verbal explanation and a pictorial guide demonstrating the user interface with key features. They were then provided with installation instructions and granted full access to the app for a 7-day trial. In terms of the duration for this trial, a study by Steele et al [19] in Durham, North Carolina, United States, found that brief intensive internet-delivered cognitive behavioral therapy on social anxiety for 7 days was feasible, with low premature dropout rates. Similarly, a 7-day mobile tracking study [20] on sleep in students found that there was sufficient variance in terms of the data provided. Hence, the decision was made to use a 7-day trial.

Participants were encouraged to explore all functions without a prescribed recording schedule to reflect real-world use. Intake data (feeding, activity, and growth) could be logged ad libitum. Following the 7-day trial, participants promptly provided an interview time. During the online video interview, the System Usability Scale (SUS) questionnaire was administered via screen sharing, and responses were recorded accordingly. Subsequently, participants continued in a semistructured interview format with open-ended questions. Interviews were audio recorded with consent and transcribed verbatim. All interviews were completed within 1 month from the time of recruitment.

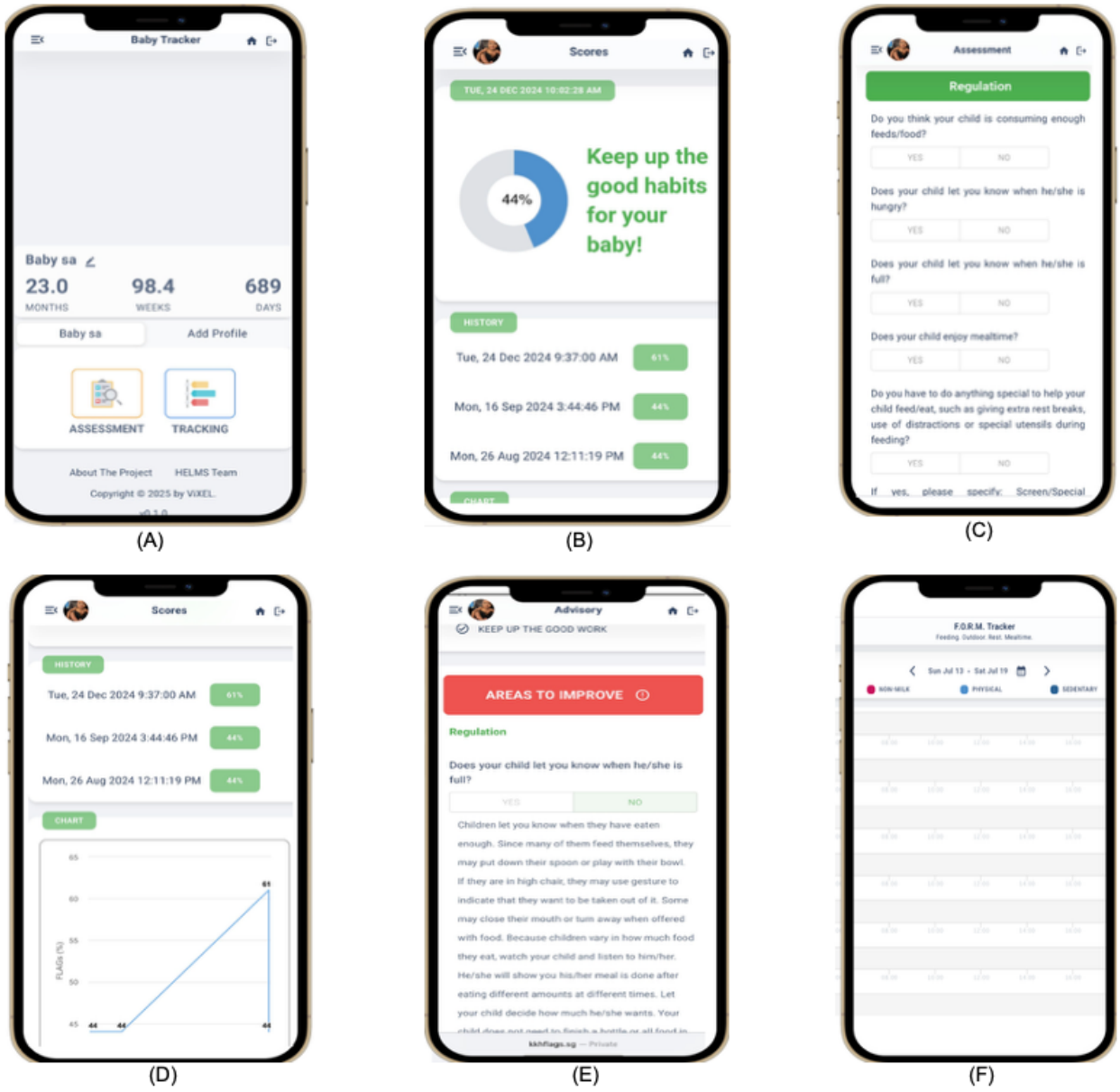
FLAGs Digital Health App

To address the need for an optimized, medically guided feeding intervention, our team at KK Women's and Children's Hospital first developed a validated assessment instrument—the FLAGs digital health app—to evaluate infant feeding and lifestyle behaviors. The team comprised neonatologists, pediatricians, obstetricians, and dietitians. Psychometric evaluation of the app revealed strong clarity, relevance, and simplicity. Overall, the Cronbach α was 0.71, and the intraclass correlation coefficient of 0.861 ($P<.001$) indicated statistically significant test-retest reliability, supporting the instrument's validity and reliability [18]. Subsequently, the instrument was converted into a digital health app that enables caregivers to log and track their infants' dietary intake, physical activity, and growth parameters, generating visual summaries (graphs and trends) and personalized, evidence-based recommendations. Another framework that provided a foundation for our digital health app was the theory of planned behavior [21]. This theory looks at the close relationship between infant feeding practices and parents' behaviors, which are shaped by subjective norms and perceived control.

The app consists of several user modules, beginning with a secure log-in and profile setup that personalizes questions based on the child's age and feeding stage. The assessment module comprises 11 to 18 items categorized into 3 core domains: regulation, which assesses recognition of hunger and satiety cues, feeding responsiveness, and infant self-soothing; weaning, which covers complementary feeding initiation, food texture progression, and parental feeding approaches; and habituation, which evaluates sleep duration, screen exposure, and daily activity routines. Each question is age specific and uses either a binary ("yes" or "no") or categorical (eg, 5 to 30 minutes per meal or ≤1 hour vs >1 hour of screen time) response format. Responses are automatically scored within the app: a healthy, age-appropriate behavior is awarded 1 point, whereas an at-risk or suboptimal response receives 0 points. Domain-specific subscores and an overall FLAGs composite score (0% - 100%) are then computed in real time. Upon scoring, the app instantly generates personalized advisory feedback displayed on the "Advisory" and "Scores" pages, providing parents with clear, actionable recommendations to support healthy feeding and lifestyle practices. The app also features daily and weekly tracking modules that allow users to record milk intake, food consumption, physical activity, sedentary time, and sleep. Input forms are editable for flexibility, with weekly summaries enabling trend visualization over time. The behavioral nudges within the FLAGs app are automatically tailored to the child's age group and corresponding developmental stage. Key interface elements of the intervention are shown in Figure 1.

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Figure 1. Screenshots of the Feeding, Lifestyle, Activity Goals (FLAGs) digital health app: (A) main landing page, (B) score display screen, (C) FLAGs questionnaire, (D) trends in feeding and lifestyle scores, (E) tailored parental advisory and recommendations, and (F) daily feed and physical activity log.



Outcomes and Measures

The primary outcome was usability, assessed using the validated 10-item SUS [22] (score range 0 - 100, with ≥70 indicating acceptable usability for digital tools). This was interviewer administered, with a standardized script for each question; no prompts, explanations, or leading cues were provided beyond the original wording of the SUS items, and participants were given time to consider each question and respond accordingly.

The secondary outcome was acceptability, assessed via open-ended, semistructured interviews. Participants were asked the following five questions: (1) “what did you like about the digital health application?” (2) “What did you dislike about the digital health application?” (3) “What features would you like to see retained in the digital health application?” (4) “What features would you like to remove or change in the digital health application?” (5) “Do you have any other comments about the digital health application?” These questions were designed to elicit both positive and negative experiences, feature-specific feedback, and additional suggestions for improvement. An interview guide that includes the SUS and acceptability questionnaire used is provided in Multimedia Appendix 1.

Data Analysis

Quantitative data analysis was conducted using Stata (version 18; StataCorp LLC). Participant demographic and baseline characteristics were tabulated to provide a descriptive overview of the sample. For the SUS, the mean and SD, as well as sample size and frequency, were calculated for each individual item to identify variability in responses and for the total SUS score to assess overall system usability.

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To qualitatively analyze user experience of the FLAGs app, all audio recordings of participant interviews were transcribed and analyzed using Microsoft Word. Using the grounded theory approach [23], data analysis involved line-by-line coding, axial coding, and selective coding by 2 independent researchers to generate broad conceptual themes. In the later stage of analysis, all major categories, themes, and subthemes were operationalized. Relationships between themes and subthemes were proposed and substantiated with relevant quotes from participants. To ensure research rigor and trustworthiness of the findings, stringent mechanisms were put in place. These included maintaining an audit trail of research decisions, changes, and data analysis; interresearcher consensus in finalizing themes; and frequent peer debriefing to review interpretations and findings so as to minimize researcher bias [24,25].

Results

Participant Characteristics

A total of 34 participants were recruited and assessed for eligibility for the study. Subsequently, of the 34 assessed participants, 11.8% (4/34) were excluded as they were unable to understand English, which is the working language of the app and survey questionnaires. Eventually, of the remaining 30 participants, 86.7% (26/30) were interviewed as 10% (3/30) were lost to follow-up and 3.3% (1/30) withdrew from the study for personal reasons. Figure 2 shows the flowchart of the included and excluded participants and those who completed the study.

Figure 2. Flowchart of participant selection for the Feeding, Lifestyle, Activity Goals digital health app study.

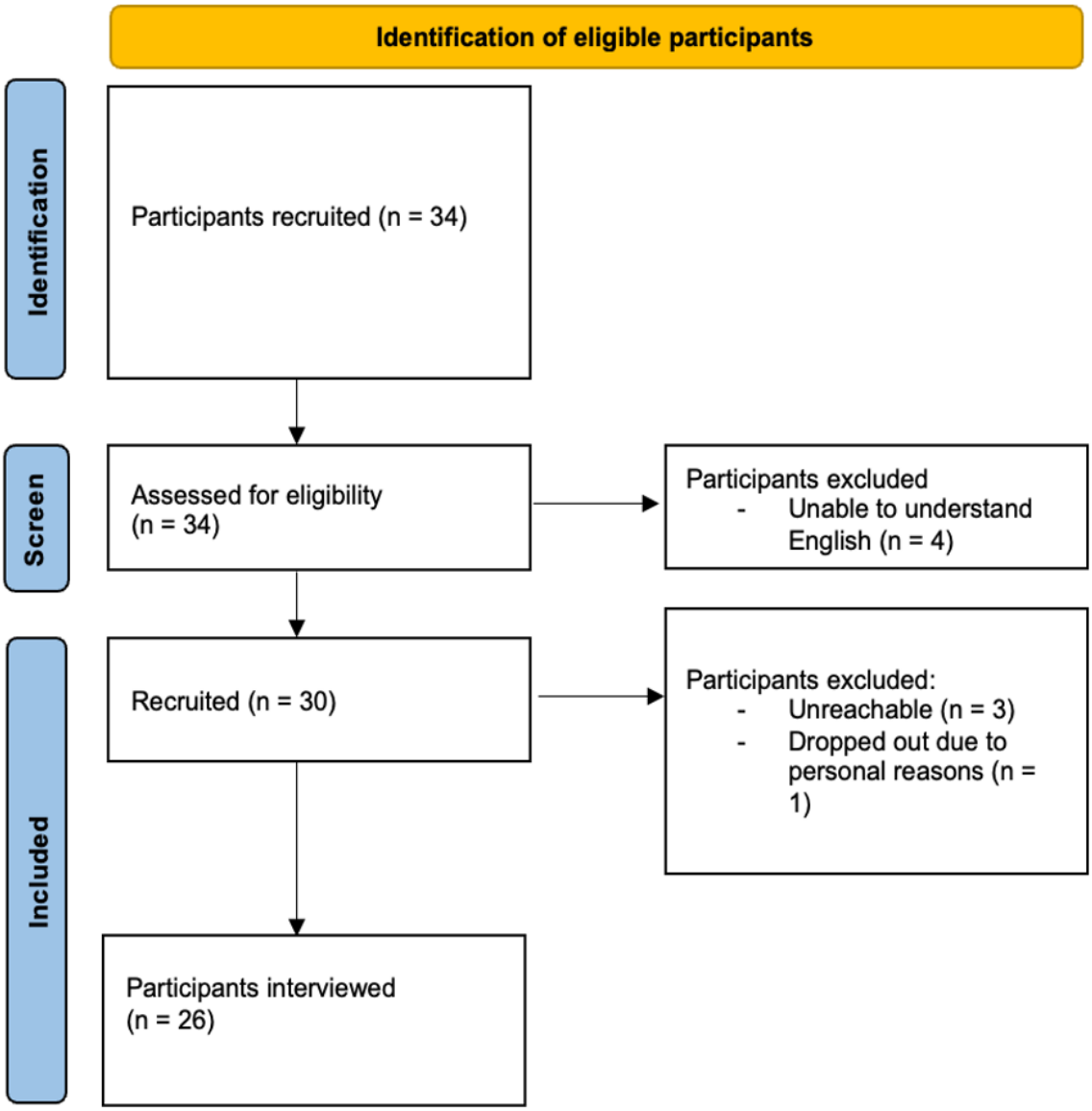


Table 1 describes the baseline characteristics of the parents and their children. Of the 26 parents, 73.1% (19/26) were female, and the mean age was 33.7 (SD 5.2) years. In terms of educational level, most parents were diploma holders (10/26,

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38.5%) and degree holders (10/26, 38.5%). Regarding the demographic characteristics of the children, 53.8% (14/26) were males. The mean age was 7.4 (SD 5.0) months, with ages ranging from 3 weeks to 23 months.

Table . Baseline characteristics of the participants (N=26).

Characteristics	Participants
Caregiver's age (y), mean (SD)	33.7 (5.2)
Caregiver's relationship to the child, n (%)	
Mother	19 (73.1)
Father	7 (26.9)
Caregiver's monthly household income, n (%)	
<SGD 10,000 (US $7830.60)	17 (65.4)
≥SGD 10,000 (US $7830.60)	9 (34.6)
Child's age (mo), mean (SD)	7.4 (5.0)
<12, n (%)	18 (69.2)
≥12, n (%)	8 (30.8)
Child's sex, n (%)	
Male	14 (53.8)
Female	12 (46.2)
Child's ethnicity, n (%)	
Chinese	13 (50)
Indian	9 (34.6)
Malay	4 (15.4)
Child's gestational age at birth (wk), n (%)	
Full term (≥37)	21 (80.8)
Preterm (<37)	5 (19.2)

Usability

Table 2 shows the proportion of responses and the mean scores for questions from the SUS. Scores for each item on the questionnaire range from 1 to 10, with a maximum possible score of 100. The mean SUS score for our FLAGs app was 71.3 (SD 11.0). Half (14/26, 53.8%) of the participants reported that they would use this digital intervention frequently to improve their children's feeding behavior and nutritional choices. In addition, more than two-thirds (19/26, 73.1%) thought that the product was easy to use. Most (21/26, 80.8%) disagreed that they required technical assistance to use the digital intervention. Overall, this reported ease of use of the product appeared to translate into confidence in the implementation of the app into their lifestyles (20/26, 76.9%).

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Table . Breakdown of responses to the System Usability Scale (SUS) questionnaire. The SUS score was calculated based on processes originally developed by Brooke [26] (N=26).

	Score, mean (SD)	Disagree, n (%)	Neutral, n (%)	Agree, n (%)
I think that I would like to use this product frequently.	3.4 (1.2)	6 (23.1)	6 (23.1)	14 (53.8)
I found the product unnecessarily complex.	2.6 (1.1)	17 (65.4)	2 (7.7)	7 (26.9)
I thought the product was easy to use.	4 (1.0)	3 (11.5)	4 (15.4)	19 (73.1)
I think that I would need the support of a technical person to be able to use this product.	1.7 (1.0)	21 (80.8)	3 (11.5)	2 (7.7)
I found the various functions in the product were well integrated.	3.6 (0.9)	4 (15.4)	7 (26.9)	15 (57.7)
I thought there was too much inconsistency in this product.	2.0 (0.7)	7 (26.9)	12 (46.2)	7 (26.9)
I imagine that most people would learn to use this product very quickly.	4.2 (0.9)	1 (3.8)	3 (11.5)	22 (84.6)
I found the product very awkward to use.	2.3 (1.0)	17 (65.4)	6 (23.1)	3 (11.5)
I felt very confident using the product.	4.0 (0.8)	1 (3.8)	5 (19.2)	20 (76.9)
I needed to learn a lot of things before I could get going with this product.	2.2 (1.1)	15 (57.7)	8 (30.8)	3 (11.5)

Acceptability

Overview

The acceptability of the FLAGs app was evaluated through qualitative responses from parents regarding their experiences using the digital tool. These responses were categorized into three overarching themes: (1) positive experiences, (2) challenges encountered, and (3) desired features not currently available. Each theme was further broken down into subthemes reflecting specific aspects of the user experience.

Theme 1: Positive Experiences

This theme highlights the perceived benefits of using the FLAGs app, particularly in enhancing the organization of infant care, improving self-awareness and reflection, and fostering parental empowerment. These strengths suggest strong acceptability of the app among parents and caregivers.

Better Organization of Infants' Care

Parents reported that the app supported better management of their infants' daily routines, particularly regarding feeding and sleeping schedules. This benefit was especially prominent among first-time parents or those with multiple responsibilities:

> *The tracker is very useful, and it helps me to see if my baby had fed or not. I don't have to keep recalling when I feed my baby.* [P7]

> *I'm more aware of the baby and I am very interested to log the feeding habits of baby into the app.* [P6]

Greater Clarity on Parenting Practices

The app's personalized assessments and data visualization features allowed users to reflect on their parenting practices and identify areas for improvement. This was facilitated through automated, tailored feedback based on questionnaire responses:

> *Overall, the app is good to use but there are still more apps like this, but this is special because [it has] the advisory based on what you answer in the questionnaire.* [P1]

The assessment also allowed parents to reflect and self-evaluate while visualizing their progress over time through graphics such as bar graphs and charts:

> *The advisory is very helpful so it can show me roughly where I stand in terms of what to improve as a parent for my baby.* [P7]

Empowerment in Infant Care

Parents expressed that the app supported evidence-based parenting while reducing their dependence on health care providers for day-to-day concerns:

> *I like the fact that this app is like a guide. Like for example, they will tell you what is good and what is*

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> *not good. For example, I can know how long of a nap is good for my baby.* [P5]
>
> *As (a) first-time parent I feel like I don't need to seek for doctors help or ask doctors on a regular basis.* [P11]

Other Strengths

Other less common but pertinent strengths included the fact that the app was supported by KK Women's and Children's Hospital, a public tertiary maternal-child hospital, thus improving parental trust:

> *Maybe there are more apps, but this is maybe more trustworthy because it's from [a] hospital.* [P8]

Others appreciated the delivery of behavioral nudges via WhatsApp:

> *I quite like the concept of this whole thing [the app] including the nudges which is a fresh idea to be sent [through] WhatsApp.* [P9]

Theme 2: Challenges Encountered

Despite the positive experiences, several challenges with the app were identified, primarily related to usability—including operational issues, the complexity of the tracking process, and the relevance of the content—which helped further contextualize the SUS score.

Further Improvements Required in the User Interface

Many users described the app as being visually unrefined and having navigation issues. Issues ranged from log-in troubles to technical bugs:

> *For the login page, I had to keep logging in for the 7 days and I find it a bit troublesome and time consuming and there is no password view option, so I took very long to login to the app initially.* [P9]
>
> *When I did the assessment, I cannot look back at it after I complete it. Like there is no record of my assessment. When I did it one time, I cannot see the output of like the results of it. I briefly saw the results but when I tried to find it again, it is disappeared.* [P8]

Cumbersome Tracking Process

Users expressed difficulty in consistently inputting feeding and sleep data, especially when multitasking or without prompts from the app:

> *Since I do not really know the exact timing of the baby sleeping and feeding time I can't really be consistent with the app. I just try my best when I'm at home to try login. Also, when I'm helping to take care of the baby I try to put away my phone from sight, so the baby doesn't try to take it. So, I can use only based on my memory.* [P18]

This was especially relevant as the app did not auto-suggest entries based on previous entries, thereby increasing the cognitive load on parents:

> *I feel like the macro of the food is necessary information for medical side but for me I feel stressed to put in so many things. [The app they were using previously] is better comparatively because I can choose the food from previous options I have keyed in the app.* [P11]

Wordy Content

The app's advisory section was seen as too text heavy, with users preferring more concise and targeted information:

> *I think I find it very wordy generally. There are more things to input, and the advisory is also very wordy. I think bite sized information is preferred by most of the parents because everything is fast moving now. And maybe if user can choose like a certain topic that they are more interested then, it can give a full explanation. Like if I'm worried about my baby's sleep then I can click on the sleep advisory for more details.* [P9]

Furthermore, some feedback suggested that the assessments could be misleading or stressful due to a lack of sufficient personalization:

> *"Your child doesn't need any distraction or effort when feeding." That was not true for our child who really did not enjoy mealtimes despite countless efforts. [The recommendations] should be stated clearly that it may not always be the case.* [P27]

Theme 3: Desired Features Not Currently Available

Several participants proposed enhancements to improve the app's usability and collaborative potential. These fell into 3 subcategories: shared access, simplified input methods, and better access to historical data.

Shared Access for Different Caregivers

Users expressed a desire for options for multiple caregivers, emphasizing the importance of collaborative tracking. Suggestions included a shared account for caregivers and ease of log-in for multiple users:

> *And it will provide better communication between caretakers.* [P12]
>
> *I try to login using my husband phone also so I use only evening time. So I could not every time login the food and sleep. I just put in what I remember.* [P17]

Simplified Input Methods

Participants expressed a need for more intuitive input methods, such as preset options, visual timers, and icons to reduce manual entry burden:

> *As for the inputting the details of the data, it could be easier. To be honest, because I am using another app, I haven't been using it regularly also but whenever I get the time I use it. So even for that app when it's easier to type the data, I don't seem to use it often, so this app I don't see myself being very frequently using it. In terms of icon, there can be a new icon for breast feeding to show like breast milk*

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> *vs formula. It's like for easier navigation so I don't have to type out what type of milk I'm feeding all the time. Inputting the timing is also quite tedious, instead they can have like a stopwatch like the baby time app I'm using now. There is an instant update of the current time the mummy Is feeding.* [P21]

Photo uploads were another frequently requested feature, especially for food tracking and medical documentation:

> *It's easier to upload a picture and will be easier for your reference as well. And when I want to show let's say to my doctor also, he can get the idea of how the food actually looks.* [P12]
>
> *Good to also include option to upload photos...i.e. stool consistency and color.* [P22]

Archiving and Access to Past Assessments

A common request was for a feature that allows users to revisit previous assessments and advisories. This allows for longitudinal tracking and review of prior advisories and scores:

> *I want to look back at the advisories and maybe have like an archive of previous advisories and assessment scores so that we can see the improvement and refer easily to the advice.* [P6]

Discussion

This study evaluated the usability and acceptability of an mHealth app designed to support parents of infants aged 3 weeks to 23 months with evidence-based resources and personalized advice on feeding, physical activity, and growth. Overall, the digital health app demonstrated good usability, as evidenced by the mean SUS score. This places FLAGs in a range consistent with functional but improvable health technology [19]. In terms of acceptability, parents emphasized several positive aspects of the app, suggesting that it was generally well accepted within the study population. In particular, parents valued the structured organization of caregiving tasks, the ability to visualize progress, and the provision of evidence-based feedback in real time. These features created a sense of confidence and empowerment, particularly for first-time parents and for those balancing multiple caregiving roles. Many participants expressed that FLAGs offered reassurance and guidance that might otherwise be unavailable between clinical encounters, reflecting both the app's acceptability and its potential to bridge gaps in routine parenting support. Challenges, particularly on the usability front, still remain and will guide subsequent work to improve the app's usability. For example, the interface was perceived to be occasionally unintuitive, and data entry, while comprehensive, was regarded as burdensome and overly manual, limiting sustained engagement in day-to-day use. Advisory content was sometimes experienced as verbose, which risked diluting its impact and reducing its immediate applicability. Frequently suggested improvements included the ability to share access across multiple caregivers, streamlined logging features such as photo uploads and visual timers, and the capacity to archive and retrieve past assessments. Taken together, these findings suggest that FLAGs has achieved sufficient baseline usability and acceptability to justify further development, with a road map for further iteration.

When considered in relation to the wider literature, our findings reinforce both the promise and the challenges of parent-facing digital health interventions in early childhood, consistent with evidence from preschool interventions. For example, the MINISTOP (Mobile-Based Intervention Intended to Stop Obesity in Preschoolers) trial demonstrated improvements in composite diet and activity behaviors among children aged 4 years, underscoring the feasibility of app-based parent engagement [13]. Similarly, the Food4toddlers study revealed that parental access to the Food4toddlers website improved the frequency of intake of vegetables among toddlers immediately after the 6-month intervention period ended [27]. Building on these works, the Early Food for Future Health trial noted that an internet-based tool for parents of children aged between 6 and 12 months was appropriate and feasible to propagate information on healthy infant feeding to Norwegian mothers, leading to an increase in young children's daily vegetable and fruit intake [28]. More generally, meta-analyses confirm that digital health interventions can promote healthier nutrition behaviors in children and families [11] and are effective in weight management among adults [14]. At the same time, reviews of pediatric nutrition apps have raised concerns regarding lack of clinical input, inadequate behavior change mechanisms, and poor usability [15,16]. A scoping review on child health promotion apps by Blakeslee et al [29] similarly acknowledged the importance for apps to be grounded in transparent theoretical frameworks and that content should be tailored to include intuitive and adaptive features—all challenges mirrored by parents' feedback in our study calling for clearer, more targeted content and more usable logging. These findings highlight a key point: effectiveness is unlikely to be determined by the presence of digital content alone but rather by the integration of evidence-based content, clinical oversight, and user-centered design.

Our findings carry several implications for future iterations of FLAGs and design of similar interventions. First, minimizing interaction burden is likely to be critical for engagement. Parents consistently requested features that reduce repetitive manual data entry, such as preset options for routine inputs, auto-suggestions, and smart defaults [20,21]. Incorporating semipassive data capture where feasible could further enhance efficiency and lower friction. Second, personalization emerged as a strong driver of acceptability. Tailoring advisory content to infant age, feeding stage, and parent preferences and delivering messages in concise, layered formats would likely improve both perceived relevance and usability [29,30]. Third, supporting the broader caregiving ecosystem will be essential. Parents emphasized the need for shared caregiver accounts, secure photo uploads, and archival functions that support continuity of care, reflecting the reality that infant caregiving is rarely the responsibility of a single individual. Embedding FLAGs into routine pediatric follow-up visits such as growth monitoring or immunization appointments may normalize its use and provide opportunities for light-touch reinforcement by clinicians without imposing additional workload. Finally, equity considerations must be foregrounded in subsequent iterations,

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including the development of multilingual content, culturally appropriate guidance, offline-tolerant features, and accessible visual design.

Moving forward, our study team intends to evaluate the efficacy of the FLAGs app through a randomized controlled trial (NCT06457750) in improving anthropometric outcomes and establish its broader behavioral and health impacts [30]. This prospective interventional study aims to examine changes in infant feeding practices; mealtime routines; and anthropometric outcomes such as weight-for-length, BMI, and adiposity. Incorporating validated behavioral scales such as the Baby Eating Behavior Questionnaire and Children's Eating Behavior Questionnaire [31] alongside growth metrics would provide a robust assessment of efficacy. Equally important will be the systematic evaluation of mediators (such as engagement dose and message exposure) and moderators (such as parity and baseline feeding difficulties). Use analytics, including log-in frequency, feature taps, and completion of advisories, should be analyzed a priori to explore "dose-response relationships" and fidelity of engagement [20,21,30]. Such an approach would advance understanding of not only whether the app works but also how it works and for whom it is most effective.

This study has several strengths. The FLAGs digital health app was developed through a clinically informed, framework-based process integrating evidence-based recommendations with input from health care professionals. The mixed methods design is a comprehensive process of evaluation that allowed for triangulation of quantitative and qualitative insights, enriching interpretation and ensuring that usability ratings were contextualized by lived experiences. Rigorous qualitative analysis procedures, including independent coding, consensus discussions, and audit trails, enhanced the trustworthiness of the findings.

Nevertheless, several limitations should be acknowledged. The sample was small, clinic based, and restricted to English-speaking participants, which limits generalizability. The 7-day evaluation period was limited in duration and did not permit the assessment of long-term engagement or sustained behavioral effects. Outcomes relied primarily on self-report, introducing potential recall and social desirability biases, whereas the clinic-based recruitment may have contributed to selection bias. These constraints are typical of a pilot study but must be addressed in future work. Larger and more diverse samples; extended follow-up; and incorporation of objective measures, including food photo diaries and automated tracking of physical activity, will be useful in validating these findings and evaluating real-world impact.

In conclusion, our pilot study showed that FLAGs, a medically guided digital health app, was deemed to be usable and acceptable by target end users, providing structured, evidence-based support for infant feeding and lifestyle practices while identifying areas for refinement such as data entry, personalization, and multicaregiver access. With further system and interface optimization, as well as robust evaluation of its efficacy in a subsequent interventional study, our tool has potential as a scalable strategy to promote healthy routines in early life and support obesity prevention.

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Data Availability

All data generated or analyzed during this study are included in this published article and its supplementary information files.

Authors' Contributions

DC and SLL conceptualized the study. SJ conducted data collection, patient interviews, and all statistical analyses. MA, NT, and DC wrote the manuscript. CWK, CO, SLL, FY, CMC, and KYJC provided critical revisions to the manuscript. All authors contributed to manuscript refinement and approved the final version.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview guide including the System Usability Scale and acceptability questionnaire.
[DOCX File, 93 KB - pediatrics_v9i1e86139_app1.docx]

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Abbreviations

FLAGs: Feeding, Lifestyle, Activity Goals
mHealth: mobile health
MINISTOP: Mobile-Based Intervention Intended to Stop Obesity in Preschoolers
SUS: System Usability Scale

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Use of WhatsApp in Children's Oral Health Education Among Mothers in a Maternal and Child Cohort: Qualitative Content Analysis

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Abstract

Background: Research indicates that social media platforms play an important role in disseminating health information. Mothers, in particular, frequently seek guidance on child health through digital resources. Given the growing demand for health-related content, it is necessary to understand how these tools contribute to maternal health education, especially regarding the ability to interpret and apply health information.

Objective: This study aims to investigate how WhatsApp influences the health education processes of mothers, as well as to identify the interests and competencies related to infant oral health among mothers participating in a maternal and child cohort.

Methods: This was a qualitative, exploratory study grounded in the Bardin content analysis framework. Text messages exchanged between mothers and health professionals in a WhatsApp group linked to the Curitiba Maternal and Child Health Cohort (COOSMIC) were analyzed, referring to the years 2020 and 2021.

Results: The corpus was composed of 36 dialogues: 28 concerning infant oral health and 8 regarding the group's impact. The recording units were categorized by themes and interpreted according to emerging core meanings. We identified 2 main themes: eruption of primary teeth (mentioned 12 times) and bruxism in children (mentioned 5 times). Furthermore, in the topic related to the group's impact, we observed a pattern among participants in recognizing the group as a source of support, guidance, and mutual help, highlighting the role of professionals and peer-to-peer exchanges in overcoming doubts and insecurities. Mothers demonstrated an active search for information and collaborative interaction with health professionals, establishing WhatsApp as a support and education network. Competencies linked to oral health literacy ranged from autonomy, empowerment, and security to insecurity, misinformation, and knowledge limitations regarding infant oral health information.

Conclusions: WhatsApp proved to be a relevant tool for accessing information and guidance on infant oral health, favoring mutual support and communication among peers and professionals. The competencies and limitations identified in the mothers' oral health literacy highlight the importance of professionally mediated educational strategies aimed at improving the quality of information and promoting autonomy in infant care.

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KEYWORDS

health literacy; HL; health education; digital health; social media; WhatsApp; mobile health; mHealth; oral health; oral health literacy; child health; maternal and child health.

Introduction

Oral health constitutes an essential dimension of general health, as the oral cavity is directly related to quality of life [1]. From a broader perspective, health involves an individual's living conditions and interactions with the environment, which are related to various social determinants [2]. In this context, education plays a prominent role, as it promotes the development of skills and competencies that contribute to quality of life. Thus, it is considered a prerequisite for health [3].

Among these skills, health literacy (HL) stands out, referring to the capacity to interpret, comprehend, and apply health

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information [4,5]. When this concept is applied to child health, maternal HL becomes especially relevant, since mothers play a fundamental role in the life and health of their children, directly influencing the formation of good habits [1]. Evidence indicates that children of mothers with higher oral HL have lower rates of dental caries [6], while low levels of oral HL negatively impact children's oral health [7].

Research indicates that social media can play an important role in the dissemination of health information [8]. The active search for health-related content through digital resources has frequently been used by mothers interested in obtaining guidance on child care [9]. Furthermore, these resources offer connection spaces [10] that are specifically present in the maternal routine, providing emotional support and promoting the exchange of experiences between mothers [11,12].

With the growing use of social media by mothers seeking information about their children's health, it becomes necessary to understand how these digital tools contribute to health education, especially concerning the maternal capacity to interpret and apply reliable information. Therefore, this study aims to investigate how WhatsApp (Meta Platforms, Inc) influences the health education processes of mothers, focusing on child health. Furthermore, it seeks to characterize interests in infant oral health, analyze the questions raised, and identify competencies related to infant oral HL within this population.

Methods

Study Design

This study is nested within a cohort of pregnant women, mothers, and their children included in the Curitiba Maternal and Child Health Cohort (COOSMIC), conducted by the Pontifical Catholic University of Paraná (PUCPR), in partnership with the Municipal Health Secretariat of Curitiba [13]. The cohort population includes pregnant women at any gestational stage, aged 16 years or older, residing in Curitiba and receiving care through the "Rede Mãe Curitibana" health network. Participants are followed from pregnancy until the child reaches 2 years of age. The cohort sample consists of 1046 participants, with a mean age of 27.95 years.

This is a qualitative, exploratory study design based on the analysis of secondary data derived from text messages within a WhatsApp group. WhatsApp is a real-time messaging platform that allows for text-based communication and the exchange of various media formats, including photos, videos, documents, and location data [14]. This group was created by the cohort to provide maternal and child health guidance to participants, with an average of 85 members, including mothers and the health care professional (HP) team.

Data Source and Selection Criteria

Data were collected by exporting the WhatsApp group conversations to a text file, which exclusively contained text-based interactions between participating mothers and HPs. The selection of messages was conducted through manual reading, allowing for a comprehensive evaluation of the content shared in the group and ensuring that no relevant themes were missed. Additionally, the search function for specific terms (eg, tooth, mouth, and pain) within the text file was used to complement the manual reading. Only messages addressing doubts related to infant oral health were selected. Messages that did not specifically address this theme were excluded, ensuring that the corpus remained focused on the research's central topic. In addition to this criterion, only data referring to the years 2020 and 2021 were analyzed.

Data Analysis

Data interpretation was conducted using the content analysis method, as proposed by Bardin [15]. Through an exhaustive reading of the material, core meanings related to the investigated topic were identified. Initially, all dialogues were organized in a spreadsheet, where each row contained a question and its corresponding responses, preserving the original interaction flow. The material was reviewed repeatedly to identify recurring patterns in the mothers' questions. Based on these patterns, dialogues addressing similar themes were grouped, allowing thematic categories to emerge inductively from the data. These categories subsequently served as the coding framework for data organization. The final count of dialogues was performed manually after the complete tabulation of all interactions. The coding and thematic categorization process was performed by the primary researcher (NGV) and subsequently reviewed and validated by a senior supervisor (RIW). Any disagreements or uncertainties regarding the definitions of the categories were resolved through consensus meetings between the researcher and the supervisor.

Data collected from the WhatsApp group were organized based on the doubts presented by the mothers. Each dialogue was defined as a single doubt (question), accompanied by one or more responses or interactions from other participants and HPs. Accordingly, dialogues were counted based on each new doubt sent to the group. A single mother could initiate more than one dialogue throughout the analyzed period; thus, the individual participant did not determine the number of dialogues. Cases where a question received no response were also recorded as initiated dialogues, even without subsequent interaction. In addition to dialogues related to infant oral health, a second thematic axis regarding "valuing the group as a support space" was analyzed. In these instances, dialogues were defined by spontaneous messages containing feedback from mothers about their experience in the group.

To facilitate visualization, consecutive messages sent by the same participant within a single dialogue were transcribed on a single line, separated by a forward slash (/). The dialogues were initially analyzed in Portuguese, maintaining the original spelling and informal language to preserve the authenticity of the interactions. For the purposes of this publication, the dialogues were translated into English. This process involved linguistic adaptations designed to ensure clarity and comprehension for the audience while carefully maintaining the informal tone and original intent of the participants' messages.

For the analysis, a standardized nomenclature was adopted to identify participants. Mothers who initiated dialogues with questions or doubts were identified as "Mother A," while those who participated in the interactions by responding were

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identified as “Mother B.” Responses from the HPs linked to the project were identified as “HP”. In addition to this classification, each participant was assigned a sequential number corresponding to the chronological order of their first intervention in the group. This numerical identification was maintained consistently throughout the entire analysis, regardless of whether the participant initiated new dialogues or interacted in dialogues started by others.

The use of this nomenclature and sequential numbering was adopted to preserve the identity of the participants, protecting personal information such as names and phone numbers. Beyond ensuring data confidentiality, this strategy facilitated the organization and visualization of the dialogues during the analytical process. All identifiers were removed, and quotes were deidentified before analysis to ensure the protection of participant information.

Ethical Considerations

The COOSMIC project was submitted to and approved by the Research Ethics Committees of the PUCPR (approval numbers 4.819.028 and 2.672.385), and the Municipal Health Secretariat of Curitiba (approval number 4.859.861). The current analysis used secondary data from the COOSMIC cohort. At the time of inclusion in the cohort, participants provided informed consent authorizing the collection, storage, and future use of the data for research purposes. All data extracted from the WhatsApp interactions were completely anonymized before analysis and were used with authorization from the COOSMIC coordination team.

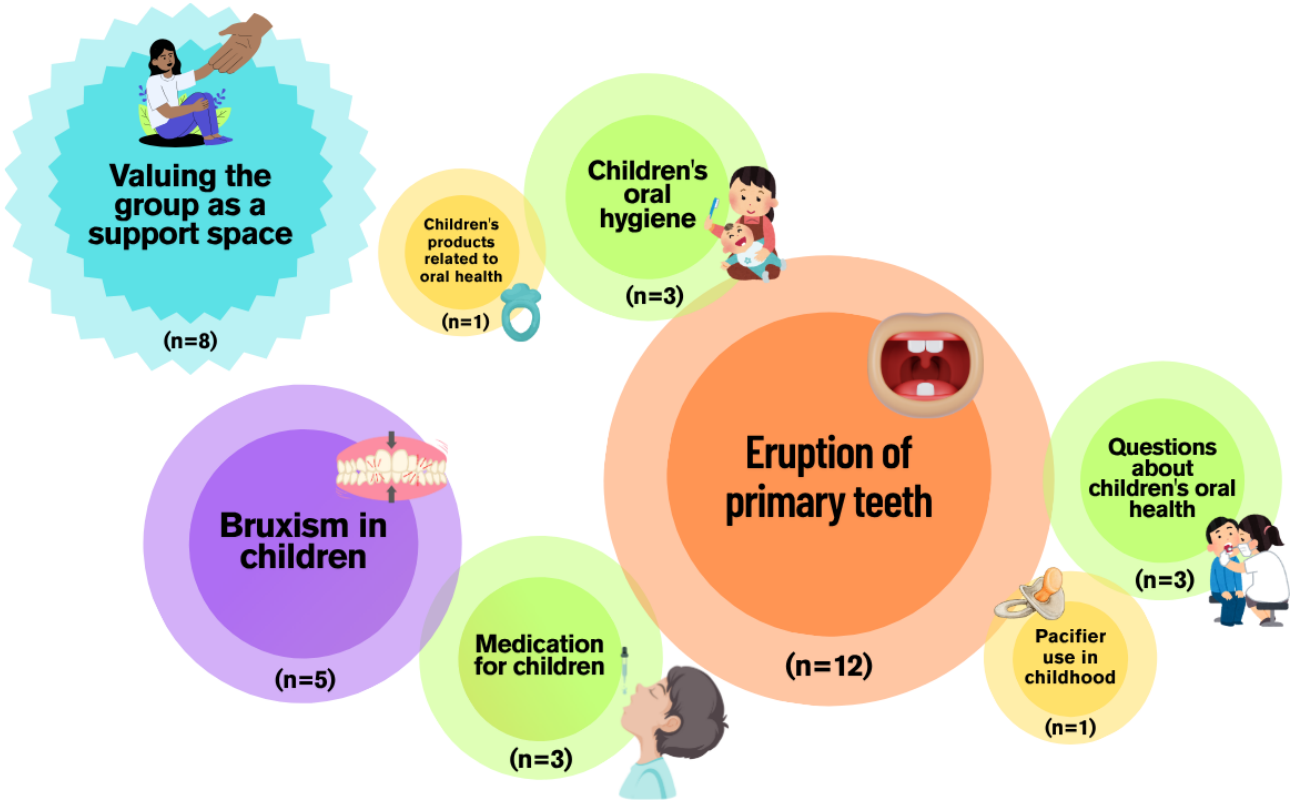
Results

Principal Findings

In the coding stage for the theme “infant oral health,” conducted in a Microsoft Excel spreadsheet, the selected material was reorganized and categorized, giving rise to the following themes: eruption of primary teeth, medication for children, bruxism in children, children’s oral hygiene, pacifier use in childhood, children’s products related to oral health, and questions about children’s oral health. Additionally, in a second spreadsheet, dialogues referring to valuing the group as a support space were arranged, in which spontaneous reports from participants praising the team and the group’s operation were observed. After defining the analysis corpus, the data were organized in a Microsoft Excel spreadsheet, totaling 36 dialogues: 28 related to oral health and 8 to the group’s impact.

The most recurrent themes related to “infant oral health” were eruption of primary teeth (mentioned 12 times) and bruxism in children (mentioned 5 times). Additionally, “valuing the group as a support space” was mentioned 8 times. The frequency of mentions of each theme by the participants is represented in Figure 1.

Figure 1. Frequency of themes related to infant oral health. Representation of themes, where the size and color of the circles vary according to the frequency with which each theme was mentioned in the dialogues. Larger circles indicate higher frequency of the theme. Colors correspond to the number of mentions: orange (n=12), blue (n=8), purple (n=5), green (n=3), and yellow (n=1). The number in parentheses (n) indicates the total number of times each theme was cited. The circle with serrated edges represents a theme not directly related to infant oral health and is shown in a distinct format, unlike the other circles, which represent health-related content.



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From these data, it was possible to identify the most recurrent themes in the dialogues, as well as the frequency with which they were mentioned by the participants.

Analysis of the Identified Categories

Based on this information, the second stage of the research proceeded, aiming to deeply comprehend the core meanings generated by the mothers regarding the themes discussed.

Eruption of Primary Teeth

Dialogue 1

> ***Mother A1:*** *Any dentist in the group? My daughter is very irritated with her teeth coming in... Besides Camomine [supplement used to relieve teething symptoms] and Nenedent [oral gel for gum pain and itching], what else can I do to relieve it?*
>
> ***HP:*** *You can use Nenedent up to 3 times a day... A teether or something soft, without sharp edges, for her to bite... Another tip is to gently massage...*

The mother's interest in seeking further guidance and her appreciation for professional knowledge are evident. This behavior reflects an active effort to seek information about her child's health in order to expand her knowledge and clarify her doubts.

Dialogue 2

> ***Mother A2:*** *Is anyone's baby having teeth come in?*
>
> ***HP:*** *...An alternative for relief is teethers with gel or water inside... you put it in the refrigerator to chill...*
>
> ***Mother B1:*** *My daughter has one with water... Very good...*

Mother B1's response enriches the dialogue by validating the professional recommendation with her personal experience, illustrating an interaction between mothers and a HP.

Dialogue 3

> ***Mother A3:*** *My baby's tooth came out 3 days before he turned 5 months My first child's came out at 6 months. These children are too early.*
>
> ***Mother B2:***
>
> ***Mother B3:*** *[Name suppressed]'s first tooth came out late at 10 months...*

Beyond resolving doubts, the group functions as a peer support network for mothers, constituting a space where participants share experiences and forge social bonds.

Dialogue 4

> ***Mother A4:*** *How long does it take for a baby's tooth to fully come out? It's been a week that my daughter's has only been tips!*
>
> ***HP:*** *That's normal. The speed varies from child to child. If it has already broken through the gum, it will come in fully soon. Keep monitoring it.*
>
> ***Mother B4:*** *It took a month to be complete... These ones have been two weeks and are coming in very slowly.*
>
> ***Mother B5:*** *It's normal, my 11-month-old baby's is like that too. It takes weeks to come out completely.*

Mother A4's inquiry is addressed with professional guidance regarding individual variations in tooth eruption timing, emphasizing the importance of continuous maternal monitoring. Furthermore, Mothers B4 and B5 contribute by sharing personal accounts of their children's dental development, illustrating the exchange of experiences within the group.

Dialogue 5

> ***Mother A5:*** *My 9-month-old daughter has a fever and is very irritable. Both bottom teeth have come in and I can't identify what it could be... should I take her to the emergency room?*
>
> ***Mother B6:*** *Take her to the doctor.*
>
> ***Mother B7:****Have the top ones come in? If not, it could be that too.*

In this interaction, Mother B7's intervention stands out as she hypothesizes that the child's irritability and discomfort may be associated with the eruption of the upper teeth.

Medication for Children

Dialogue 6

> ***Mother A6:*** *Girls, does anyone here give iron [supplement used to prevent anemia] to their baby? The pediatrician prescribed it, but I see that some children develop rotten teeth when given it. Is it mandatory to give?*
>
> ***Mother B8:****I give it every day. I haven't seen this "rotten tooth" thing, but it was recommended to avoid anemia. I also give Adtil [vitamin A and D supplement]. You have to clean the baby's mouth after giving it, to avoid cavities, according to the baby's dentist.*
>
> ***Mother B9:*** *I give it. And I haven't had any problems with cavities.*
>
> ***Mother B10:*** *I give it and I also give vit. [vitamins] Do I clean the mouth after giving the iron ?*
>
> ***HP:*** *When pediatricians prescribe vitamins (like Ad-til) or minerals (like iron), these serve to supplement the body's nutrient amounts and should be given. Ferrous sulfate can stain teeth.... That's why cleaning the mouth after administering prevents these stains.*

Mother A6 shares her inquiry regarding the necessity of iron supplementation and her concerns about potential dental damage, while Mother B8 recounts her experience and the hygiene instructions provided by a dentist. The dialogue features an intervention by a HP, who clarifies the importance of supplementation and provides guidance on oral hygiene practices to prevent dental staining.

Dialogue 7

> ***Mother A7:*** *...My son's first tooth is showing, so I bought Nenedent [oral gel for gum pain and itching] ointment and applied it for the first time today. I*

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would like to know how often I can use it? How many times a day? ... Can it be close to mealtimes?

HP: *...every 6 hours... It can be after, because then the gel stays in contact with the gum longer...*

In this dialogue, Mother A7 seeks detailed instructions regarding the frequency of use and the appropriate timing for applying an oral gel to her child.

Dialogue 8

Mother A8: *...[Name suppressed] is 5 months old and his first tooth broke through the gum today. He's in pain, and very tearful. Can I give him baby paracetamol [acetaminophen]?*

Mother B11: *My experience with my [name suppressed] only the original Camomilina C [herbal medicine used to relieve teething symptoms] worked... even generic didn't help*

HP: *Yes, you can give Tylenol baby [acetaminophen formulated for infants].... Draw up the amount corresponding to his weight in the syringe and... every 8 hours... You can give it for 5 days.*

Mother A8: *I gave paracetamol [acetaminophen], 8 drops directly into his mouth. I did it wrong. Did it really have to be in the syringe??*

In this scenario, Mother A8 seeks guidance regarding the possibility of administering medication to her child and subsequently expresses doubts about the correct method of administration, even after receiving instructions from the HP.

Bruxism in Children

Grouped Dialogues

Similar dialogues were identified among Mothers A9, A10, and A11, who expressed doubts related to their children's habit of grinding their teeth. It was observed that Mothers A9 and A11 received guidance from HPs, while Mother A10 received an answer from another group participant:

Mother A9: *I have a question about my son, is it normal for him to grind his teeth? He is almost 12 months old.*

HP: *It is very common at this age. Take a look at this image I sent!*

Mother A10: *My 7-month-old baby is having teeth come out. But she keeps grinding her teeth, it gives me anxiety*

Mother B12: *My son used to "weirdly move" his jaw... it gave me anxiety..lol I used to tell him "Stop that." But he stopped on his own, never did it again. Oops: "Clicking"*

Mother A11: *My girl is 8 months old and has 4 teeth and grinds her teeth, is it normal? She grinds all the time, it seems like they will break*

HP: *It is very common at this age. Only if the teeth are wearing down too much is a dentist's examination necessary. But up to 2 years of age, the behavior is normal. I sent an image for you to read more about this habit*

In these interactions, mothers share similar experiences and concerns regarding tooth grinding (bruxism) in their children. Consequently, the HP intervenes by providing technical guidance and informative images aimed at addressing the doubts and concerns expressed by the participants.

Dialogue 9

Mother A12: *Guys, my baby started grinding his teeth I keep trying to make him stop. He is 10 months old... He grinds during the day. Not at night*

HP: *This habit is very common at his age. It is only worrying when he hurts himself or his teeth wear down significantly. I will forward an image with more explanations*

Mother B13: *I have bruxism... I have 4 broken teeth... I had several problems, the best thing is early diagnosis and treatment*

In this dialogue, a similar situation is observed with Mother A12, who expresses concern regarding her child's habit of bruxism. In response, the HP provides guidance and seeks to reassure her.

Children's Oral Hygiene

Dialogue 10

Mother A13: *...Is cleaning the baby's mouth after every feeding and meal? I'm doing it after meals... The teeth haven't come in yet, but it's very swollen and almost coming out. I'm cleaning with a cloth and water, I don't know if that's correct. She is seven months old*

Mother B14: *It's recommended to clean with gauze 3 times a day. I only clean when bathing when I give iron [supplement to prevent anemia], after a few minutes. Just so she doesn't get thrush on her tongue. But if there is enough time, you can clean more often*

Mother A13 demonstrates attentiveness to her daughter's oral hygiene by seeking validation of her existing routine. In addition, Mother B14 provides detailed information regarding frequency, materials, and the underlying purposes of the practice, sharing guidance that reflects previous access to technical knowledge on infant oral health.

Pacifier Use in Childhood

Dialogue 11

Mother A14: *...My daughter uses a pacifier, and she turned 6 months old. Do I need to change her pacifier to the 6 to 12 month pacifier?*

Mother B15: *I changed it. My son uses the Mam brand. He used number 1 until six months, then I changed. He accepted it very well. Because Mam pacifiers are all anatomical and always follow the same model, only the size changes... Everything has to evolve as the child evolves... That's why everything is right according to the child's age, right?*

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> ***Mother B16:*** *In the beginning, it's strange because of the size... But then you'll see that it fits perfectly.. lol*

In this interaction, Mother B15 provides a detailed personal account of the transition to a new pacifier size and her child's adaptation to the product. Mother B16 complements the dialogue by reporting her own perceptions and initial experiences regarding the size change, thereby illustrating the peer interaction and exchange of experiences among mothers within the group.

Children's Products Related to Oral Health

Dialogue 12

> ***Mother A15:*** *What kind of teether should I buy?*
>
> ***Mother B17:*** *Here I have that little hand from BDA, a butterfly, and a Fisher Price one... There was never a risk of her biting my chest due to confusion. Don't buy a very soft one so there's no confusion during breastfeeding*
>
> ***HP:*** *...those with gel or water inside are great! When the teeth are coming in, you can put them in the refrigerator... The cold relieves local irritation*

In this dialogue, Mother A15 receives information from distinct sources. While Mother B17 shares a personal account, the HP provides guidance based on technical knowledge. This scenario highlights the diversity of information circulating within this digital environment.

Questions About Children's Oral Health

Dialogue 13

> ***Mother A16:*** *My baby has a black spot on his tooth... I don't know what it is. It looks painted, you know? Can anyone tell me if it's normal?...*
>
> ***HP:****Is your child taking any iron medication? We can talk better in private contact.*
>
> ***Mother A16:*** *He takes ferrous sulfate. You can call me*

Mother A16 demonstrates attentiveness and vigilance regarding her child's oral health by reporting observed changes and seeking guidance. In response, the HP seeks to understand the clinical condition in order to provide appropriate guidance. This interaction illustrates how this digital environment facilitates direct communication between the HP and the participant.

Unanswered Questions

During the analysis, doubts raised by participants related to infant oral health were observed; however, these did not have continuity in the dialogue, whether due to a lack of response or a lack of interaction. These records nevertheless highlight mothers' active and recurrent efforts to seek information related to their children's oral health:

> ***Mother A17:****My[name suppressed] is 5 months old, complaining about gum itching and certainly pain too. I've used Camomine C [supplement used to relieve teething symptoms], Nenedent [oral gel for gum pain and itching], Ibuprofen is helping a little... Do you have anything to suggest that helps minimize the discomfort? Please share with me if you have anything to recommend.*
>
> ***Mother A18:*** *I have a question, do I clean after her teeth start to come in or even before?*
>
> ***Mother A19:*** *My 5-month-old baby's teeth are coming in, he is very tearful and not sleeping well. What can I do?*
>
> ***Mother A20:*** *Any tips for when the first tooth breaks through?*
>
> ***Mother A21:*** *How do I perform good oral hygiene if my baby no longer opens his mouth or bites?*
>
> ***Mother A22:*** *Guys, my baby will be 2 months old and doesn't take her hand out of her mouth, she's very irritable*

The excerpt below reveals a series of important elements related to the barriers faced by mothers during the COVID-19 pandemic:

> ***Mother A23:****...I believe the back teeth are coming in (I know because I managed to see, and the gum is super swollen), but she puts her hand in her mouth a lot and complains. Would anyone be able to help me with what to do? Keeping in mind that we are in the COVID-19 pandemic and taking her to the dentist at this moment is complicated. Not to mention that she is autistic, and she has certain rejections.*

The situation described by the mother highlights the difficulties faced in accessing in-person dental care, especially when caring for children with special needs during the health crisis. In this scenario, the group was configured as an accessible support tool given the limitations imposed by the pandemic.

Audiovisual Questions

Dialogue 14

During the analysis, dialogues were observed in which participating mothers used audiovisual media to express their doubts, such as audios, photographs, and videos. However, access to the WhatsApp group interactions was through a text file, making it impossible to view and analyze these other media formats. Therefore, only textual messages were considered. To signal the use of these media, brackets were inserted to indicate the type of media shared by the participant:

> ***Mother A24:****[sent image] It's purple, looks like a sore. He had a fever of almost 40 degrees. The COVID test was negative.*
>
> ***Mother B18:****That tooth is the most painful one, poor thing. There is Nenedent [oral gel for gum pain and itching]... when my children had this discomfort, I applied the ointment and alternated with Novalgin infant solution [dipyrone oral solution for infants]. And I also gave those cold teethers to bite. Check correctly with the pediatrician or pharmacist how much Novalgin you can give, to help with the pain he is feeling.*

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HP: *You can use Nenedent or Ad Muc gel [both topical oral gels used to relieve gum discomfort during teething]. Apply about 4 times a day. And you can use an analgesic to help too. The most suitable for babies is Paracetamol [acetaminophen]. 1 drop per kilogram of weight every 8 hours.*

Mother B19: *[link suppressed] Watch this video. Cold things help a lot*

Mother B20: *Mallow tea or mallow compress helps a lot*

Mother B21: *How many months is he? My baby is also 8 and doesn't have any teeth, I'm starting to worry*

Mother B22: *...teeth can take up to 1 year of age to come in. My friend's son had his first ones come in when he turned 1 year old.*

Following Mother A24's question, several interactions took place among the participants, including guidance, suggestions, and the sharing of personal experiences. Mother B19's sharing of a web link illustrates mothers' use of social media to seek health-related information.

Dialogue 15

Mother A25: *[sent audio and image, indicated by the responses as a question regarding the eruption of the baby's dentition]*

Mother B23: *Oh my God. Mine will turn one and it's swollen and still no sign of the first one*

Mother B24: *...I think it's not a rule... Mine's first ones came out at 7 months, one on top and one on the bottom... Then the others came out.*

Mother B25: *Mine had two bottom teeth come out between 5 and 6 months. Now the top is mega swollen for 1 month already and hasn't come out... He turned 10 months*

Based on the audio message and an image shared by Mother A25, the other participants contributed by sharing their personal experiences regarding the timing and sequence of their children's tooth eruption. This type of interaction illustrates the exchange of similar experiences among mothers.

Dialogue 16

Mother A26: *[sent audio, indicated by the responses as a question regarding bruxism in children]*

Mother B26: *It is normal for the baby to grind his teeth. Also because he is discovering himself and because he doesn't have a posterior bite.... But regarding taking the baby to the dentist, this can be done from the first month, to learn how to care...*

In this interaction, Mother B26 responds to the audio message sent by Mother A26, reassuring her about bruxism in children. In addition, she highlights the importance of an early dental consultation, demonstrating confidence and clarity when sharing knowledge about children's oral health.

Dialogue 17

Mother A27: *[sent image] My mother said it's thrush.*

Mother B27: *Does it look like angular cheilitis? Or an aphthous ulcer? Is there only one? Did you notice if she feels pain there?*

Mother B28: *Only one? Does she have a fever?*

Mother B29: *Something she ate that was hot.*

Mother B30: *Thrush. Put gentian violet on it. Put it on a gauze and apply it to the baby's mouth.*

HP: *It could be stomatitis*

In this dialogue, Mother A27's question prompted a series of responses and hypotheses from the other participants, ranging from informal diagnostic suggestions to recommendations for home remedies, such as the use of gentian violet. This interaction highlights the high volume of information and the diversity of guidance shared within the digital environment.

Dialogue 18

Mother A28: *[sent image] Hello, my daughter is 2 months old, and I found this white spot.... Could it be a tooth trying to come out?*

HP: *This spot is likely what we call an Epstein pearl... It is just an alteration in the gum... but it disappears on its own.*

Mother A28: *Thank you.... it's not a tooth! Lol!*

The intervention of the HP was essential in clarifying the mother's concern, promoting her understanding of an unexpected clinical sign. By providing a clear explanation, the HP enabled the mother to correctly interpret the information received, thereby providing reassurance.

Valuing the Group as a Support Space

Reports shared by the mothers reveal the importance attributed to the group as a support space during motherhood. Participants highlight the exchange of experiences and support as differentiators in the maternal experience:

Mother A29: *Welcome[name suppressed], this group is great, we exchange a lot of experience and help each other too*

Mother A30: *This group is truly blessed We are blessed to have the support of professionals 24/7 here*

Mother A31: *Guys, the best thing about being a mother is having this group and this exchange of experiences we have here, it's very good to be able to share our experiences*

Mother A32: *...It's great when you are a first-time mother and have a group like this to clear up doubts...*

Mother A33: *You are angels! The whole team! Thank you very much! ".*

Mother A34: *This team rocks ❣ I am also very grateful to every professional present here... you are fundamental in our lives and our children's lives!...*

Mother A35: *Thank you[name suppressed]! Your call was very important. I felt great*

Mother A36: *Just stopping by to congratulate this Coosmic team!* ❤

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Finally, the mothers expressed their appreciation for and satisfaction with the group, highlighting positive aspects such as the opportunity to participate in this space, the possibility of clarifying doubts, the support received, and the strengthening of the support network. In addition, they expressed gratitude for the support provided by the HPs.

Discussion

Principal Findings

This study contributes to the understanding of health education delivered through WhatsApp, highlighting mothers' proactive interest in seeking information about children's oral health. Health guidance provided by HPs through the platform was associated with positive outcomes, facilitating the resolution of mothers' questions while strengthening a peer support network. Our findings further reinforce the idea that the active involvement of HPs is essential to ensure the reliability of oral health information disseminated and shared through digital platforms.

The findings of this study reveal that mothers actively seek information related to their children's oral health through WhatsApp. This behavior reflects their interest in expanding their knowledge and clarifying doubts, as observed in *Dialogue 1* and *Dialogue 11* and in the *Unanswered Questions*. These findings are consistent with the literature, which indicates a growing trend among mothers to use social media as a source of information on child health [9,11].

Beyond information seeking, interactions within the group revealed other relevant behaviors. Among these, the search for opinions, observed in *Dialogue 14*, stands out. Previous studies have also shown that mothers use digital platforms to support decision-making regarding childcare, attributing considerable value to these spaces as sources of information [11]. Another identified aspect was the exchange of experiences, advice, and suggestions among participants. This pattern, observed in *Dialogue 3*, *Dialogue 4*, *Dialogue 14*, and *Dialogue 15*, reinforces collective support and highlights a frequent need for connection and validation of motherhood experiences [11].

In this context, the group extends beyond its role as a space for clarifying doubts and functions as a peer support network, providing an environment in which participants share experiences, recognize common situations, and establish social bonds. This environment is valued by mothers for promoting mutual validation, reassurance, and support, as reported in the findings of this study. Similar findings have been reported in previous studies, which indicate that digital platforms can contribute to mothers' emotional well-being [11] by fostering support, information sharing, and a stronger sense of connection among participants [12].

This study also demonstrates that WhatsApp can be used as a strategy for health promotion. Across several dialogues, HPs play a key role by providing guidance that promotes maternal autonomy. This is illustrated in *Dialogue 4*, in which the mother is advised to monitor her infant's tooth eruption, and in *Dialogue 6* and the *Grouped Dialogues*, where HPs help clarify questions and improve participants' understanding. These findings highlight the potential of social media as a strategic tool for health education [16]. Furthermore, they underscore the importance of professional guidance, as clear explanations enable mothers to correctly understand and independently apply health information, as illustrated in *Dialogue 18*.

In this context, WhatsApp facilitates communication between HPs and mothers. This practice has also been described in previous studies, in which HPs use digital technologies to provide health guidance and information [17,18], reflecting the field of teledentistry, which refers to the use of technologies, such as mobile communication devices, to deliver dental services and health education activities [19]. In *Dialogue 13*, the HP's suggestion to continue the conversation privately illustrates the delivery of health education through remote care, characterizing a teledentistry practice. This approach has emerged as an alternative for providing health guidance while strengthening the relationship between HPs and patients [18]. Similarly, another study identified a similar scenario, highlighting teledentistry as a tool that can be used by HPs for oral health promotion, particularly through text messages and mobile apps [20].

Teledentistry gained particular prominence during the COVID-19 pandemic [21], when limited access to in-person dental care led digital technologies to become an accessible resource for addressing health-related concerns [8,18]. In the *Unanswered Questions* section, mothers sought guidance regarding their children's oral health during this period, using the group as one of the available sources of professional support. This finding further reinforces the potential of WhatsApp as a tool for delivering health guidance and information.

However, these digital interactions also reveal potential risks and limitations. In *Dialogue 9*, 1 mother compares her experience of bruxism in adulthood with another mother's report of bruxism in her child during infancy. This example illustrates the risk of sharing inaccurate information that is not supported by scientific evidence. This is particularly important because bruxism is considered a common finding in early childhood [22], whereas in adults it is associated with different etiologies [23].

Another example is observed in *Dialogue 17*, in which a mother recommends applying gentian violet to the infant's mouth. Information shared by individuals without health care training may contribute to the phenomenon known as an infodemic, characterized by an overabundance of information, often including unreliable content, that can compromise health promotion [24]. A similar situation is observed in *Dialogue 12*, where a participant states that soft teething rings should not be used because they could interfere with breastfeeding. This recommendation contradicts current evidence supporting the use of soft, flexible teething rings because of their significant soothing effect during tooth eruption [25]. Therefore, unreliable information may circulate within the group, highlighting the importance of HPs in providing accurate, evidence-based guidance [24].

Taken together, these findings emphasize the importance of the presence and active mediation of HPs. Their involvement is essential to provide technical clarification, prevent the

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dissemination of inaccurate information, and promote access to reliable health information. Conversely, the absence of such active mediation may increase maternal uncertainty and contribute to the spread of misinformation [24].

Although inaccurate information was shared by some participants within the group, the findings also identified mothers who demonstrated knowledge related to children's oral health. In *Dialogue 5*, for example, 1 mother critically assessed the situation by suggesting that tooth eruption could be the cause of her infant's discomfort, demonstrating a higher level of oral HL. This ability reflects critical appraisal skills [4,5], as she associated a clinical sign—irritability, which is commonly related to the eruption of primary teeth [17]—with the timing of tooth eruption.

In *Dialogue 7* and *Dialogue 10*, mothers sought information regarding the appropriate use of medications and oral hygiene practices for their children, suggesting more advanced HL skills by demonstrating the ability to seek, understand, and apply health information—competencies typically associated with individuals who are better able to manage health-related situations, as described in the literature [5]. These HL skills were also evident in other situations, including mothers' vigilance regarding their children's oral health, as observed in *Dialogue 13*, and their confidence in discussing bruxism and recognizing the importance of early dental care, as illustrated in *Dialogue 16*.

Conversely, *Dialogue 8* illustrates HL skills that were still developing. The mother's uncertainty regarding the correct administration of the medication, even after receiving guidance, suggests difficulties in understanding and applying health information in practice. This dialogue reflects competencies consistent with more basic levels of HL, in which health information is applied with less autonomy than in more advanced manifestations of HL [5].

Taken together, these findings indicate predominantly advanced manifestations of HL among the participating mothers, reflected in a more proactive attitude and a greater understanding of children's oral health information. This familiarity with the topic was demonstrated not only through the ability to interpret health information but also through the ability to share it with others, thereby contributing to collective knowledge [5]. Furthermore, greater attention to children's oral health care was observed, consistent with previous studies which show that higher levels of maternal HL are associated with increased attention to child health care [6,26].

Limitations

This study presents some limitations. First, the number of text messages collected for the analysis of infant oral health is small, which restricts the analysis and may not reflect the diversity of experiences among mothers. Second, as this research is based exclusively on text messages, it was not possible to directly evaluate the impact of the information on mothers' daily lives, which limited understanding of the effectiveness of digital technologies within health education processes. To address this, complementary data, such as interviews, observations, or objective outcome measures, would be necessary. Given these limitations, it is recommended that future studies use mixed methods, integrate impact measures, and include longitudinal evaluations, in order to deepen the understanding of the effectiveness of digital technologies in mothers' health education processes.

Conclusions

WhatsApp proved to be a useful tool for mothers seeking guidance related to infant oral health. Participants reported positive impacts resulting from the guidance received from HPs, as well as the peer support built within the group. Furthermore, the study allowed for the identification of a diverse range of patterns related to the competencies and limitations in infant oral HL within the studied population, such as empowerment, autonomy, insecurity, knowledge gaps, and misinformation.

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The authors used the generative AI (GenAI) tools ChatGPT (OpenAI; [27]) and NotebookLM (Google; [28]) to support the preparation and revision of this manuscript. These tools were specifically used for linguistic support and readability enhancement (including grammatical correction and suggestions for text revision), structural standardization according to the journal's guidelines, and technical translation of sections of the manuscript. Although the GenAI tools generated draft text and translation suggestions, all outputs underwent active curation, critical review, and substantial revision by the authors. The authors reviewed and verified all scientific content and accept full responsibility for the integrity of the final manuscript. The transcripts of the interactions with the GenAI tools are available in Multimedia Appendix 1 (ChatGPT) and Multimedia Appendix 2 (NotebookLM), respectively.

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Data Availability

The data used in this study are part of the database of the COOSMIC and consist of sensitive secondary data derived from private WhatsApp (Meta Platforms, Inc) interactions between participants and health care professionals. Due to the ethical, legal, and privacy restrictions established for the COOSMIC cohort, these data cannot be shared publicly or deposited in open repositories.

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Researchers interested in accessing this data may contact the COOSMIC cohort coordination team. Access to the database is subject to the cohort's internal policies and procedures.

Authors' Contributions

Conceptualization: NGV, RIW
Data curation: NGV
Formal analysis: NGV
Funding acquisition: LRAA
Investigation: NGV
Methodology: NGV, RIW
Project administration: NGV
Resources: ROCdS, JSA, JSR, DC
Supervision: RIW
Visualization: NGV
Writing – original draft: NGV
Writing – review & editing: RIW, NGV, ROCdS, JSA, LRAA, JSR
All authors approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Transcripts of ChatGPT conversations.
[DOCX File, 116 KB - pediatrics_v9i1e89204_app1.docx]

Multimedia Appendix 2
Transcripts of NotebookLM conversations.
[DOCX File, 62 KB - pediatrics_v9i1e89204_app2.docx]

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Abbreviations

COOSMIC: Curitiba Maternal and Child Health Cohort
HL: health literacy
HP: health care professional
PUCPR: Pontifical Catholic University of Paraná

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Health System Community Partnership to Design an Online Resource to Address Perinatal Information Needs for Black Families: Action Research Study

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Abstract

Background: In the United States, Black mothers and their infants experience higher rates of maternal and infant mortality than other racial or ethnic groups. North Carolina mirrors national trends with worse perinatal outcomes for Black families compared with other groups. Most ongoing efforts to address these disparities focus on policy and systems change. Few initiatives focus on education and resource navigation for families.

Objective: This study aimed to design an online resource hub to provide information to support timely access to care and resources to improve perinatal health outcomes for Black families in Mecklenburg County, the largest metropolitan area in North Carolina.

Methods: We used an iterative community-informed process, including focus groups and meetings, to develop and refine the layout and content of an informational website. We conducted focus groups during 2022 and 2023 with Black mothers (n=14) who had given birth in the prior 2 years or were pregnant. A semistructured interview guide explored participant perspectives on (1) information that would be most helpful during the perinatal period, (2) website usability and content, (3) appropriateness of imagery and topics, and (4) effective dissemination strategies. Additionally, the research team met regularly with a multisector community partner group to get feedback on website iterations and solicit community resources to include. All content was reviewed for health literacy. Focus group participants were recruited through local clinics and partnering community-based organizations. Our multisector community partner group included individuals representing public health, patients, providers, social services, and health system leaders. The Reach, Effectiveness, Adoption, Implementation, and Maintenance framework was used for evaluation.

Results: Key themes for website focus areas included (1) vetted information presented in lay terminology, with tools to identify local, affordable, and culturally competent care; (2) information related to the week-to-week changes they could expect during pregnancy; and (3) alternative birthing options. The most common suggestions for improvement related to the navigation, amount of text, color scheme, and the use of images. The final Mecklenburg Birthing Connections resource hub provides educational and informative resources for every stage of the perinatal care journey, from preconception to childcare, and links to community resources to address health care and social needs. Results from outreach and marketing efforts to increase awareness of the resource within the community had a broad reach. In-person events attracted >800 community members and social media marketing

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engaged >145,000 unique accounts. Focus group discussions revealed that Black mothers feel that the website addresses important informational needs for Black families.

Conclusions: Partnership with community members enabled the design of a tailored online tool for providing timely information to educate and empower Black families. Ongoing maintenance and dissemination may help address local inequities in perinatal health outcomes.

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KEYWORDS

perinatal care; patient education; health disparities; social determinants of health; community partnership; maternal health; infant health

Introduction

Maternal and infant mortality rates in the United States far exceed those of other high-income countries. In the United States, more than 700 women die of pregnancy-related complications each year, and approximately 50,000 women experience severe maternal morbidity [1]. In 2022, there were 22.3 maternal deaths per 100,000 live births, representing 817 women who died from maternal causes [1]. Infant mortality rates are on the rise, increasing from 5.4 deaths per 1000 live births in 2021 to 5.6 deaths per 1000 live births in 2022 [2]. Underpinning these stark statistics are persistent racial and ethnic disparities that have yet to be comprehensively addressed by the US health care system. Black and American Indian and Alaska Native (AIAN) women are more than 2-3 times more likely to die from pregnancy-related complications [1]. Black, AIAN, and Native Hawaiian and Other Pacific Islander experience higher preterm births, low birthweight births, or births where they receive inadequate or no prenatal care [3]. Consequently, infants born to Black, AIAN, and Native Hawaiian and Other Pacific Islander women have higher mortality rates than their White counterparts [3].

Several strategies have been proposed to mitigate disparities in maternal and infant health. Ongoing policy initiatives are aimed at the promotion of expanded access to prenatal and postpartum care and coverage for Medicaid beneficiaries who are disproportionately Black, Hispanic, or AIAN [4]. Other efforts have focused on improving the racial diversity of the maternal health workforce to match that of the population [5,6]. Community-based programs such as Healthy Start [7,8] that offer care coordination and service referrals, and home visiting programs [9,10] are other promising strategies. In addition to addressing these structural determinants, there remains a need for person-centered and community-centered approaches that equip and empower families with information to navigate resources available to support their perinatal care needs.

Digital media tools, including websites, mobile apps, SMS, or discussion forums, have been shown to reduce barriers to traditional forms of perinatal care and increase accessibility [11]. For example, digital tools have been used to provide educational information regarding reproductive life planning, postpartum care, anxiety reduction, and health management [12-16]. In a systematic review of 55 studies of digital patient education interventions in the perinatal period, more than two-thirds of studies (n=38) reported a significant positive outcome related to improved patient knowledge, emotional benefit, or improved health behaviors. These tools have the potential to complement other efforts aimed at reducing maternal and infant health disparities by increasing patient empowerment and self-efficacy, supporting patient-provider relationships, and strengthening connections to community resources that lead to improved health outcomes [17,18].

Perinatal populations have indicated a preference for digital health resources that highlight what is typical to expect during pregnancy, provide access to a provider when needed, and offer information on fetal development [19]. Another important consideration in the development of perinatal digital health tools is the quality of health information hosted on these platforms. A scoping review of 30 studies by Li et al [20] concluded that perinatal women were dissatisfied with the quality of maternal and infant health information available on digital media, raising skepticism about the credibility of those delivering the information, the irrelevant or repetitive content amid an overwhelming amount of information, and the lack of scientific evidence. Platform usability and commercialization of digital media platforms have also been criticized by perinatal women using digital media platforms for health information [20].

The increased prevalence and use of digital media provide an opportunity to deliver perinatal health information directly to Black families in health care and community settings. Approximately 87% of Black adults own a smartphone and 94% use the internet [21]. Yet, few digital tools are tailored to the needs of Black people. There is scarce research on the development and testing of digital tools specifically designed to address maternal and infant health disparities among Black birthing people. One study testing the effect of a culturally tailored conversational agent for preconception health education among 528 Black women from 35 US states found a 16% increase in action to improve preconception health risks among intervention versus control participants [22]. Exploring different avenues for digital health research among historically underrepresented perinatal populations is critical as the field moves forward. Research on tailored digital tools that span the life course may further enhance efforts to improve disparate perinatal outcomes.

Guided by the literature, we designed a health system–hosted online resource hub to raise awareness, educate, and empower Black birthing people and their families. The online resource hub was an output of a larger project called the Perinatal Access to Care Campaign, which aimed to provide information to support timely access to care and resources to improve perinatal

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health outcomes for Black families. This paper describes the collaborative and iterative design process and early evaluation of the online resource hub and provides recommendations for future research and implementation.

Methods

Overview

We followed a community-engaged participatory action research approach. Community engagement is defined as "the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people" [23]. To that end, we used a collaborative approach guided by an established multisector partnership group, the Bridges Community Partner Group, which served as a steering committee across all phases of project design and execution. The Bridges Community Partner Group prioritized informational resources as a need for the community and participated in the curation of content and resources.

Setting and Participants

This project was conducted in Mecklenburg County, North Carolina, a large metropolitan area with more than 1 million residents. The US Census indicates that 33% (383,645/1,163,701) of residents identified as Black or African American in 2023 [24]. Racial and ethnic disparities in infant mortality in Mecklenburg County mirror state and national trends, with Black infants 2.6 times more likely to die before their first birthday than White infants in 2021 (12.6 vs 4.8 deaths per 1000 live births) [25]. At the state level, the North Carolina Perinatal Health Strategic Plan provides guidance to improve maternal and infant health by addressing social and economic inequities, strengthening families and communities, and improving health care for all people of reproductive age [26]. Within the county, Mecklenburg County Public Health leads initiatives to improve maternal and child health, including home visiting programs, care management, and community health worker programs [27]. Atrium Health is a large not-for-profit health care system headquartered in Mecklenburg County, which delivers the full spectrum of care, including maternity care and pediatric care, through its hospital and outpatient clinic locations. Atrium Health extends care into the community through a variety of programs and partnerships [28]. This project was led by a multidisciplinary team of investigators from Atrium Health in partnership with collaborators from Mecklenburg County Public Health and the University of North Carolina at Charlotte.

Members of the Bridges Community Partner Group were identified through a snowball approach. Snowball sampling is a method used to identify individuals from a specific target population and involves starting with a small initial group and then using referrals to identify additional group members [29,30]. Beginning with an initial group of members from departments across Atrium Health, the group was expanded to include additional internal and external partners and community members to ensure representation of diverse perspectives including birthing professions, public health, social services, community, patient, provider, health system, and research, with a final membership of 42. From August 2022 through August 2024, monthly meetings were scheduled virtually for 1 hour in the afternoon to provide the group with project updates and seek input from partners. All meetings began with a reflection on current news and events related to perinatal health to build common ground around the group's work. Meetings included discussions on the progress of the project and perspectives on the campaign development from the initial website wireframe through the marketing strategy for disseminating the resource.

Ethical Considerations

The Wake Forest University School of Medicine Institutional Review Board reviewed this project and determined that it did not meet the federal definition of research involving human participants, with no need for continuing review (IRB00087620). Verbal consent was obtained from all focus group participants prior to data collection. Focus group participants received lunch (in-person sessions only) and were offered a US $50 prepaid debit card as compensation for their time. Survey data were collected anonymously, with an acknowledgment that participation was voluntary and that data would be reported in aggregate. No compensation was provided for survey data collection. All data were stored without identifying information to preserve privacy and confidentiality.

Conceptual Frameworks

We used a life course perspective to guide project design. The life course perspective posits that observed health and health outcomes are the cumulative result of experiences that happen prior to birth and throughout the lifespan [31]. In the case of Black infants, a life course approach highlights the importance of accessing health care across the life course, investing in community building, and closing the education gap, among other strategies [32]. Extending this perspective, we focused on providing education and resources that spanned preconception and prenatal care in addition to delivery, postpartum, and early childcare experiences. The racism as a root cause framework [33], a solutions-focused approach for addressing racial health disparities, also informed our approach. Using this framework, we devised strategies to address the framework's 4 domains with a specific focus on long-term impact (Textbox 1).

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Textbox 1. Applying racism as a root cause framework to the development of an online resource hub.

Strategies applied for each domain of the racism as a root cause framework:

- Precise impact
  - Target Black mothers and caregivers.
  - Identify target zip codes with >50% Black, >9% low birth weight (county median), and median age of <40 years.
- Systems change
  - Develop internal messaging and provider-facing communication about campaign.
  - Connect with decision makers regarding current policies about where women can go for care.
- Long-term
  - Develop a website with information that can be updated beyond the campaign.
  - Create a plan for keeping information current.
- Reparations
  - Invite Black mothers in target communities to focus groups and pay them for their time.
  - Use feedback from Black community members to guide approach (how, what, and where).

Iterative Website Development

There were several iterations of the website content beginning with the wireframe, or alpha scripts, in March 2023. The evolution of the website was grouped into 4 major stages (alpha, beta 2.0, beta 3.0, and beta 4.0) representing major transitions in website design and content curation over an 18-month period. Feedback from focus groups and our community partner group informed each stage of iteration.

Focus Groups

Across the study period, we held 5 focus groups with community members to gather information on the content that would be most useful to include on the website, usability of the design, and feedback to guide development through the various iterations. Focus group participants were recruited from community organizations located in target zip codes and through associations with the Bridges Community Partner Group. Residents of Mecklenburg County were eligible to participate in focus groups if they identified as Black or African American, were aged 18 years or older, were pregnant at the time of participation, or had a baby in the past 2 years.

Four focus groups were held in person at locations in the community (a local recreation center, a local library, and a residential care organization for expectant mothers). One session was held via videoconference. The first 2 focus groups were held in December 2022 (prior to initial website prototype), and subsequent sessions occurred in August, September, and October 2023. A semistructured interview guide developed based on literature review and input from our community partner group explored participant perspectives on (1) information that would be most helpful during the perinatal period, (2) website usability and content, (3) appropriateness of imagery and topics, and (4) effective dissemination strategies. A total of 14 Black mothers participated across all sessions, with some attending up to 2 sessions. An informed consent document was reviewed with participants prior to the start of each focus group, and verbal consent was obtained from all participants. Focus groups lasted approximately 1 hour and were recorded and transcribed. Focus groups were designed to get iterative feedback on the development of the resource hub. Data collection continued until no new themes emerged. Thematic analysis was used to identify key themes and recommendations across sessions to inform the iterations of website build. Three members of the study team (HB, MI, and YT) led data analysis, and discrepancies were resolved via discussion among all study team members.

Community Partner Meetings

In addition to collecting feedback from focus groups with Black mothers, the Bridges Community Partner Group and the project team also contributed feedback to guide the development of the website in a series of iterations. The Bridges Community Partner Group met once a month virtually to review project updates and solicit input on content and delivery of information for the online resource. Biweekly, the project team met to review partner feedback, identify additional resources based on that feedback, and discuss the organization of the information on the website. Changes to the copy, organization of content, or design were collated by a project manager, who organized information into a script for the health system's website development team to implement.

Language and Health Literacy

All website content was framed using a strengths-based approach. Strengths-based approaches are increasingly used in health interventions to give agency and empower the target audience to take action to achieve their goals for health and well-being [34]. We incorporated language such as "I want" rather than "I need" and imagery that appropriately reflected the target audience. It was important for the website to be relatable to community members to encourage connection and relevance to their own care planning. Content was also reviewed for health literacy to ensure accessibility to a broad audience.

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Marketing and Outreach Campaign

We collaborated with the health system marketing team to design and implement a marketing and outreach campaign for the website. We used the Charlotte-Mecklenburg Quality of Life Explorer [35] to identify target neighborhoods with >50% Black population, median age <40 years, population size >1000, and low birth weight rate >9% (the county overall rate). We identified 9 neighborhoods across 4 zip codes (28205, 28206, 28208, and 28217) that became targets for marketing and outreach following review and input from our community partner group. To assist our outreach efforts, the marketing team developed flyers in both English and Spanish for distribution at community events and clinic locations and via community organizations and partners. The marketing team also developed a campaign that ran from August to October 2024 and included advertisements through the Atrium Health social media channels on Instagram and Facebook as well as out-of-home marketing (billboards) across the target zip codes.

Evaluation Framework

We used the Reach, Effectiveness, Adoption, Implementation, and Maintenance evaluation framework [36] to assess the early impact of the online resource hub and our marketing and outreach efforts. Reach was measured using website and social media statistics, along with attendance at community events. Website traffic was captured by unique visit data and QR code scan totals driving traffic to the site. Social media metrics included impressions, link clicks, likes, and shares. Billboard impressions, a measure of actual and potential ad views based on traffic patterns, were provided by our marketing partner. At community events, attendance was used as an indicator of website reach, as attendees were informed about the resource or received promotional materials. Effectiveness was measured using qualitative feedback from community members. Adoption and implementation in the short term were assessed with an anonymous survey sent to the Bridges Community Partner Group. The 10-item online survey assessed partners' perspectives on whether the campaign met the intended goal, overall satisfaction with the website, and the website usability, readability, accessibility, and cultural relevance. In addition, partners were asked to report how they were disseminating the resource to their personal and professional networks. As part of the final email to thank the partner group for their effort on the project, a request to participate in the feedback survey was embedded in the email with a response window of 2 weeks. A single reminder was sent. This process feedback collected voluntarily did not constitute human participants research or require institutional review board review. Survey results were reported as counts and percentages. Finally, maintenance was assessed by our ability to develop a plan for maintaining and updating website content and integrating it into routine health system workflows.

Results

Key Themes From Focus Groups and Community Partner Meetings

Themes from initial focus groups informing the website design are included in Table 1. Black mothers participating in the focus groups shared what they would like to see in an informational resource. Key themes for focus areas included vetted information presented in lay terminology, with tools to identify local, affordable, culturally competent care, information related to week-to-week changes to expect during your pregnancy, and alternatives to the care options of the hospital. Participants favored having information in a mobile app but were open to having the information in a mobile-friendly website, which was the most feasible option for the project. These findings were reviewed with community partners who agreed with these focus areas and added content for caregivers and connections to community resources.

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Table . Themes from focus groups with Black mothers to inform initial website prototype. Participants were asked about their informational needs and what to include in a resource for Black families.

Theme	Representative quote
Have vetted and distilled information, as to not overwhelm.	"You don't want to go too crazy on the Internet. Because I have tried to diagnose myself with certain stuff, and you'll get scared."
Include current and updated information.	"With my third daughter, it had been a while, and I had nursed, but I needed a refresher."
Have a way to save pregnancy-related details.	"I can't keep up with that stuff [scheduling regular specialist appointments]."
Include personalized recommendations.	"It was like, they read a book. And they thought that book applied to every patient."
Have information on what to expect, week-to-week, during your pregnancy.	"Being able to map it out, so that we can mentally be prepared."
Answer basic questions about pregnancy.	"There was this assumption that I should know. But it's my first time. Why would I know?"
Provide information on sources of culturally competent care.	"I was literally calling saying, hey, do you have a doctor that looks like me?"
Foster community and allow for the sharing of birthing/pregnancy experiences.	"If no one does it for us, we have to be able to seek out things. You need to know who you express these concerns to along the way."
Discuss and explain affordable alternatives to the care options of the hospital.	"I felt like the only option they were trying to give was medicine."
Be comprehensive.	"...I was given an app…but I will say, interface-wise, compared to What to Expect and all that, I don't like the app. So, I don't even really use it because it wasn't as user-friendly and didn't have as much information…it would have made a difference for me to have all [the information] in one place. Because I wanted to like the one they gave me. The doctor said I should download and keep up with it, but I didn't like it. It didn't have all the things I felt it needed to have."

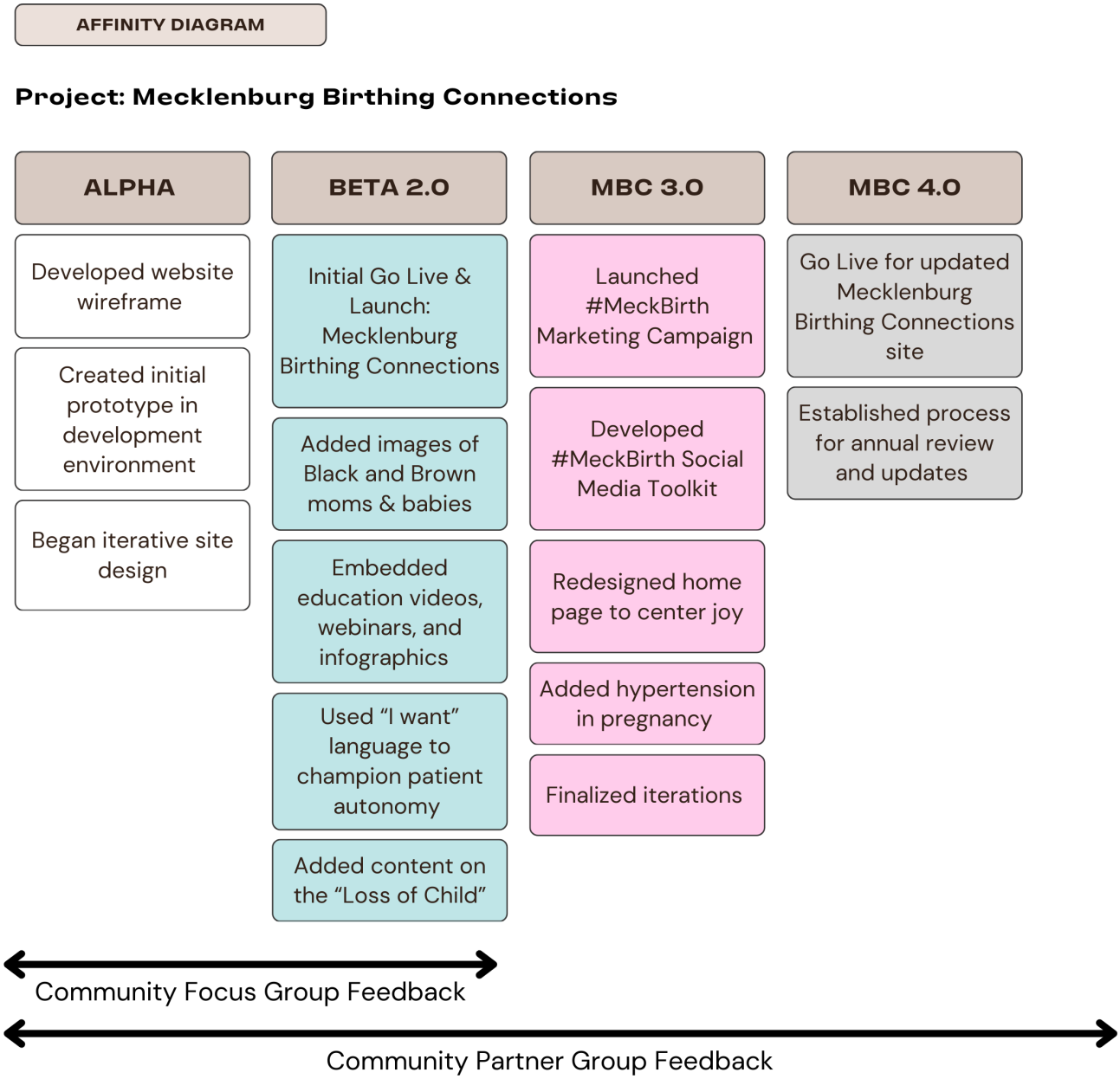
Black mothers attending focus groups where drafts of the website were reviewed had a positive initial reaction to the organization of the website, finding the organization and esthetic clear, and the naming communicative of the site's purpose. The most common suggestions for improvement related to the navigation, amount of text, color scheme, and the use of images. Focus group participants expressed shock at the statistic on the home page, which revealed that Black infants were twice as likely to die as White infants in Mecklenburg County. This topic came up often in feedback, with community partners recommending a "focus on joy" on the home page along with the benefits of the website. Community members still found the statistics informative and recommended that they appear less prominently on the page. Mothers found the use of images containing Black women and babies comforting and familiar, making the information personal to them. Additional feedback included providing more information on topics such as insurance, healing milestones in the postpartum period, lactation, pregnancy symptoms and complications to be aware of, resources for dads, honoring the loss of a child, and changing family dynamics.

Iterative Website Evolution

Major stages of website development are outlined in Figure 1. In the alpha stage of development, the website wireframe began as a PowerPoint slide deck that provided a general layout of the website content with sections for information on preconception care, pregnancy, postpartum, early childcare, and community resources as informed by focus groups and meetings with community partners. Once the general layout was approved by our community partner group, we started to curate content in a document with headers, text, and links. Content was curated from reputable websites such as the Centers for Disease Control and Prevention, American College of Obstetricians and Gynecologists, and from experts within our community partner group. We shared the copy of the curated content with the Atrium Health Marketing and Web Design team, who then created the first website prototype in a development environment behind the health system firewall.

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Figure 1. Stages of development of the Mecklenburg Birthing Connections online resource hub.



The beta 2.0 stage included additions to the resource beginning with the selection of a website name, Mecklenburg Birthing Connections, which was voted on by our community partner group. We built out linkages to the health system's community resource hub, a searchable database of community resources by zip code, for topics including housing, childcare, and food. We also developed and added 27 infographics highlighting select website content in a brief, visually pleasing format. Other modifications during this stage included adding introductory text with header images to each page and reviewing website language to ensure alignment with goals for empowering our target audience. New topic areas added included elective abortion, miscarriage, and induction. This phase of development included iterations for content, text, or format and concluded in April 2024 with the official go-live of the public-facing website [37]. This marked the end of the primary content development phase. To celebrate the official launch of Mecklenburg Birthing Connections, the project team hosted a community forum and resource fair to bring awareness to the newly launched resource, collect feedback, and connect community members to local organizations serving families during the perinatal period. This also marked the beginning of grassroots community outreach to increase awareness of the resource within the community.

The 3.0 stage had a focus on dissemination and expanding partnerships. Our grassroots approach involved identifying and participating in local community events focused on maternal, child, and family well-being. We prioritized events that focused on Black families and events that focused on families with low incomes. Events included community resource fairs, health fairs, conferences, walks, runs, and other virtual speaking opportunities within the health system (ie, local provider meetings) and the local community. We used this approach to reach people living in the community and those serving in health care and social service organizations. A central output of our outreach activities was identifying new partners and resources to add to the website and expand our reach. For example, the

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project team partnered with local doulas and a local university to cosponsor a webinar titled, “Black Birthing Matters” on the role of doulas, midwives, and obstetricians in the birthing room. The webinar recording was subsequently added to the website as a resource. Another collaboration with a local social service organization to cohost an event focused on fathers also provided an opportunity to solicit feedback from fathers on the content of the online resource. Other modifications to the website at this stage included a redesign of the home page, addition of a social media tool kit for sharing with community partners, and a collaboration with another health system initiative to build out content on hypertension in pregnancy, which disproportionately affects Black mothers.

The 4.0 stage marked the final phase of development. We obtained sign-off from our partners and closed the website for major revisions. The final Mecklenburg Birthing Connections website includes educational and informative resources for every stage of the perinatal care journey, from preconception to childcare, and links to a searchable database of community resources to address health care and social needs. In addition, downloadable infographics highlighted vital website content in a graphically engaging format.

Marketing and Outreach Campaign

Reach

Community outreach events are outlined in Table 2. Across 13 events between March and October 2024, we reached more than 800 community members. Events included conferences, networking meetings, webinars, and community forums. In addition, we delivered 1170 flyers and rack cards across 9 clinic and community locations for further dissemination.

Table . Community outreach activities.

Event title	Date	Type of event	Host	Numerical reach, n
Atrium Health Nurses Meeting	March 27, 2024	Clinical Leaders Meeting	Atrium Health	60+
MBC[a] Community Forum	April 17, 2024	Community Outreach	MBC Project Team	60+
Community Health Worker-Resource Fair	April 20, 2024	Community Outreach	Atrium Health	150+
Black Maternal Health Conference	April 11, 2024	Conference	Care Ring	100+
Black Maternal Health Week Walk	April 20, 2024	Walk/Run	Care Ring and BirthRight	30
Regional Breastfeeding Conference: 25th Annual Mother’s Special Gift Breastfeeding Conference: We’ve Come a Long Way Baby!	April 22, 2024	Conference	Area Health Education Center	30
Public Health Lunch & Learn Webinar	May 22, 2024	Webinar	Mecklenburg County Public Health	10
Queen City Community Connect Coalition- Q2 Meeting	June 4, 2024	Networking and Advocacy for Community Health Workers	Queen City Community Connect Coalition	30
Superman & Me: Celebrating Fatherhood	June 22, 2024	Community Outreach	MBC Project Team and Smart Start	15
Meck Pre-K Orientation	July 20, 2024	Orientation for new Pre-K families	Smart Start	60
Hey Moms, Hey Dads	August 3, 2024	Community Outreach	Department of Health and Human Services	150+
Black Birthing Matters	September 20, 2024	Webinar	MBC Project Team and Charlotte MCH[b] Workgroup	136
Jace’s Journey 5k Run/Walk	October 26, 2024	Walk/Run	Jace’s Journey	50+

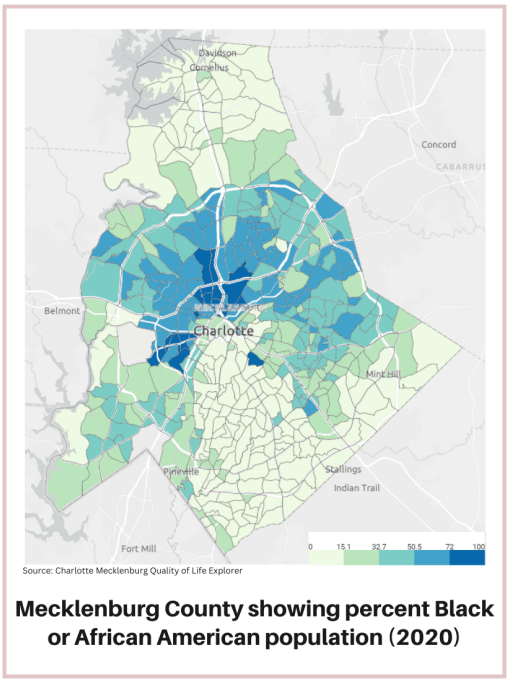
[a]MBC, Mecklenburg Birthing Connections.

[b]MCH, Maternal Child Health.

Marketing campaign results are summarized in Figure 2. Paid social advertising reached 145,932 unique accounts and resulted in 789,336 impressions (the number of times individuals were exposed to ads) and 1183 link clicks. Engagement with posts on social media reached 1237. Billboard placement was optimized to high-traffic street posters in select zip codes to drive high impressions efficiently. Billboards were placed for 6 weeks from August 12 to September 22, 2024, with a total reach of 4,094,072 impressions (number of times individuals were exposed to billboards) across 10 locations.

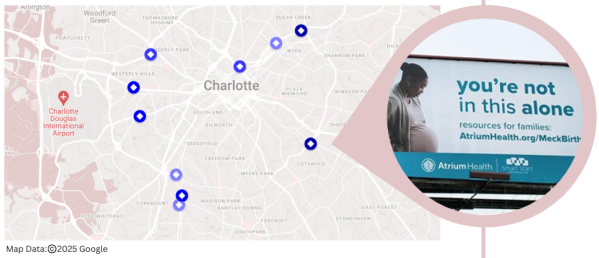
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Figure 2. Reach of the Mecklenburg Birthing Connections marketing campaign.



Mecklenburg County showing percent Black or African American population (2020)

Performance metrics by marketing strategy	Paid social	Social media posts	Billboards
Impressions	789,336	--	4,094,072
Engagements	1183	1237	--
Unique Accounts	145,932	--	--



Billboard locations

Effectiveness

Qualitative feedback from community members captured website effectiveness regarding goals for providing content that met the needs of Black families in a format that was accessible. Major themes included informational gaps for Black families, clarity and organization of content, and practical use and accessibility. Regarding informational gaps, community members found the website informational and helpful for answering questions that are not typically addressed elsewhere. One focus group participant commented, "Yeah, I think it's very informational. It's very detailed. It actually answers a lotta questions that a lot of us may have that aren't given on the regular website." And another shared, "I was surprised that y'all had postpartum depression because it's not really talked about in the Black community a lot. That's a good asset as well." With respect to clarity and organization, community members shared positive feedback about the structure of the website. A focus group participant commented:

> *Feel like it was structured pretty well. It broke it down, the stages of pregnancy, like before. Some people think about it. Some people don't. When you get pregnant, the resources that you can do while you're pregnant to prepare for the pregnancy, and then after the pregnancy. You even catered to those that might have a stillbirth or a miscarriage or somethin' of that sort.*

Community members also shared thoughts on the practical use and accessibility of the website. When asked about how they would use the information, 1 focus group participant responded, "I think I would use this if I was pregnant 'cause it gives you, pretty much, every step. It walks you through most of the pregnancy and the whole being pregnant, after pregnant. I would definitely look into this if I was just pregnant." Another commented:

> *I mean, it's very helpful...I can just come here and get the information, and I can pinpoint exactly what I'm looking for, it's very helpful. I haven't come across anything where I can say, 'Oh. If I can look at this...' If I can go through the information and all in one place, it would be very helpful for me. Yeah. I could even pass it along to anybody else.*

Other themes included inclusivity and representation and community connection and peer support. Community members felt that the website used imagery effectively to represent diverse Black women and recommended more explicit focus on fathers and extended family members. Community members also expressed interest in being able to connect with other parents via support groups and meetups and identified that as an area that the resource hub could improve upon.

Adoption and Implementation

Feedback from the Bridges Community Partner Group was requested following the launch of Mecklenburg Birthing Connections. Six community partners responded to an anonymous online evaluation survey exploring satisfaction with the website and adoption and implementation of the resource. Unanimously, the respondents felt that the goals of the project to provide targeted communication to prioritized communities with poor outcomes were met "to a great extent" (6/6, 100%). Feedback about meeting the goals included, "I believe that the website has become a comprehensive place with information from a variety of partners to represent a variety of resources," and "The focus was targeted to Black mothers and Black birthing parents. The information shared was very specific and with a focused aim." Partners' (n=6) average satisfaction with the overall experience on the website was 8.67 out of 10 (SD 1.21). Website navigation was rated an average of 8.83 out of 10 (SD 0.75). Partners (n=6) assessed the readability of information on the website with an average of 9.5 out of 10 (SD 0.84). Most partners believe that the website meets the needs

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of their average client regarding cultural resonance (5/6, 83%), readability (5/6, 83%), and accessibility (4/6, 66%). The other respondents indicated these factors to be "somewhat met."

With the recent launch of the website, partners were asked to share how they have implemented the website within their organization. The majority shared the website with a colleague (4/6, 67%) or provided clients with a direct referral link (3/6, 50%). Two of the 6 (33%) respondents promoted the link in email distributions (eg, newsletters). Only 1 out of 6 respondents (17%) indicated the use of printed materials to promote the website within their organization. When exploring resource distribution outside of their organizations, partners described sharing the direct link with friends and family.

Maintenance

Maintenance of the online resource hub as a tool to promote positive perinatal health outcomes for Black families focused on integration with health system workflows and connections to community. Within the health system, the Women's Care Service Line, which includes oversight of the Department of Obstetrics and Gynecology, was identified as a primary avenue for ongoing dissemination. In addition, we engaged the health system's Community Health Worker team for ongoing dissemination among community members. The plan for regular updates to the online resource hub included adding a feedback link that will be reviewed annually by the project team to prioritize updates and reviews. Future evaluation of maintenance will include tracking visits to the site and gathering input from partners regarding their use of the resource in the community.

Discussion

Principal Findings

Improving maternal and infant outcomes for Black mothers and babies in the United States is an urgent priority [38]. However, many efforts do not fully address the impact of social, economic, or environmental factors that contribute to disparities in maternal and infant health [39], and few focus on education and empowerment for families. Our efforts to develop a community-informed informational resource addressed an important gap by incorporating diverse community perspectives and focusing on the continuum from preconception health to early childhood. Moreover, the integration of this resource within a local health system lent support to ongoing efforts to engage health care providers in addressing social determinants of health, while providing a path for ongoing use and dissemination of the tool. Our focus on the Black birthing experience and patient, family, and caregiver empowerment is an additional unique contribution that community members found useful and needed.

Our work aligns with other similar efforts to address maternal and child health disparities using community-engaged approaches, as recommended by the National Institutes of Health [40]. For example, the Commonwealth Fund supported the development of the Maternal Health Hub operated by the Health Care Transformation Task Force [41]. The Maternal Health Hub is an online resource that contains resources and best practices to enhance health equity, increase value-based health care payment models, and promote public policy to reduce maternal health disparities. Furthermore, the National Institutes of Health Office of Research on Women's Health created a Maternal Morbidity and Mortality Web Portal providing a central hub of information regarding the maternal health crisis.

Similar to our approach of involving vested individuals in the curation of materials, Bower et al [42] describe the development of a Maternal Health Equity Toolkit in Maryland by a work group comprising health disparities researchers, hospital-based improvement specialists, perinatal health providers, and representatives of community-based organizations. Each chapter of the toolkit was reviewed by at least 2 experts, with feedback strengthening the use of inclusive language, logical sequencing of strategies, and action steps. The final product included the engagement of locally based resources by linking patients to community and social services.

Despite comprehensive searches, few papers describe educational websites dedicated to Black maternal health education. Most research focuses on the use of mHealth and social media to provide education, which differs significantly from Mecklenburg Birthing Connections [11,43-45]. A study by McFarlane et al [46] describes the pilot evaluation of a multimedia childbirth education intervention for Black women and their birth companions. The intervention, which involved animations and games that were designed in consultation with a Black doula organization and experts in obstetrics and gynecology, was found to be feasible and acceptable for education on Black maternal health disparities, with moderate impacts on self-efficacy and agency [46]. This study differed from ours in that it was not accompanied by a full website platform and had a specific focus on social support in the hospital setting. However, it provides additional evidence for the need for culturally tailored birthing education for Black families, feasibility of web-based tools, and the benefit of co-design when developing such interventions.

Health System–Community Partnership

The health system–community partnership model used to develop the online resource offered benefits as well as challenges to navigate. Benefits included access to health system resources for web development and marketing expertise as well as a platform to engage providers and administrators on the topic of patient education and empowerment to reduce health disparities. This work also aligned with ongoing efforts within the health system's women's care service line to advance maternal health equity. For example, the health system had launched a women's care bus that toured target neighborhoods with limited access to primary and preventive care and was developing a doula program to address poor Black maternal health outcomes. Challenges experienced were due touncertainty in policies and decision-making hierarchy related to the health system's active mergers and integrations, and shifting timelines due to capacity and prioritization of other projects. This required remaining flexible and maintaining regular communication with health system partners. For example, we had to delay aspects of our marketing plan that depended on health system resources because of competing priorities and begin with grassroots outreach. Ultimately, these opportunities proved to be beneficial

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in brand recognition and relationship development, not only with families who may use the website but also with the community organizations who hosted or cohosted events with the project team.

Community partnership was invaluable for achieving a product that community members felt reflected their needs. Including community partners from the beginning and engaging community members in decisions regarding what information to include on the resource hub, identification of additional impactful partners in the community, and review of website content during development phases were important aspects of our approach. This required the project team to lean into principles that build trust, such as acknowledging that our community members were experts who we needed to learn from along the way, and building relationships that would extend beyond the time frame of this funded project [47].

Limitations

Our approach had a few limitations. While we benefited from perspectives of a diverse community partner group that included male and female Black parents and caregivers, we included only Black mothers in our focus groups. Additional data collection from Black fathers in the future would help gather more insights into their informational needs and additional content that would benefit them. The potential for selection bias among focus group participants is another limitation that we were able to mitigate by triangulating focus group findings with community partner feedback. Also, hosting the final website within the domain of an established health care system limited our ability to incorporate resources from organizations identified as competitors. Notwithstanding, we were able to leverage the health system's broad reach within the local community, its many existing community partnerships, and its position as the largest Medicaid provider in the state. Finally, we were able to capture only the early effectiveness of the resource, and the adoption and implementation results were based on small sample sizes. Future evaluation could examine the impacts of the resource hub on perinatal care experiences of community members and assess the adoption and implementation among a broader sample of community members.

Implications for Practice and Translation

Our work offers opportunities for future dissemination and translation in clinical and community settings. For example, this online resource could be used to connect to resources where clinics lack embedded social work resources. The user-friendly online format also allows patients to review content at their leisure, thus bridging gaps in timely access to information. Tools like ours that extend beyond the clinical setting to home and community settings have potential for increased impact on reducing racial and ethnic disparities in care and outcomes by considering the social and cultural context in which patients live [48]. Patient empowerment also aids in the reduction of health disparities by giving patients increased agency in their health care decisions [49]. This online resource was designed to equip patients and families to navigate resources in their communities, a crucial component of patient-centered care. The design of Mecklenburg Birthing Connections as a resource hub further supports its ongoing use as a repository for information about programs and services provided by the health system and community partners to support Black families in the future. Other health systems and communities can adapt our approach by soliciting feedback on local perinatal needs and using those findings to tailor resources in collaboration with families and multisector community-based partners. In particular, with the limited and diminishing resources available to support adequate perinatal health in rural areas of the United States [50], developing tailored resource lists for rural families may help supplement care for high-risk populations. Our tool could serve as a foundation for rural counties surrounding the metropolitan area, or within the state, as some of the listed organizations and community partners have multiple locations.

Conclusions

An online resource hub is a valuable approach for providing timely information to educate and empower Black families and caregivers during the perinatal journey. Community members value having a comprehensive tool that focuses on the perinatal experiences of Black families. Communities seeking to improve access to care for Black families may consider a similar approach to identifying and collating local resources in collaboration with local community members and partners to provide easy access to education and information to address local inequities in perinatal health outcomes. Future efforts should plan implementation evaluations to measure impact.

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Data Availability

Deidentified data reported in this manuscript may be obtained by email request to the corresponding author.

Authors' Contributions

YT contributed to conceptualization, methodology, investigation, data curation, formal analysis, writing—original draft, writing—review and editing, visualization, supervision, and funding acquisition. AD participated in methodology, investigation, data curation, formal analysis, writing—original draft, and writing—review and editing. MI contributed to data curation, writing—original draft, writing—review and editing, visualization, and project administration. CS participated in data curation, writing—original draft, and writing—review and editing. LS participated in methodology, investigation, and writing—review and editing. DF, CH, RW, and SM participated in investigation and writing—review and editing. HB participated in formal analysis and writing—review and editing. JS participated in investigation, writing—review and editing, and funding acquisition. PC participated in methodology, investigation, data curation, writing—review and editing, supervision, and funding acquisition.

Conflicts of Interest

None declared.

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Abbreviations

AIAN: American Indian and Alaska Native

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Original Paper

Developing a Music-Based Mobile Health Intervention for Parents and Staff in Neonatal Care and Beyond: Online Focus Group Study

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Abstract

Background: Creative music therapy (CMT) in preterm infants has been associated with improved health outcomes in both parents and infants while promoting parent-infant bonding. However, access to CMT is limited.

Objective: This study aimed to explore the needs and preferences of parents of preterm infants and health care professionals as a first step in developing a CMT-based mobile health (mHealth) intervention.

Methods: An iterative qualitative study combining multistakeholder online focus groups with mind mapping. Map contributions were analyzed using reflexive thematic analysis.

Results: A total of 20 participants (7 parents, 1 grandparent, and 12 health care professionals) contributed to creating the mind map, offering insights into the identified five themes: (1) aims of the mHealth intervention, (2) desired functions and design, (3) content, (4) important factors for acceptability, and (5) usability beyond the neonatal intensive care unit.

Conclusions: The study highlights critical considerations for designing a CMT-based mHealth intervention. The in-depth user insights gathered will inform iterative development and refinement of the intervention, which will be evaluated in future usability, feasibility, and effectiveness studies.

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KEYWORDS

creative music therapy; family-integrated care; focus group; mind mapping; mobile health; neonatology; preterm infants; usability; user needs

Introduction

Globally, an estimated 13.4 million babies are born preterm, which is 9.9% of all births, and this number has been stable over the past decade, with only a minimal decline [1]. Preterm births, defined as delivery before 37 weeks of gestation, are a major cause of newborn mortality and are associated with long-term neurodevelopmental impairments [2-4]. Neurodevelopmental impairments may be triggered through stress responses due to unexpected parent-infant separation and trauma [5], auditory deprivation (eg, lack of exposure to intrauterine maternal heartbeat and the mother's voice), and the overstimulating, stressful, noisy neonatal intensive care unit (NICU) context [6,7].

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The traumatic nature of preterm birth, combined with uncertainties regarding the infant's health and future and the stressful situation in the NICU, profoundly affects parents as well, resulting in increased rates of anxiety [3,8], depression [3,8], posttraumatic stress [8], and feelings of helplessness [9,10] or disempowerment [11]. Such psychological issues and the physical separation of parents and infants can impact the parent-infant relationship, interaction, and the formation of a secure attachment—an emotional bond, which is formed in the first 18 months of life [3,12] and is associated with the infant's later socioemotional, behavioral, and cognitive development [3,5,13].

Conversely, in NICUs supporting active parental involvement, such as applying kangaroo-care, improved outcomes have been observed, including reductions in infant mortality and morbidity [14]. This underscores the importance of family-centered care, including free parental access to the NICU and psychological support for parents [15], as well as family-integrating care models with parents being acknowledged as primary caregivers [16].

Building on this foundation, further approaches promoting active parental involvement in the NICU include interventions such as family-integrating creative music therapy (CMT), which emphasizes meaningful multimodal stimulation. CMT uses infant-directed, lullaby-style singing to soothe and gently stimulate infants, while empowering parents through active involvement in the therapeutic process [17-19], that is, music therapy during skin-to-skin contact to foster bidirectional relaxation, attachment, and bonding. Throughout the music therapy process, parents are guided and empowered to recognize their infants' cues and tailor their responses to the infants' state and needs, while humming, speaking, and/or singing in a responsive way. CMT is associated with reduced parental stress and anxiety [20,21] and improved neurodevelopmental outcomes [5,18], as well as parent-infant bonding [20]. Moreover, previous systematic reviews demonstrated various beneficial effects of music on physiological parameters such as heart and respiratory rate, oral feeding, behavior, and stress in preterm infants [21,22], and a Cochrane review [23] confirmed an overall substantial beneficial effect of music and vocal interventions on the preterm infants' heart rate during and after the intervention. Despite these promising outcomes, access to CMT in NICUs is limited [24] due to the limited availability of therapists [25-27].

One way to address this limited access to CMT in the NICU is the use of mobile health (mHealth) interventions, delivered via an app or SMS text messages. They are increasingly applied in health care delivery and offer major advantages such as cost-effectiveness and accessibility compared to traditional face-to-face interventions and usual care [28-31]. Numerous mHealth interventions for parents exist [32], targeting pregnancy and postpartum care [33-36], parenting [35,37,38], and risk of preterm birth [39,40]. However, there is a notable lack of comprehensive mHealth interventions specifically designed for parents of preterm infants and infants born with serious illness, and, to the best of our knowledge, no music therapy-based mHealth intervention exists.

Another important consideration is that commercially available apps may not have been developed and tested with the same rigor as those created in research settings [41]. This raises concerns about their reliability, feasibility, usability, and real-world impact.

Therefore, a research and development (R&D) project was initiated [42]. It aims to develop a CMT-based mHealth intervention delivered through an app to support, coach, and motivate parents of preterm infants and health care professionals in the NICU and later at home to use their voice and music. This, in turn, will improve well-being and the parent-infant bond. The R&D project is based on a user-centered design (UCD) approach—an iterative process that involves end users throughout the whole development process to continuously refine and reshape the intervention's design [43,44]. The UCD approach is complemented by a broader human-centered perspective, which considers emotional, social, and contextual realities in which the intervention will be used. This is especially relevant in sensitive settings such as the NICU [45,46].

This study represents the first working package of this project [42], aiming to explore primary (parents) and secondary (health care professionals) end users' needs and preferences toward such an mHealth intervention. Its overall objective was to provide a basis for further iterative co-design steps, such as developing a prototype of the mHealth intervention, rapid usability testing, effectiveness evaluation, and implementation.

Methods

Study Design and Setting

The study reported in this article is an iterative qualitative study, combining multistakeholder online focus groups with mind mapping and prioritization of results to reach saturation. Study reporting was conducted in compliance with the COREQ (Consolidated Criteria for Reporting Qualitative Research) [47].

The whole R&D project is a collaboration between the University Hospital Zurich Department of Neonatology and the University of Zurich, with the Careum School of Health, part of the Kalaidos University of Applied Sciences, and amiamusica (a charity association dedicated to empowering preterm and high-risk newborns and their families through music). The project's implementation partner is Pathmate Technologies, a company that develops coaching technologies combining medicine and behavioral psychology with data and artificial intelligence. The core research team comprises an interdisciplinary group of senior researchers who have conducted research in the fields of CMT in neonatal care, public health, care and caring, movement sciences, and health sciences and technology, and are experienced in participatory and transdisciplinary research.

Ethical Considerations

The ethics committee of the Canton of Zurich reviewed the study and decided that it does not fall within the scope of the Human Research Act, which regulates research on human subjects in Switzerland (BASEC-Nr Req-2024-00635). The study was conducted in compliance with all national legal and regulatory requirements.

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Participants and Recruitment

Study participants were purposefully sampled, including parents and grandparents of preterm infants and health care professionals. We aimed to recruit German- and English-speaking mothers and fathers and, if possible, grandparents, with and without music therapy experience, all of whom experienced preterm birth at least 1 year prior to participation. We sought to include a variety of ages, genders, educational, socioeconomic, and migration backgrounds. Health care professionals, such as nurses, doctors, psychologists, and music therapists, were eligible if they had a minimum of 3 years of working experience in the NICU.

Recruitment was conducted through the parent association amiamusica, University Hospital Zurich, University of Zurich, as well as through professional neonatology and parent networks and foundations in Switzerland, Germany, and the United Kingdom. Potential participants were approached via email by BS, RMSV, FBH, and JS, and before participating in the study, they had to provide digital informed consent using the online survey tool Unipark (Tivian GmbH, 2024).

Study Procedures

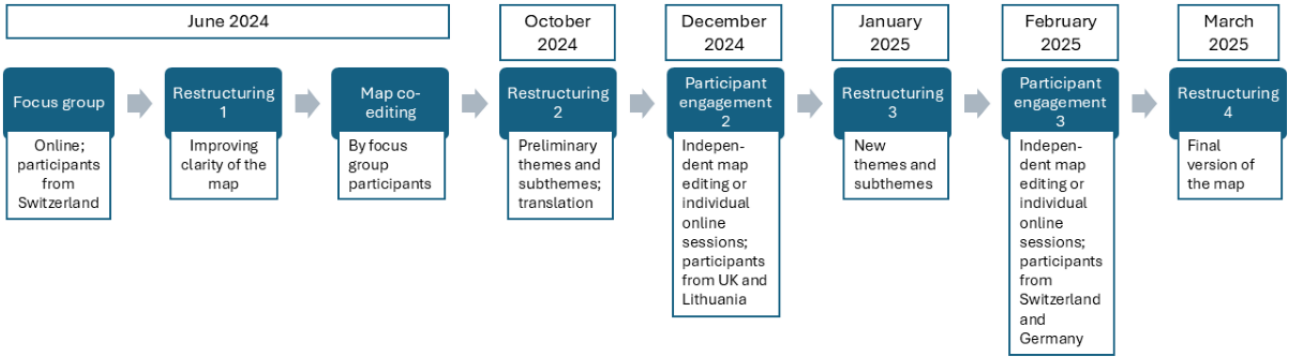
ECOUTER Approach

Study procedures followed the first step of a UCD process—user research and analysis—inspired by the ECOUTER (Employing Conceptual Schema for Policy and Translation Engagement in Research) approach proposed by Murtagh et al [48], which is based on iterative creation and coediting of mind maps by a diverse group of participants. The ECOUTER approach relies on flexibility and adaptability and aims to open up discourses. Its crucial advantage is that it can be conducted virtually, making it accessible to a broad range of people by overcoming temporal and physical limitations [48]. Based on the ECOUTER procedures and following previous research that implemented and described the approach [49], our study comprised three steps: (1) participant engagement, knowledge exchange, and prioritization of results; (2) thematic analysis of mind map contributions; and (3) result interpretation and development of recommendations.

Participant Engagement, Knowledge Exchange, and Prioritization of Results

A total of 3 groups of participants took part in this study (Figure 1). First, a 2-hour online focus group session was conducted via Zoom in June 2024 with participants from Switzerland. The session aimed to explore users' needs following a focus group guide developed by BS and FBH. FBH moderated the focus groups, while 3 additional interdisciplinary study investigators (BS, RMSV, and JH) observed the online interactions, took reflective notes, and documented the discussions on the online whiteboard Miro using mind mapping. Afterward, participants were invited to comment on the map and mark the aspects they found most central with stickers.

Figure 1. Study procedures: participant engagement and thematic map analysis.



This mind map served as a basis for two further rounds of participant engagement in December 2024 and February 2025, involving participants from the United Kingdom and Lithuania, and from Switzerland and Germany, respectively. All participants edited the mind map by adding their ideas and marking priorities—either independently on the online Whiteboard Miro or during facilitated individual online sessions with FBH and BS, JH, or JS. Participants were allowed to access the mind map as often as they preferred for a period of 1 week. All focus groups and online sessions were video recorded. We defined thematic saturation as the point at which interaction with the mind map ceased.

Thematic Analysis of Mind Map Contributions and Result Interpretation

The mind map was analyzed, inspired by the principles of reflexive thematic analysis as outlined by Braun and Clarke [50,51].

First, the initial version of the mind map, which was developed collaboratively during the first focus group session, was inspected and reviewed by each member of the research team to gain a deep understanding of the range of ideas and expressions contributed by parents and health care professionals. It then underwent four rounds of restructuring (Figure 1).

A major restructuring occurred in June 2024, immediately after the focus group session, focusing on improving the clarity and coherence of the map for subsequent commenting and prioritization by focus group participants. Another major revision was undertaken in October 2024 prior to translating and sharing the map with participants from the United Kingdom and Lithuania, with a focus on grouping related ideas and further developing and labeling preliminary themes and subthemes. Additional restructuring was conducted in January and March 2025 before and after the final round of participant engagement.

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The final version of the map can be found in Multimedia Appendix 1.

In each restructuring phase, themes and subthemes were initially developed by JS and BS and subsequently iteratively edited based on internal feedback loops, including both individual reflections and project team discussions. Themes and their labels were critically examined for internal coherence and distinctiveness. The team repeatedly cross-checked whether the emerging thematic structure reflected the diversity of participant input, while enhancing clarity. Unclear or overlapping themes were either refined or combined. Changes were made collaboratively until team consensus was reached, and no additional codes or themes emerged.

In addition to these 4 major rounds of restructuring, constant modifications by the research team occurred in parallel to participants adding annotations or stickers to enhance clarity and comprehensibility for others. Overall, this iterative coanalysis approach aimed to ensure transparency, thematic depth, and validity in theme development while maintaining the participatory nature of the data, which stemmed from the ECOUTER approach, with participants being allowed to add, relocate, and comment on mind map contributions.

The final step comprised the summary of the map structured by themes and subthemes, and their interpretation.

Results

Participants

The study involved 20 participants who actively contributed to creating the mind map (n=3 from the United Kingdom, n=2 from Lithuania, n=13 from Switzerland, and n=2 from Germany). A total of 7 of those participants were parents of at least 1 preterm infant, and 1 participant was a grandparent, while the group of health care professionals comprised medical doctors (n=3), music therapists (n=5), a psychologist (n=1), and nursing experts (n=2). One participant was both a psychologist and a music therapist. Two of the music therapists were also parents of a preterm infant, but were counted as professional experts as they were enrolled as such. All participants have completed tertiary education.

Table 1 presents the characteristics of the first 2 participant groups. To validate the findings from those groups and following the ECOUTER approach, which seeks to “open up” engagement iteratively and organically [48], the third and final round of participant involvement was conducted in a more open manner. Thus, no assignment of individual map contributions to specific participants was documented, and, as a result, detailed participant characteristics were only reliably collected for the first 2 groups.

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Table 1. Characteristics of participant group 1 and group 2.

	Total	Group 1 (focus group)	Group 2 (online interviews/Miro board)
Family members			
Participants, n	4	3	1
Place of residence, n			
Switzerland	3	3	N/A[a]
United Kingdom	1	N/A	1
Age (years), range	33-54	33-38	54
Sex, n			
Female	3	2	1
Male	1	1	0
Experts			
Participants, n	8	4	4
Place of residence, n			
Switzerland	4	4	N/A
United Kingdom	2	N/A	2
Lithuania	2	N/A	2
Age (years), range	39-53	43-53	39-45
Sex, n			
Female	7	3	4
Male	1	1	0
Profession, n			
Medical doctor	2	1	1
Music therapist	4	1	3
Psychologist	1	1	0
Nursing expert	1	1	0
Work experience (years), range	2-25	15-25	2-15
Work experience in the NICU[a] (years), range	0.5-13	7-13	0.5-9

[a]N/A: not applicable.

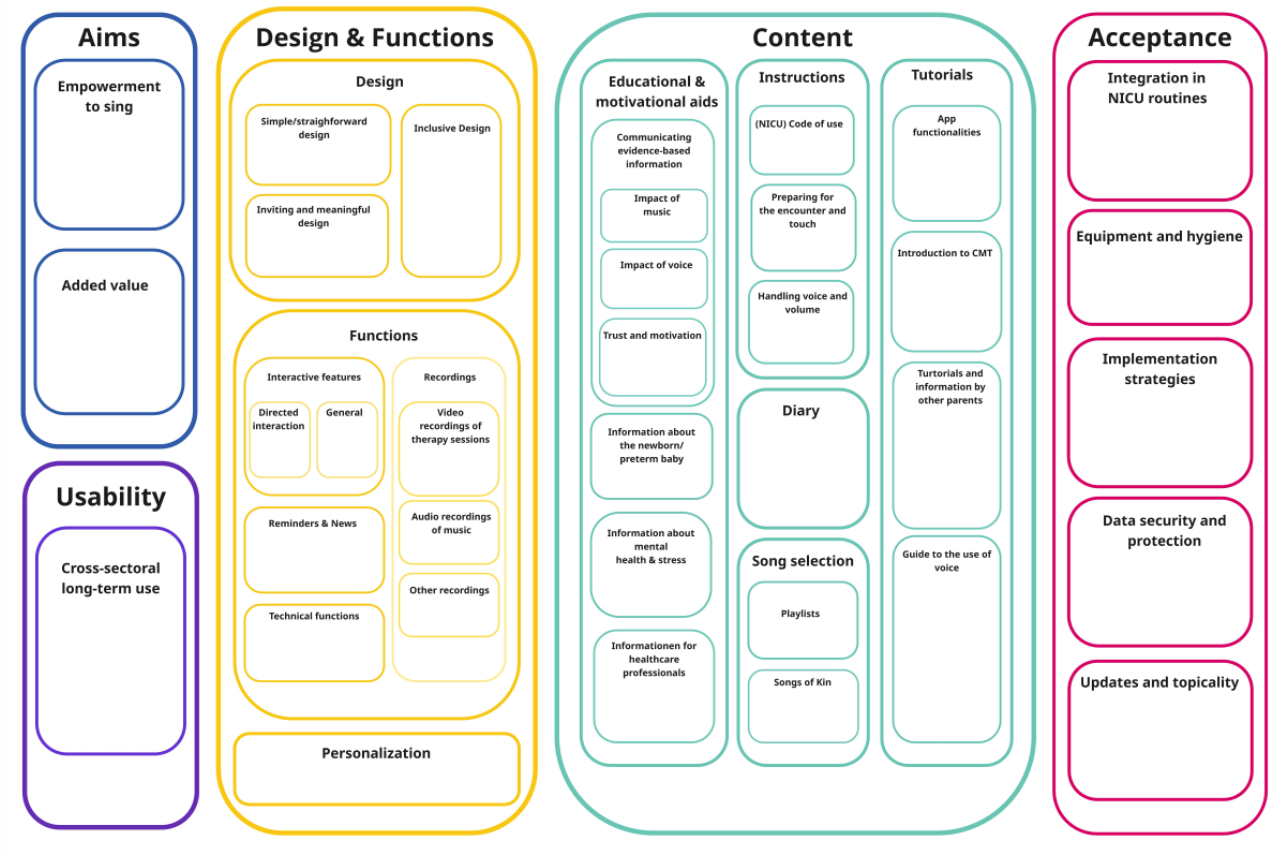
[b]NICU: neonatal intensive care unit.

Reflexive Thematic Analysis

The reflexive thematic analysis of the board resulted in five themes describing (1) aims of the mHealth intervention, (2) desired functions and design, (3) content, (4) important factors for acceptability, and (5) how the intervention can be used beyond the NICU in ambulatory care. In the following, each theme and its subthemes are described with a focus, where applicable, on prioritized aspects. A graphical overview is provided in Figure 2, while a more detailed mind-map representation, including an indication of which themes were prioritized, can be found in Multimedia Appendix 1.

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Figure 2. Overview of themes and subthemes after the final restructuring (restructuring 4). NICU: neonatal intensive care unit.



Theme 1: Aims of the Intervention

Overview

In this first theme, key goals and expectations toward the CMT-based mHealth intervention are described. A central priority of participants was to empower parents to sing to their infants and to benefit from the emotional, relational, and developmental advantages of CMT.

Subtheme: Empowerment to Sing

Participants emphasized the general importance of such an mHealth intervention for parents of preterm infants in the NICU and after discharge. Especially its relevance in NICU settings was highlighted, as they constitute an exposed restrictive space, likely inhibiting parents from singing. Therefore, the intervention's primary goal should be to create a safe space, motivate and encourage parents to use their voices, as encapsulated in the slogan "Your voice is the most beautiful," and ultimately enhance self-efficacy and empowerment. Among all participant groups, especially parents with lived NICU experience emphasized the intervention's role in fostering empowerment in such a restrictive environment. Additionally, the intervention should promote physical and eye contact between parents and their children.

To overcome any inhibitions, participants underlined the importance of an easy introduction to singing without any pressure ("Just be a parent, not a singer"). Strategies include allowing parents to listen first and involving nurses to help create a more supportive and natural singing environment in the NICU.

Subtheme: Added Value

Participants emphasized the potential benefits of the planned CMT-based mHealth intervention, including facilitation of parent-infant bonding, promotion of a sense of security for preterm infants and infants born with serious illness since they are familiar with their parents' voices from pregnancy ("Child feels safe, secured and connected with parents"), and improvement of music therapy adherence. It possibly could help parents to get in touch with peers and therapists and encourage self-care and self-efficacy through a low-threshold entry to CMT. This can help parents to relax, which, in turn, would positively affect their infants.

Theme 2: Design and Functions

Overview

This theme outlines design preferences, functional requirements, and personalization needs for the app through which the mHealth intervention is delivered.

Subtheme: Design

The subtheme design was particularly prioritized by participants. Key thematic design aspects included the need for a "simple, straightforward," and aesthetically "inviting and meaningful design" that is "inclusive," flexible, and respectful of the diversity of potential users.

Participants stressed that the app should be "simple and straightforward," thus user-friendly, easy to navigate, and logically organized ("Keep it simple and sexy"). Potential users suggested the need for a clear and consistent structural design,

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for example, a tree-like organization allowing for a continuing progression through the various functions, and emphasized the importance of a simple and intuitive menu with direct selection of the main functions from anywhere. Overall, preventing future users from feeling overwhelmed by complexity was considered key.

Participants also emphasized an "inviting and meaningful design," stressing that the target group must always be kept in mind, that is, parents "should feel addressed in their adult role," which is why the app should not be too colorful. Nevertheless, the style of the app should not be clinical and sterile either, but was proposed to be visually appealing, using a color scheme that would evoke warmth and hospitality. The use of symbols such as the octopus—a global symbol for preterm births—was proposed.

"Inclusive design" refers to the need for barrier-free access, which was emphasized by participants. The app should be accessible to individuals with vision impairments, neurodivergence, learning disabilities, or limited technical skills. Suggested solutions include using neurodivergent-friendly fonts, simple language, and voice control. Additionally, the app should be multilingual, gender-neutral, and avoid biased languages and references to reach a wider audience, achieve international visibility, and overcome language barriers ("address different cultures yet keep it simple").

Subtheme: Functions

In terms of functions, thematic aspects included "interactive features," "recordings," "reminders and news," and "technical functions."

Participants highlighted the importance of "interactive features," which, for instance, enable direct, bidirectional communication between NICU professionals and parents through images, videos, messages, and phone calls, allowing parents to stay informed about their child's development and receive updates while not being present ("being able to share beautiful moments with the children with parents as an achievement from care work [appreciation]"). It was also highlighted that parents could send questions to professionals for follow-up discussions on the ward. However, health care professionals recommended exercising caution to avoid raising unrealistic expectations among parents that health care providers could react upon queries at any time and raised the concern that not being able to account for parents' worries might lead to insecurity and worry, thus leaving them alone with their fears. A parent forum for peer-to-peer communication was also suggested, allowing the exchange of pictures, videos, experiences, and mutual understanding during the time in the NICU and for long-term use at home. Carefully moderating such a forum would be crucial to prevent the spread of harmful information.

Additionally, participants recommended incorporating feedback options for the mHealth intervention to develop and improve constantly.

Another important topic was "video and audio recordings" of CMT sessions and parent-child interactions. These recordings should be both asynchronous for sharing with family and friends and synchronous for involving other family members in real time. Participants also suggested "recordings of lullabies that can be played so babies can hear their mother's voice" and recordings of the baby's heartbeat, especially for palliative care as a special memory of the infant.

The thematic aspect "reminders and news" referred to sending weekly evidence-based updates on the benefits of CMT, which was considered an option for reminding and motivating parents to engage with the app and use their voices continuously ("Motivation for the longer run: Sharing evidence [...] why it is important [health of the baby] along with reminders").

Participants mentioned several "technical aspects" which should be considered, namely offline functionality, compatibility with different systems, the option to download all content "to easily transfer the great memories to the computer or save them on the mobile phone," and support for multiple profiles under a single account (for families with more than one child).

Subtheme: Personalization

Participants voiced personalization of the app's design, functions and intervention content to ensure accessibility and motivation. They suggested a gradual progression through various levels of experience with music, particularly for users who consider themselves unmusical ("Where do you meet someone who describes him/herself as untalented/unmusical [...] maybe via a questionnaire that records where he/she sees him/herself?"). Furthermore, the vocal range (eg, soprano or tenor) should be determined via an app function as a basis for personalized song recommendations.

Theme 3: Content on Music, Health, and Motivational Support

Overview

Participants articulated a range of content-related needs and expectations, emphasizing the app's role as an educational and motivational support tool. The theme "content" comprises the subthemes "educational and motivational aids," "instructions," and "tutorials," referring to practical and voice-use guidance, a "diary" to support memory-making, and assistance with "song selection" to build parents' confidence.

Subtheme: Educational and Motivational Aids

This subtheme describes the communication of "evidence-based information," "information about the newborn/preterm baby," "information about mental health and stress," and "information for health care professionals."

It was deemed essential that the mHealth intervention include empowering messages and "evidence-based information" on the impact of voice, singing, and CMT on child development and parental mental health to strengthen health literacy ("Develop perspectives for parents. It won't be like this forever"). "Information on preterm babies," such as their hearing abilities, way of communication, and milestones of development, was considered valuable. However, it was emphasized to carefully avoid putting pressure on parents due to the varying developmental pace of preterm babies. Instead, parents could be encouraged to track their own personal milestones in the app.

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Overall, trustworthy and reliable information was regarded as essential for fostering trust, motivation, and reducing stress resulting from the otherwise stressful search for reliable information. Additionally, motivation to use one's own voice and singing could be enhanced by highlighting the intervention's cost-effectiveness, safety, simplicity, and its significant impact on infants' health, thereby encouraging parents to use their voices as a tool for self-care during moments of helplessness as highlighted in this quote: "Let parents know why music therapy is helpful for their children (inexpensive use of voice with a major impact on health of the baby); simple but very effective, does not do any harm and helps babies grow".

According to study participants, "information for health care professionals" should comprise the same background knowledge on the benefits and impact of CMT as parents, as they may equally be unaware of its impact on newborns and parents, and additional specialist information supporting their interaction with parents ("NICU staff needs to know how families feel on NICU and how music therapy helps them").

Subtheme: Instructions

The subtheme "instructions" was found important but not prioritized compared to the other themes. It comprises thematic aspects related to "NICU code of use," "handling voice and volume," and "preparing for the encounter and touch."

Instructions on how to use the intervention ("the code of conduct") in the NICU included guidelines on phone usage (frequency, duration, volume, and privacy issues) and a reminder that the app is not a substitute for parental presence. Participants recommended instructions on "handling voice and volume" to avoid noise and overstimulation, instead of therapeutic auditory stimulation. Learning how to read and observe the babies' reactions and real-time resonance was considered key to this. Participants emphasized the importance of differentiating between newborns and premature babies in terms of their responses, as expressed in this note: "Newborns appear much more responsive. At the same time, parents need to be aware of the signs of excessive demands on premature babies." A calm atmosphere and touch should be emphasized in the context of "preparing for the encounter and touch," including ideas and possibilities on how to create a calm and private atmosphere in a noisy NICU.

Subtheme: Tutorials

A video demonstration of the app's functionalities and introductory videos on voice and singing techniques were considered essential. Such videos could provide step-by-step guides for future users with limited technological abilities or cognitive disabilities. They were also considered as alternative learning means compared to text-based content only to meet the needs of different potential users and learners, particularly when it comes to singing and music. Participants favored including real-life videos to create a feeling of relatability for parents. Personal videos from other parents sharing their experiences with voice, music, and therapy were seen as additional valuable resources ("Knowing that others are doing it and how they are doing is [in terms of motivation/peer] lets me do this, too"). Such real-life videos may also serve as a means for reducing fear of error when singing and thus support effective learning.

Participants also considered it important to provide a slow, low-threshold introduction to using voice and CMT, starting with speaking, then humming, and finally singing to promote parents' self-efficacy and overcome insecurities. Such gradual progression may support future users in progressing at their own pace, according to their skills and capabilities. Involving music therapists in this might make it even easier ("Creating a caring environment with a trusted person so as not to feel alone/overwhelmed when singing"). However, participants emphasized that gender differences should be considered, with men potentially requiring different types of encouragement compared to women. Overall, a gender inclusive design of tutorials was emphasized.

Subtheme: Diary

A digital memory box or diary function was considered a key added value, allowing parents to store and retrieve photos, videos, and musical moments even after NICU discharge. This feature was anticipated to motivate parents by showing highlights and milestones ("could have milestone markers attached to a photo or short video"), while also preserving memories, particularly for parents dealing with palliative situations ("Dealing with palliative moments from terminal phases as a video moment—a 'treasure' for parents"). Pictures of the baby were expected to encourage milk production and support breastfeeding. The diary function was considered particularly valuable, even among HCPs, as parents are already given diaries to document and remember their time in the NICU and their child's development. Therefore, the diary function could be useful in promoting the app's acceptance and adoption in clinical processes.

Subtheme: Song Selection

This subtheme comprised thematic aspects related to "playlists" and "song of kin." In accordance with participants' preference for personalization, they suggested offering "playlists" with songs tailored to different experience levels, including songs for beginners, to "regain confidence in your own voice (melody with soundtrack, karaoke, or sing-along). It was found important to provide song recommendations for different situations, such as calming or activating songs, and to include songs that could be sung along to or performed as karaoke, supporting the transition from humming to singing.

The implementation of "songs of kin" was found necessary, that is, songs identified as especially meaningful to the parents, which can "bring familiar cultural heritage to the forefront of personalized treatment" [52]. According to participants, the mHealth intervention should "give impulses to what could be a song of kin" and encourage parents to be creative in choosing their own songs, even if these, at first thought, might not be considered baby-friendly. This could empower families to "select songs in an environment, where there is little choice" in order to support feelings of control.

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Theme 4: Acceptance

Overview

In contributions clustered under "acceptance," participants discussed a range of practical and systemic factors that are crucial for the intervention's successful implementation and long-term acceptance in the NICU context. These included "integration into existing clinical routines," "implementation strategies," and "equipment availability and hygiene." Furthermore, participants highlighted the importance of "data security and protection" and "updates and topicality." These aspects were mainly emphasized and strongly prioritized by health care professionals.

Subtheme: Integration in NICU Routines

For the intervention to be accepted, health care professionals considered it crucial to take both parents' and their own needs into account and to integrate the intervention into existing NICU routines ("applicability in everyday life required"). For example, the diary function could align with the practice of creating a record of the newborn's time in the NICU ("Keep it simple and combine it with existing information (...) from daily businesses"). One concern shared among participants was the time constraint of health care professionals, which must be considered during implementation. Therefore, the app should include features that simplify or substitute existing processes, rather than adding to the workload. Finally, given the clinical restriction of the use of mobile devices in the NICU, the app should have a clear, strict code of use.

Subtheme: Implementation Strategies

Appropriate promotional or implementation strategies were found to be important to boost acceptance of the intervention. These could include preliminary written information (eg, flyers) and personal information provided by music therapists ("It is important for parents to feel welcomed: there is someone [the therapist] who accompanies me. Sensitivity is required when making first contact").

Subtheme: Equipment and Hygiene

In terms of acceptability, health care professionals stated that if tablets are provided by the hospitals, dedicated tablets for each bed would be needed to ensure accessibility and sufficient hygiene. Proper covers and disinfection should be in place to maintain cleanliness and prevent cross-contamination.

Subtheme: Data security and Protection

Data security and privacy are paramount due to the transfer and storage of sensitive clinical data and pictures of families and health care professionals ("Think about data protection for staff as well. If parents film and record, the personal rights of staff can also be violated. Involve the staff committee at an early stage"). In this regard, licensing was found to be highly relevant to increasing trustworthiness. Participants expressed a preference for the mHealth app to be free of charge, without internal advertising or subscription fees.

Subtheme: Updates and Topicality

Another subtheme was the need for continuous updates of the app. Participants highlighted that evolving needs, particularly those caused by generational shifts, necessitate regular updates ("continue to ensure the involvement of parents because of changing needs between different generations"). A feedback function for continuous improvement was therefore considered key. For example, today's young parents may require gender-inclusive language. Additionally, adaptation possibilities should be considered for international intervention implementation.

Theme 5: Usability Beyond the NICU: Cross-Sectoral Long-Term Use

The final theme focused on the mHealth intervention's application after discharge from the NICU, considering its cross-sectoral long-term use and sustainability. Key thematic aspects included "considering different developmental stages," "using and integrating music at home," "support services and networking possibilities for aftercare issues," and the need to "make data sustainably accessible." None of these aspects was prioritized by participants, but considered add-ons, which would be nice to have.

Overall, to ensure long-term usability, the intervention should be adaptable to "different developmental stages" and age, offering tailored solutions or support for each stage ("Visualize different phases of life and find answers").

Participants suggested providing input and guidance on how to "use and integrate music" into everyday home routines over a more extended period, including both very simple and in-depth information. As during the NICU stay, the app should highlight everyday situations in which music can be used for a specific purpose, such as aiding sleep or animating children ("point out everyday situations the children can be calmed [eg, after a fall] or animated/motivated [eg, when brushing teeth] by music"), also when they are growing up (playful music games).

There was a strong emphasis on the need for ongoing support in the long-term care of preterm infants and on addressing later "aftercare issues" such as difficulties in school. Possibilities included peer-to-peer networking and access to external support services, such as specialized psychologists ("support services for later concerns, as after discharge, you are on your own").

Finally, for long-term sustainability, participants proposed export options for all data, allowing parents to access their data and photos outside of the application and ensuring that the information remains "sustainably accessible" even without continued application use.

Discussion

Principal Findings

The thematic analysis of participant-generated inputs reveals a broad and multifaceted spectrum of user expectations across parents and professional groups for a CMT-based mHealth intervention as a means toward family-integrated care, which supports, coaches, and motivates parents of preterm infants in neonatal care and at home. Our findings underscore the need to develop digital solutions that focus on promoting parent-infant bonding and empowering parents to both sing to their infants and benefit from the emotional, relational, and developmental

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advantages of music therapy. Thereby, rather than focusing solely on technical functionalities, participants emphasized a diverse range of needs encompassing a straightforward and inclusive design, educational and motivational content, personalization of functions and content, social support and peer exchange, and features for cross-sectoral long-term use of the mHealth intervention. Health care professionals further stressed the importance of integrating the mHealth intervention in NICU routines to increase its acceptance. These needs reflect a broader understanding of mHealth tools as holistic systems that must consider not only instrumental use but also affective needs to engage users effectively.

The multidimensionality of user expectations beyond technical functionalities has long been recognized in diverse research, for instance on general user needs [53] in the technology acceptance model [54], the unified theory of technology acceptance [55], and in the consumption value theory, which posits that consumer choice is influenced by 5 types of value: functional, conditional, social, emotional, and epistemic [56]. These aspects have gained prominence in research on digital health and mHealth intervention development [57,58] and in the context of mHealth interventions supporting parents during, for instance, pregnancy and postpartum, or in child development [36,59,60]. Most studies agree on the importance of the following components: (1) health promotion, (2) communication—both peer interaction and communication with health care professionals, (3) health tracking, (4) personalization, (5) notifications and reminders, (6) scientific foundation, and (7) patient education [37,41,61].

All these components also emerged as prevalent themes in this study and will be discussed in the following sections, supplemented by a few additional major themes that arose only in our study.

Empowerment and Health Promotion

Most participants expected the app to inform parents about the comprehensive effects of CMT and guide them in using CMT elements to improve their own and their infant's health actively. The combination of information and actionable instructions was seen as a way to increase motivation and foster a sense of self-efficacy, defined as perceived competence [62,63]. Beyond the anticipated increase in self-efficacy, across multiple themes, participants consistently perceived the mHealth intervention as a tool for empowerment in times of helplessness, with empowerment defined as gaining control over health-related decisions and taking actions [64]. This is particularly relevant in the NICU context, where parents often experience a profound loss of agency, and highlights the value of an intervention that helps parents feel in control of their child's health and treatment. Indeed, parental empowerment is a key component of CMT [17,65,66]. It empowers parents, for instance, by promoting their sense of agency and self-confidence [17,67], reducing stress [17,20,68], and enhancing well-being, the parent-infant bond, and interaction quality [69,70]. This aligns with and extends the family-integrated care approach, which redefines parents as primary caregivers in the NICU rather than passive observers [16]. A previous randomized controlled trial suggests that this approach leads to improved outcomes for both preterm infants and their parents compared to standard NICU care [16] or even family-centered care [71,72].

However, while some participants of this study perceived the mHealth intervention as a solution to overcome hesitations to sing in a public space, previous research, which also observed this reluctance to sing in the NICU [70], emphasizes the essential role of guidance and support from music therapists. Similarly, other studies identified personal support complementary to the mHealth intervention as 1 out of 4 crucial factors for adherence to these interventions [73]. This suggests that a blended therapy approach might be needed at the beginning of the intervention, with the mHealth intervention complementing face-to-face interventions to receive the advantages from both [74].

Design: Inclusivity, User-Centeredness, and Simplicity

Given the intervention's intended use across diverse user groups, inclusive design is crucial to ensure accessibility and usability for individuals with different physical, cognitive, and social backgrounds. Moreover, participants highlighted the need for a user-friendly and intuitive design that simplifies interaction.

This is in line with previous research showing that successful technology adoption and uptake depend on perceived costs, such as cognitive costs and self-efficacy beliefs [75,76]. Complex mHealth apps that are complicated to navigate can increase cognitive costs, reduce self-efficacy beliefs, and ultimately reduce the users' willingness to engage with them.

Functions: Communication, Notifications, and Reminders

Participants clearly preferred an app that includes interactive elements enabling communication with health care professionals and peer-to-peer support. This interest in integrating social interaction and emotional support in mHealth tools aligns with previous studies, which found that both are crucial for engagement in all kinds of mHealth interventions [77,78]. Such features have been shown to foster feelings of support and connectedness, particularly when users perceive that someone has taken the time to send messages and engage with them [79]. Nevertheless, it indicates again that a blended therapy approach might be warranted to preserve the unique benefits of face-to-face communication [74].

Another required function was notifications and reminders. Both are generally seen as helpful for improving user engagement and adherence to mHealth interventions. However, it appears crucial that notifications are tailored to individual progress and specific user needs—for instance, in terms of their schedule and routines, behaviors and preferences—rather than providing generic or frequent alerts, which can become annoying or be ignored [73,80,81]. Furthermore, the reminders' language has been shown to play a role [80].

Reminders are not the only form of notifications, which might be worth implementing in an mHealth intervention. Preliminary evidence suggests that theory-driven trigger messages based on behavior change theories can have beneficial effects on user engagement by providing reinforcement and targeting motivation, self-efficacy, knowledge, and self-care [81].

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Personalization

Personalization emerged as a cross-cutting theme across multiple topics, particularly regarding design and functionalities. For instance, participants would like the app to provide customized content, such as a tailored introduction to and progression through the use of music. This is consistent with other research on mHealth interventions, which shows that personalized designs and functions lead to greater satisfaction, long-term adherence, and effectiveness [73,77,82,83]. Gosetto et al [82] described 4 dimensions of personalization of mHealth: users, system functionalities, information, and app properties. All these aspects were also mentioned by participants, either explicitly or implicitly, in the context of personalization.

Content: Scientific Foundation, Education, and Health Tracking

Regarding content, participants emphasized the importance of providing scientifically validated information to ensure the intervention's credibility and trustworthiness and, consequently, a reduction of stress. This suggests that participants viewed the app not only as a tool for using music for health but also as a means of transmitting medical and health education. Furthermore, clear instructions and tutorials on how to use the app and interpret the information were seen as crucial for facilitating usability. This finding aligns with previous literature underlining the importance of mHealth interventions with high standards of content quality, ensuring that information is not only accurate but also understandable and actionable (eg, [84]). Additionally, increasing parents' knowledge on essential aspects of preterm birth can improve their decision-making, which, in turn, affects maternal and infant health [40].

Thereby, to foster adherence to the intervention, it appears especially important to emphasize the positive effects of music therapy [19,52,85] and kangaroo care alone [14] on parents and preterm infants as well as the additional effects stemming from a combination of both [70,86].

Furthermore, incorporating a diary option was frequently mentioned as a valuable tool for parents. This might be explained by the positive impact of narrative diaries in the NICU, which has already been shown [87]. According to a systematic review, these diaries can "improve humanization, communication between NICU staff and parents, parents' coping, and closeness to their newborn" [87]. A diary as part of an mHealth intervention might have similar promising effects. Another advantage is that they can easily be integrated into existing routines, which, as mentioned above, might enhance an mHealth intervention's acceptance. Diaries are already implemented in many NICUs and could just be expanded by adding music and sounds next to pictures of the infants.

Sustainability and Long-Term Use

The concept of sustainable, long-term use emerged as another critical topic. Previous research indicates that music therapy generally has potential for long-term use and impact on preterm infants and their families, even after NICU discharge [70,88,89]. For instance, combining music with reading has been shown to improve language development in preterm infants at 2-3 years of age [89], and music became an integral part of their families' daily life even after supervised interventions ended [70].

Many participants indicated that the long-term use of mHealth interventions depends on the app's usability across different stages of the child's development. As mentioned earlier, personalization in the form of tailored, acutely relevant content, functions, and design might play a key role in long-term intervention adherence. Previous research supports the importance of personalized design, functions, and knowledge transfer and adds personal goals as crucial factors for long-term application of mHealth interventions [83].

Therefore, an mHealth intervention integrating music therapy elements, ongoing support, tailored information, personalization, and coaching is likely to enhance the intervention's sustainability, long-term use, and overall effectiveness.

Acceptance: Addressing Diverse User Needs, Updates, Data Security

Acceptance emerged as a recurring theme, with participants—in particular health care professionals—underscoring the importance of addressing the diverse needs of both parents and clinical staff, particularly given the time constraints faced by the latter. This demonstrates that a human-centered design is imperative, considering the perspectives and daily realities of both as well as the context of use from early on in the design process [45], thereby reinforcing the value of the ECOUTER approach's participatory principles. In addition, participants expressed the need for regular updates to ensure that the app content remains relevant and engaging. This is also reflected in their desire for continuous improvement and responsiveness to users' needs. Furthermore, data security was identified as a critical concern. Participants stressed that ensuring privacy and protection of personal health data would significantly influence their willingness to adopt and continue using the app. This aligns with existing literature on digital health adoption, which emphasizes privacy concerns as a considerable barrier to the widespread use of health technologies (eg, [79,90]). Interestingly, in other studies on digital interventions, this concern was not shared by patients or therapists [91], suggesting that perceived risks may vary depending on the type of data involved.

Strengths and Limitations

Given the increasing focus on family-centered and family-integrating care in neonatology, involving family members of preterm infants in developing this mHealth intervention appears crucial for ensuring their needs are met. At the same time, experts from a range of health care professions could contribute valuable expertise and insights into the needs of NICU staff and how a CMT-based intervention may be integrated into the dense and demanding setting of NICUs. Thus, including both groups of participants and the diversity of their roles is a clear strength of this study. Moreover, the large number of contributions, their level of detail and their diversity—reflecting the broad spectrum of perspectives—along with continuous coediting and iterative restructuring led to a comprehensive framework of user needs and preferences for a usable and acceptable mHealth intervention. Saturation was

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assumed once no new input emerged, and participants confirmed that nothing more could be added. This demonstrates that following the ECOUTER approach was both meaningful and effective. Furthermore, as the approach is based on iterative feedback loops, it allowed us to conduct multiple rounds of participant engagement and to focus on purposeful sampling for the final round, specifically recruiting scientific advisory board members, experts, and parent representatives from premature infant organizations.

However, several limitations of this study should also be acknowledged, primarily related to the study sample. First, while the qualitative design and iterative ECOUTER-informed engagement enabled in-depth exploration and yielded convergent themes across multiple rounds of participant input, the overall sample size was small, which may limit the transferability of the findings. However, the ECOUTER approach facilitated sustained, reflective engagement and enhanced analytic depth, partially mitigating constraints typically associated with single focus group designs [48]. In addition, participants were purposefully selected to represent a range of relevant stakeholder perspectives (including parents, clinicians, music therapists, and psychologists), which strengthened the relevance of findings for intervention development but also resulted in a sample with a high overall educational level. As all participants had completed tertiary education, the perspectives of people with lower socioeconomic status and lower health literacy may be underrepresented, potentially limiting applicability to more socioeconomically diverse populations due to potential differences in information needs, comprehension, and access. Furthermore, participants were recruited from several countries; however, these countries are culturally comparable, and the study did not aim to examine or compare health care systems. While contextual differences may still have influenced individual perspectives, this relative cultural similarity supports thematic coherence. Nonetheless, these factors should be considered when interpreting the findings and applying them to the development of an mHealth intervention for parents.

Second, the questions posed during the focus groups were primarily formulated by FBH. Her professional background and experience as a music therapist in the NICU might have influenced them. However, the question guide was cocreated with other interdisciplinary members of the core research team, and all discussions were held and documented by several interdisciplinary researchers.

Third, this study adopted a real-world, pragmatic approach based on an online collaboration tool. Due to this and anonymization requirements, the contributions on the digital board could not always be attributed to individual participants. Meanwhile, the online format of focus groups may have limited spontaneous, dynamic discussions that are typically seen in in-person settings and are characteristic of group processes. Prior research suggests that virtual focus groups may hinder nuanced dialogues and the ability to pick up nonverbal communication cues (eg, [92,93]). However, these ambiguities were considered a trade-off in favor of the flexibility the online format offers in terms of time and location.

Finally, while stickers allowed participants to visually emphasize certain aspects of the mind map, this method may have created the impression of a consensus or dominant views. Items marked more frequently might be perceived as more important than they are, and it might have biased those prioritizing later. Despite this potential bias, the approach provided valuable insights into participants' priorities and highlighted the path for future developmental work.

Conclusion and Implications

To our knowledge, this is the first study that provides in-depth insights into the needs, expectations, and concerns of parents and health care professionals regarding a CMT-based mHealth intervention in neonatal care. The NICU—characterized by emotional intensity, parental vulnerability, and clinical pressure—requires particularly sensitive and well-integrated digital solutions. Findings from this study highlight the importance of a user-centered and participatory design approach, engaging diverse user groups, to respond to their individual needs and ensure emotional sensitivity as well as clinical acceptability in the NICU.

The results show that the proposed CMT-based mHealth intervention is seen as a meaningful complement to traditional CMT, which ensures wider access, promotes equity, and fosters parental engagement and empowerment in a situation often marked by helplessness. Key user needs toward the intervention include a simple and inclusive design, personalization, interaction possibilities with health care professionals and peers, and the integration into the daily realities of users. Addressing those needs is critical for the mHealth intervention's acceptance and effectiveness.

Findings from this study provide a unique, valuable foundation for developing and codesigning the intervention. Subsequently, following a UCD approach, the intervention will be tested for usability, feasibility, and effectiveness, with each research step followed by system refinements before advancing to the next step [42].

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Data Availability

The raw data, including the different stages of map development, supporting the conclusions of this study, will be made available by the authors without undue reservation to any qualified researcher upon request.

Authors' Contributions

Conceptualization and methodology: FBH, JH, RMSV, BS, DB
Funding acquisition: FBH (lead), JH (equal), RMSV (equal), DB (supporting)
Data curation: FBH (lead), JH (equal), RMSV (equal), BS (equal), JS (supporting)
Formal analysis: JS (lead), BS (equal), FBH (supporting), JH (supporting), RMSV (supporting)
Supervision: FBH
Writing – original draft: JS
Writing – review and editing: FBH, JH, RMSV, BS, DB

Conflicts of Interest

None declared.

Multimedia Appendix 1
Final version of the mind map structured in 5 themes and subthemes.
[DOCX File , 6345 KB - pediatrics_v9i1e85344_app1.docx]

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Abbreviations

CMT: creative music therapy
COREQ: Consolidated Criteria for Reporting Qualitative Research
ECOUTER: Employing Conceptual Schema for Policy and Translation Engagement in Research
mHealth: mobile health
NICU: neonatal intensive care unit
R&D: research and development
UCD: user-centered design

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Professional Performance of Assistant Teachers Supporting Children With Autism in the United Arab Emirates: Mixed Methods Observational Study

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Abstract

Background: Assistant teachers play a central role in supporting children with autism spectrum disorder in United Arab Emirates inclusive classrooms. Despite this importance, no prior study has used validated observational instruments to systematically evaluate assistant teachers' competency profiles across classroom practice and parent interaction domains simultaneously in this cultural context.

Objective: This program evaluation study assessed the professional performance of assistant teachers supporting children with autism spectrum disorder, examining classroom instructional competencies and parental engagement behaviors within a single United Arab Emirates diploma training program.

Methods: A convergent mixed methods design was used. Ten assistant teachers who completed a national diploma training program were assessed by 3 independent expert evaluators across 50 site visits (n=25, 50% classroom observations; n=25, 50% parent meeting observations) conducted in January 2025 and March 2025. Tool 1 assessed 11 standardized classroom competency criteria, and tool 2 assessed 8 parent interaction criteria, both using a 5-point Likert scale. Mean scores were calculated by averaging all evaluator ratings across observation sessions per criterion. Internal consistency was assessed using the Guttman λ (λ=0.79 for tool 2). Formal interrater reliability was not computed; consensus-based resolution was used in cases in which evaluator ratings differed, which is acknowledged as a methodological limitation. Qualitative field notes were analyzed using the 6-phase thematic analysis by Braun and Clarke.

Results: Classroom performance means were 4.56 (SD 0.19; very high) in phase 1 (January 2025) and 4.55 (SD 0.23; very high) in phase 2 (March 2025). All teachers (10/10, 100%) achieved ceiling scores for daily living skill support and cultural adherence (mean 5.00, SD 0.00) across both phases. Safety and hygiene criteria scores were in the high range (mean 4.00, SD 0.00 to 4.10, SD 0.32). In parent interaction assessments (tool 2), the overall mean was 4.75 (SD 0.20; very high). The highest-ranked criteria were empathetic family treatment (mean 4.92, SD 0.28) and meeting preparation (mean 4.88, SD 0.33). The lowest-ranked criterion was clarity of structured communication (mean 4.48, SD 0.51; very high). Qualitative themes identified culturally responsive communication, emotional attunement, and individualized education plan–aligned practice. Repeated SD values of 0.00 and the absence of formal interrater reliability statistics are limitations that should be considered when interpreting these findings.

Conclusions: Within this program-specific evaluation, assistant teachers demonstrated consistently high professional competence. These preliminary findings suggest that diploma-based training can support culturally aligned and technically proficient inclusive practice. Targeted professional development in proactive safety and hygiene integration and structured individualized education plan–linked parent communication are recommended. Replication with larger, multi-institutional samples is required before broader conclusions can be drawn.

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KEYWORDS

assistant teachers; autism spectrum disorder; inclusive education; mixed methods study; classroom observation; parent engagement; teacher competency; program evaluation; diploma training; special education; classroom practice; parent-teacher meetings; observational assessment; cultural responsiveness; professional development; individualized education plan–aligned practice; IEP-aligned practice; autism support

Introduction

Background and Rationale

Autism spectrum disorder (ASD) presents a heterogeneous constellation of behavioral, communicative, and social challenges requiring individualized and responsive educational approaches. In the United Arab Emirates (UAE), national policy has progressively mandated equitable access to inclusive education for all children with disabilities, yet the pedagogical workforce supporting this mandate remains underexamined. Assistant teachers serve as the primary point of daily contact between children with ASD and the broader educational environment, occupying a strategically critical but often underresearched role [1,2]. They collaborate with lead educators to implement individualized education plans (IEPs), manage behavior, provide adaptive learning support, and facilitate daily routine transitions.

Despite their centrality, assistant teachers are frequently absent from formal performance evaluation frameworks in the region. Prior research has focused predominantly on lead teachers or on Western educational contexts where cultural and organizational structures differ substantially from those in the UAE [3,4]. Recent work by Opoku et al [5] and Benson and Perepa [6] has begun to document the expanding roles and training needs of teaching assistants in Gulf Cooperation Council contexts; however, no study to date has applied validated observational instruments to assess competency profiles across both classroom practice and parent interaction domains simultaneously in this setting. The systemic dimension of inclusive education is also relevant: Mahmood et al [7] demonstrate that teacher and administrator support together shape the adaptation of students with special needs, underscoring that evaluating teacher competencies in isolation provides only a partial picture of inclusive practice quality.

Theoretical Framework: Culturally Responsive Pedagogy in the UAE Context

This study is informed by the framework of culturally responsive pedagogy (CRP), which holds that effective teaching requires active integration of students' and families' cultural values, linguistic practices, and community norms into instructional design and relational interactions [8,9]. Gay [8] identifies cultural competence, cultural communication, and inclusive curriculum as the 3 core dimensions of CRP, arguing that educators who embed cultural knowledge into practice produce stronger academic and social outcomes for culturally diverse learners. In the UAE context, CRP takes a distinctive form: assistant teachers are professionally expected to use Modern Standard Arabic (Fusha Arabic)—the formal, standardized register of Arabic used in education, religious practice, and official communication, distinct from regional colloquial dialects (*ammiyya*)—as the instructional medium; embody Islamic behavioral norms, including modest dress, respectful greetings (such as *As-salamu alaykum* ["Peace be upon you"]), and the integration of faith-based values into classroom routines; and serve as cultural mediators between school and family environments [10]. These expectations are not informal customs but formally incorporated into UAE educational policy [10] and into the diploma training program evaluated in this study. Ladson-Billings [9] argues that such culturally embedded practice is not supplementary but foundational to student belonging and learning efficacy, particularly for children with disabilities who are additionally vulnerable to social marginalization. This theoretical lens situates the study's findings within a broader international framework, enabling comparisons across culturally specific inclusive education contexts beyond the UAE.

Aims

This study was a program-specific evaluation, not a representative study of UAE assistant teachers broadly. It aimed to (1) document the overall and domain-specific professional performance of assistant teachers within 1 UAE diploma training program, (2) identify areas of consistent strength and relative development need within this sample, and (3) derive practice-based recommendations for training program improvement.

Three research questions guided the evaluation: (1) what were the overall and domain-specific professional performance levels of assistant teachers as assessed through structured observational tools? (2) How did assistant teachers demonstrate alignment with Emirati cultural and Islamic values, and what behavioral forms did this alignment take? (3) What practice-level gaps in safety, hygiene, and parent communication are indicated by these evaluation findings, and what training responses are appropriate?

Methods

Study Design

A convergent mixed methods design was used [11] combining structured quantitative observational ratings with concurrent qualitative field notes. Quantitative data provided standardized performance measurement across predefined criteria; qualitative data provided behavioral depth, contextual nuance, and interpretive triangulation. Both data streams were analyzed independently and subsequently integrated at the interpretation stage.

Observational data collection was conducted in January 2025 and March 2025 (phases 1 and 2, respectively) as part of a formal quality assurance evaluation initiated by the Zayed Authority for People of Determination in collaboration with the National Academy for Childhood Development. The diploma program itself had been developed and delivered over the

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preceding years; this evaluation assessed graduates at 2 time points approximately 2 months apart.

Participants and Sampling

Participants were 10 assistant teachers who had recently completed the National Academy for Childhood Development's assistant teacher diploma program in early childhood education and were actively employed in settings serving children with ASD. Purposive sampling was used to select a theoretically homogeneous posttraining sample. The sample of 10 is appropriate for the intensive, multi-visit observational design used in which each participant was assessed across multiple sessions by 3 evaluators, yielding 50 total site visits. However, given that all participants were drawn from a single diploma program, these findings must be understood as program specific and not generalizable to UAE assistant teachers broadly. Three independent expert evaluators, each with formal special education qualifications and experience in ASD-inclusive settings, conducted all observations.

Instrumentation

Two purpose-built observational rubrics were developed and validated for this evaluation. Tool 1 assessed 11 standardized performance criteria covering classroom management, student supervision, transition monitoring, preparation of materials, daily living skill support, health and nutrition knowledge, safety and risk management, hygiene practices, emotional engagement, and cultural adherence. Tool 2 assessed 8 criteria for parent interaction: trust building, active listening and shared decision-making, meeting preparation, communication clarity, empathetic engagement, IEP-aligned guidance, professional communication style, and cultural sensitivity. The identical 11-criterion wording was used across both observation phases to ensure measurement consistency. Both instruments used a 5-point Likert scale (1="strongly disagree"; 5="strongly agree"). Content validity was established through review by a panel of 3 special education specialists. Internal consistency for tool 2 was estimated using the Guttman λ (λ=0.79), indicating acceptable reliability for small-sample educational research [12]. Tool 1 reliability was assessed using the same approach, yielding comparable internal consistency.

Data Collection Procedure

A total of 50 site visits were conducted: 25 (50%) classroom observation sessions and 25 (50%) parent meeting observation sessions. Each session was observed in its entirety. Observations were unannounced (ie, teachers were not informed of the specific evaluation criteria in advance) to reduce social desirability bias. Evaluators independently completed quantitative rubric ratings and open-ended qualitative field notes after each session.

Data Analysis

Quantitative Analysis

Mean scores were calculated by averaging all evaluator ratings across all observation sessions per criterion (ie, the unit of analysis was individual observation sessions aggregated across teachers and evaluators). SDs reflect variability across these aggregated ratings. Performance was classified using the range-based framework in Table 1. Three criteria yielded an SD value of 0.00, indicating complete uniformity across all evaluators and sessions; while theoretically possible for behaviorally anchored competencies, this pattern is unusual in applied educational research and may alternatively reflect limited rubric sensitivity, observer-related score compression, or reactivity effects from being observed, as discussed further in the Discussion section. The substantially higher SD for criterion 6 in phase 2 (1.15) is examined as a criterion-specific finding in the Results and Discussion sections. Formal interrater reliability (intraclass correlation coefficient [ICC] or κ) was not computed: evaluator ratings were averaged per criterion per session, and discrepancies were resolved through structured consensus discussion. The absence of a formal agreement statistic is acknowledged as a methodological limitation that affects the interpretive confidence that can be placed in individual criterion scores.

Table . Performance level classification based on mean score ranges.

Score range	Performance level
1.00 to <1.80	Very low
1.80 to <2.60	Low
2.60 to <3.40	Moderate
3.40 to <4.20	High
4.20 to 5.00	Very high

Qualitative Analysis

Field notes were analyzed using the 6-phase thematic framework by Braun and Clarke [13]: (1) data familiarization, (2) initial code generation, (3) theme development, (4) theme review, (5) theme definition, and (6) report production. Triangulation between quantitative and qualitative datasets was conducted to assess convergence and identify discrepancies.

Ethical Considerations

This study constituted a formal institutional performance evaluation conducted as part of a structured quality-assurance process within an established professional training program. It did not involve recruitment of human research participants, experimental intervention, or collection of sensitive personal data requiring ethics board oversight. The evaluation was initiated and authorized by the Zayed Higher Organization for People of Determination and the National Academy for Child

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Development under their respective institutional quality-assurance mandates. All participating assistant teachers provided institutional consent through their professional program enrollment agreements. No data pertaining to children, families, or identifiable individuals were collected or reported. In accordance with the research ethics policy of Emirates Scholar Center for Research & Studies, Abu Dhabi—which stipulates that internal program evaluations and posttraining competency assessments conducted within institutional quality-assurance frameworks are exempt from formal ethics board review—independent ethics approval was not sought for this evaluation. All data were handled confidentially and reported in aggregate form without individual identification.

Results

Performance Classification Framework

Table 1 presents the scoring rubric used to classify all performance means.

Classroom Observations: Phase 1 (January 2025; Tool 1)

Table 2 presents mean scores and SDs for the 11 classroom performance criteria in phase 1. The overall mean was 4.56 (SD 0.19; very high). All teachers (10/10, 100%) achieved the maximum score for criteria 3 (transition monitoring), 5 (daily living skill support), and 11 (cultural adherence; mean 5.00, SD 0.00 for each). All teachers (10/10, 100%) scored in the high range for criteria 7 (safety knowledge), 8 (hazard-free environment), and 9 (hygiene; mean 4.00, SD 0.00; mean 4.00, SD 0.00; and mean 4.10, SD 0.32, respectively). The items with an SD of 0.00 indicate complete uniformity across all evaluators and sessions; possible interpretations are discussed in the Discussion section.

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Table . Mean scores and SDs for classroom performance—phase 1 (January 2025).

Criterion number	Criterion description	Score (1-5), mean (SD)[a]	Rank	Rating
1	Assisted in classroom management to ensure a responsive learning environment.	4.60 (0.52)	7	Very high
2	Supervised students during structured activities (eg, reading, assignments, and motor therapy).	4.50 (0.53)	9	Very high
3	Closely monitored students' entry to and exit from the classroom.	5.00 (0.00)[b]	1	Very high
4	Prepared and effectively used classroom tools and resources (eg, audiovisual aids).	4.80 (0.42)	4	Very high
5	Supported students in daily living skills (eg, eating, dressing, and toileting).	5.00 (0.00)[b]	1	Very high
6	Demonstrated knowledge in health and nutrition relevant to child development.	4.75 (0.46)	5	Very high
7	Displayed knowledge of safety and security procedures relevant to children.	4.00 (0.00)[b]	10	High
8	Maintained a physically safe learning environment based on best practices.	4.00 (0.00)[b]	10	High
9	Ensured classroom hygiene and sanitation to prevent infectious diseases.	4.10 (0.32)	9	High
10	Demonstrated enthusiasm and emotional presence while interacting with children.	4.70 (0.48)	6	Very high
11	Adhered to Emirati cultural values, customs, and Islamic principles at all times.	5.00 (0.00)[b]	1	Very high

[a]Overall mean 4.56 (SD 0.19; very high).

[b]SD of 0.00 indicates complete evaluator and session uniformity; possible interpretations include genuine ceiling-level performance, observer-related score compression, or limited rubric sensitivity at the upper end of the scale (see the Discussion section).

Classroom Observations: Phase 2 (March 2025; Tool 1)

Table 3 presents phase 2 data using the same standardized criteria. The overall mean was 4.55 (SD 0.23; very high), virtually identical to that of phase 1 (mean 4.56, SD 0.19). All teachers (10/10, 100%) again achieved ceiling scores for criteria 5 and 11 (mean 5.00, SD 0.00 each). Safety and hygiene criteria (7, 8, and 9) remained in the high range (mean 4.00, SD 0.00 in all cases), unchanged from phase 1. Criterion 6 (health and nutrition knowledge) showed the most substantive phase 2 change: the mean decreased from 4.75 (SD 0.46) to 4.33 (SD 1.15) but with a markedly higher SD. This criterion-specific increase in variability—against the background of otherwise compressed SDs across the dataset—is discussed separately in the Discussion section as a domain-specific finding rather than a general measurement issue.

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Table . Mean scores and SDs for classroom performance—phase 2 (March 2025).

Criterion number	Criterion description	Score (1-5), mean (SD)[a]	Rank	Rating
1	Assisted in classroom management to ensure a responsive learning environment.	4.70 (0.48)	4	Very high
2	Supervised students during structured activities (eg, reading, assignments, and motor therapy).	4.70 (0.48)	4	Very high
3	Closely monitored students' entry to and exit from the classroom.	4.60 (0.84)	7	Very high
4	Prepared and effectively used classroom tools and resources (eg, audiovisual aids).	4.80 (0.42)	3	Very high
5	Supported students in daily living skills (eg, eating, dressing, and toileting).	5.00 (0.00)[b]	1	Very high
6	Demonstrated knowledge in health and nutrition relevant to child development.	4.33 (1.15)[c]	8	Very high
7	Displayed knowledge of safety and security procedures relevant to children.	4.00 (0.00)[b]	9	High
8	Maintained a physically safe learning environment based on best practices.	4.00 (0.00)[b]	9	High
9	Ensured classroom hygiene and sanitation to prevent infectious diseases.	4.00 (0.00)[b]	9	High
10	Demonstrated enthusiasm and emotional presence while interacting with children.	4.70 (0.48)	4	Very high
11	Adhered to Emirati cultural values, customs, and Islamic principles at all times.	5.00 (0.00)[b]	1	Very high

[a]Overall mean 4.55 (SD 0.23; very high).

[b]SD of 0.00 indicates complete evaluator and session uniformity; possible interpretations include genuine ceiling-level performance, observer-related score compression, or limited rubric sensitivity at the upper end of the scale (see the Discussion section).

[c]SD of 1.15 indicates substantially higher interindividual variability in health and nutrition knowledge application; this criterion-specific finding is discussed in the Discussion section.

Comparative Analysis: Phases 1 and 2

The near-identical overall means across phases (4.56, SD 0.19 vs 4.55, SD 0.23) indicate performance stability at the aggregate level over the 2-month interval. The identical domain strength pattern (daily living skills and cultural adherence) and development pattern (safety and hygiene) across both phases confirms that these represent consistent rather than transient characteristics within this sample. The sole criterion-level cross-phase difference was the increased SD for criterion 6 in phase 2, which is examined further below.

Qualitative Findings: Classroom Observations

Table 4 presents the key behavioral patterns identified through thematic analysis of classroom field notes. Modern Standard Arabic (Fusha Arabic)—the formal register of Arabic used in UAE education and official discourse, distinct from colloquial spoken dialects—was universally used for instruction, reflecting the program's explicit linguistic and cultural expectations.

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Table . Key observed behavioral patterns during classroom visits—thematic summary.

Criterion number	Competency area	Key observed practices
1	Classroom management	Gave clear instructions before each activity, used a calm tone with visual cues, and divided the class into small groups to reduce distraction.
2	Supervision of activities	Maintained constant presence, used varied materials (cards, blocks, and sensory tools), and coordinated effectively with the lead teacher.
3	Attendance and transitions	Strictly adhered to entry and exit procedures, accurately documented attendance, and guided children to their belongings in an orderly manner.
4	Preparation of materials	Used age- and ability-appropriate audiovisual tools and prepared all materials before each session.
5	Daily living skill support	Encouraged self-help behaviors (eating and dressing) through verbal reinforcement and provided individualized bathroom guidance respecting developmental level.
6	Health and nutrition awareness	Communicated handwashing advice using age-appropriate language and explained the nutritional value of foods during mealtime.
7	Safety knowledge	Avoided hazardous tools, prompted children to sit safely, and demonstrated basic environmental risk awareness during transitions.
8	Hazard-free environment	Organized pathways, maintained visual supervision, and used child-sized furniture with safe spacing between activity areas.
9	Hygiene and sanitation	Disinfected tables before activities, prompted handwashing multiple times daily, and cleaned tools and materials after use.
10	Emotional engagement	Maintained consistent eye contact and warm demeanor and used an encouraging tone and expressive gestures.
11	Cultural and religious sensitivity	Delivered instructions in Modern Standard Arabic (Fusha Arabic), promoted Islamic values and etiquette, and wore modest attire aligned with UAE[a] professional norms.

[a]UAE: United Arab Emirates.

Qualitative data largely corroborated the quantitative profile. Assistant teachers consistently demonstrated culturally aligned, emotionally attuned, and instructionally organized practice. Regarding safety and hygiene, evaluators noted that, although basic safety behaviors were present, they appeared reactive rather than proactively embedded within structured daily routines. This behavioral distinction is not fully captured by the Likert scale and has direct implications for training design.

Parent Interaction Observations (Tool 2)

Table 5 presents mean scores for the 8 parent interaction competencies. The overall mean was 4.75 (SD 0.20; very high). All teachers (10/10, 100%) scored in the very high range across all 8 criteria. The highest-ranked criteria were empathetic family treatment (mean 4.92, SD 0.28; criterion 5), meeting preparation (mean 4.88, SD 0.33; criterion 3), and cultural respect (mean 4.88, SD 0.33; criterion 8). Clarity of structured communication (criterion 4; mean 4.48, SD 0.51) and IEP-aligned guidance (criterion 6; mean 4.52, SD 0.51) were the lowest-ranked criteria, both still classified as very high, representing the relative lower bound of an otherwise uniformly strong parent interaction profile.

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Table . Mean scores and SDs for parent interaction competencies—tool 2.

Criterion number	Competency area	Score (1-5), mean (SD)[a]	Rank	Rating
1	Building relationships with parents based on mutual trust and cooperation	4.76 (0.44)	4	Very high
2	Listening to parents and involving them in decisions about child safety, health, and education	4.76 (0.44)	4	Very high
3	Adequate preparation for parent meetings and effective time management	4.88 (0.33)	2	Very high
4	Clarity and professionalism in delivering useful information and responding to questions	4.48 (0.51)	8	Very high
5	Treating all families fairly and empathetically, with sensitivity to their psychological context	4.92 (0.28)	1	Very high
6	Providing guidance based on the child's individualized academic and behavioral plan	4.52 (0.51)	7	Very high
7	Effective communication using positive body language and a professional demeanor	4.76 (0.44)	4	Very high
8	Respect for Emirati cultural values and Islamic principles at all times	4.88 (0.33)	2	Very high

[a]Overall mean 4.75 (SD 0.20; very high).

Qualitative Findings: Parent Interaction

Table 6 presents behavioral themes from parent meeting observations.

Trust building, cultural respect, and preparedness were pervasive across all participants. The use of Modern Standard Arabic, respectful Islamic greetings, and professional attire aligned with UAE norms were consistent across observations. Regarding communication clarity (criterion 4), evaluators noted that 40% (4/10) of the teachers across multiple sessions showed difficulty organizing complex verbal information in a sequential, parent-accessible manner when presenting multicomponent student progress data. This was a recurring qualitative theme that was consistent with the lowest quantitative ranking for this criterion.

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Table . Key behavioral observations during parent meetings—thematic summary.

Criterion number	Competency area	Key observed practices
1	Trust and rapport	Demonstrated warm, approachable demeanor and created an atmosphere of comfort and confidence for parents.
2	Active listening and shared decision-making	Showed strong listening skills, responded constructively to parental concerns, and involved families in discussions about child development.
3	Preparation and time management	Arrived prepared with individualized plans and materials and communicated the meeting structure clearly.
4	Clarity of communication	The information was accurate and aligned with child needs; occasional inconsistencies in verbal organization were observed across cases.
5	Fairness, empathy, and family sensitivity	Treated all families with fairness and calm reassurance and was sensitive to the emotional state of parents.
6	IEP[a]-aligned guidance	Offered concrete, actionable guidance drawn from the student's academic and behavioral framework and linked recommendations to home and school contexts.
7	Professional communication and body language	Maintained professional posture, eye contact, and tone; nonverbal cues complemented verbal explanations.
8	Cultural and religious sensitivity	Used Modern Standard Arabic and respectful greetings, avoided culturally inappropriate behaviors, and their professional appearance aligned with UAE[b] norms.

[a]IEP: individualized education plan.

[b]UAE: United Arab Emirates.

Discussion

Principal Findings

This program-specific evaluation found that assistant teachers trained through 1 UAE diploma program demonstrated consistently high professional competence across classroom and parent interaction domains. Overall classroom means were 4.56 (SD 0.19; phase 1) and 4.55 (SD 0.23; phase 2), and the parent interaction mean was 4.75 (SD 0.20), all classified as very high ratings. Two criteria—daily living skill support and cultural and Islamic adherence—reached the maximum score in both phases. Safety, hygiene, and structured parent communication occupied the lower end of the performance distribution, classified as high, high, and very high, respectively. These findings are best understood as an initial evaluation of one specific professional preparation pathway; they should not be interpreted as representative of UAE assistant teachers generally.

Measurement Considerations: SD of 0.00, Interrater Reliability, and Score Interpretation

The repeated findings of an SD of 0.00 across multiple criteria and evaluator sessions merit more than a brief acknowledgment. At least 3 interpretations must be considered. First, these values may reflect genuine ceiling-level uniformity for behaviors that the training program explicitly and systematically cultivated—particularly cultural adherence and daily living skill support—where the program's clear behavioral expectations may have produced genuine compliance across all assessed teachers. Second, the pattern of an SD of 0.00 may reflect observer-related score compression: evaluators aware of the program's cultural expectations may have rated cultural and routine behaviors at ceiling as a matter of professional expectation rather than independent behavioral discrimination. This is a form of observer-related scoring bias that cannot be excluded in the absence of formal interrater reliability testing. Third, the rubric itself may have limited sensitivity at the high end of the performance scale, producing floor effects at ceiling that compress discriminant variance regardless of actual performance differences.

The absence of formal interrater reliability statistics (ICC or κ) is the most significant methodological limitation of this study. Because quantitative scores were the product of 3 evaluators whose ratings were averaged rather than independently verified for agreement, it is not possible to determine with confidence whether high means reflect genuine uniformity of performance or shared evaluator assumptions. The consensus-based discrepancy resolution used in this study reduced obvious discrepancies but did not quantify the extent of agreement. Future evaluations must incorporate ICC or weighted κ statistics to establish measurement robustness. These findings should be interpreted as indicative rather than confirmatory, acknowledging this uncertainty.

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Regarding the reactivity of being observed, even in unannounced observations, the presence of an expert evaluator may have elevated performance, particularly in culturally salient domains where social conformity expectations are strong. This form of observer-related reactivity is well documented in educational observational research [14] and may have contributed to the ceiling-level scores observed for cultural adherence criteria across all participants.

Criterion 6 (Health and Nutrition; Phase 2): A Domain-Specific Finding

The substantially elevated SD for criterion 6 in phase 2 (1.15 vs 0.46 in phase 1) requires specific interpretation rather than treatment as a general measurement irregularity. This criterion uniquely combines applied nutritional knowledge with real-time classroom communication skills—a domain that may be more susceptible to individual variation in prior professional experience, health literacy background, and deployment context than procedurally anchored criteria such as transition monitoring or cultural adherence. The wide variability in phase 2 suggests that, among the 10 participants, some had developed sophisticated practical nutrition communication skills whereas others had not despite similar training exposure. This heterogeneity has specific implications: health and nutrition content in future training cohorts may benefit from differentiated instruction or competency-based checkpoints to ensure baseline consistency rather than uniform delivery.

Performance Stability and Training Program Evidence

The near-identical overall means across the 2-month interval are consistent with the view that the diploma program produces competencies that are retained rather than decaying over short-term posttraining periods, as predicted by models of practice-based professional learning [15]. However, this stability in aggregate scores must be interpreted cautiously given the measurement limitations noted above, and it does not confirm that the program is responsible for observed competencies as no pretraining comparison data are available. Evidence-based professional development models integrating autism-specific content with coaching and peer learning are associated with the most robust competency gains [16,17], and the apparent stability of this program's outcomes is encouraging as a preliminary finding pending more rigorous investigation.

CRP: Theory and Practice

The consistent ceiling-level scores for cultural and Islamic value adherence across both observation phases and both evaluation domains provide behavioral evidence for the theoretical proposition by Gay [8] that cultural competence, when systematically embedded in teacher preparation, is reliably acquirable. The observed behaviors—Modern Standard Arabic instruction, modest attire, Islamic greeting conventions, and faith-integrated classroom routines—are precisely the behavioral dimensions of CRP that Ladson-Billings [9] identifies as foundational to culturally inclusive practice. Massouti et al [10] document that UAE inclusive education policy explicitly mandates these practices, suggesting that the evaluated diploma program successfully operationalized national policy expectations at the classroom behavioral level. The contribution of this finding for international readers lies in demonstrating that a culturally specific form of CRP can be formally assessed through observational rubrics, offering a methodological model for evaluating cultural competence in other non-Western inclusive education contexts [18].

Safety, Hygiene, and Reactive-to-Proactive Training Design

The consistent high rating classification for safety and hygiene criteria across both phases, combined with qualitative findings documenting reactive rather than proactively integrated safety behaviors, points to a specific training gap: not in awareness but in procedural habituation. This distinction matters for training design: awareness-level interventions (information delivery and safety briefings) are insufficient if the goal is automatic, routine-embedded safety practice. There is evidence from analogous professional development contexts suggesting that behavioral rehearsal, scenario-based simulation, and routine-embedding protocols are more effective than didactic instruction for achieving procedural automaticity [19]. The uniform SD of 0.00 for safety items also raises the possibility that the current rubric may not discriminate adequately between reactive and proactive safety integration, suggesting that future instrument development should include behavioral indicators specifically targeting routine embeddedness.

Parent Communication and IEP Translation

Communication clarity (mean 4.48, SD 0.51; very high; lowest ranked) and IEP-aligned guidance (mean 4.52, SD 0.51; very high; second-lowest ranked) occupied the lower end of the parent interaction profile. These criteria are conceptually distinct from the empathy and cultural responsiveness in which assistant teachers excelled: translating technical IEP data into accessible, sequential verbal guidance for parents requires meta-cognitive and expressive language competencies that are not routinely developed through general training. Structured communication tools—including scripted meeting frameworks, standardized IEP progress summary templates, and bilingual communication resources—represent evidence-supported interventions for this domain [20]. Mahmood et al [7] emphasize that administrative support structures also shape family engagement quality, suggesting that training-level interventions should be complemented by institutional frameworks that provide assistant teachers with preparation time, parent communication templates, and supervisory guidance.

Scope and Generalizability

It bears repeating that these findings are derived from 10 assistant teachers drawn from a single diploma training program operating within a specific institutional partnership. The conclusions that can legitimately be drawn are as follows: (1) within this program, assistant teachers demonstrated high and stable competency profiles; (2) the evaluated program appears to successfully develop cultural competence and daily living skill support to ceiling level; and (3) safety, hygiene, and structured parent communication represent areas for targeted training improvement within this program. Claims about UAE assistant teacher performance broadly or about national policy

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implications exceed what this evidence can support and have been deliberately moderated in this study.

Recommendations

The following practice-based recommendations are offered for this program's future development:

- Develop safety and hygiene training modules incorporating behavioral rehearsal, scenario-based simulation, and routine-embedding protocols to promote proactive rather than reactive safety integration.
- Implement structured parent communication training using scripted meeting frameworks, standardized IEP progress summary templates, and bilingual communication resources complemented by institutional preparation time structures.
- Incorporate formal interrater reliability assessments (ICC or weighted κ) into all future observational evaluation protocols to strengthen measurement rigor.
- Revise the observational rubric to include behavioral indicators that discriminate between reactive and proactive safety integration, addressing the possible ceiling and sensitivity limitation identified.
- Consider differentiated instruction or competency checkpoints for health and nutrition content to address the interindividual heterogeneity identified in phase 2.

Limitations

This study has several important limitations. First, the sample (N=10) drawn from a single diploma program substantially restricts generalizability; the findings describe this program's graduates and should not be extrapolated to UAE assistant teachers broadly. Second, formal interrater reliability (ICC or κ) was not computed; the consensus-based resolution method used is insufficient to confirm score stability, and this materially limits confidence in individual criterion means. Third, the repeated SD values of 0.00 may reflect observer-related score compression, reactivity to observation, or limited rubric sensitivity rather than true performance uniformity. Fourth, the absence of pretraining comparison data means that no causal claims about training program effects can be made. Fifth, the study did not assess child developmental outcomes, precluding any inference about the relationship between teacher competence and student progress. Sixth, the 2-month observational window is insufficient to characterize longer-term performance trajectories.

Future Research Directions

Future studies should (1) replicate this evaluation with larger multi-institutional samples across different UAE emirates to enable comparative analysis and normative data development, (2) incorporate formal ICC or weighted κ statistics and pretest-posttest training designs to strengthen methodological rigor, (3) examine the relationship between assistant teacher competency profiles and child developmental outcomes, (4) investigate the specific mechanisms through which health and nutrition knowledge variability (criterion 6) develops differentially across training cohorts, and (5) evaluate the effectiveness of the targeted training interventions recommended above through controlled or quasi-experimental designs.

Conclusions

This program evaluation provides preliminary evidence that assistant teachers trained through 1 UAE diploma program demonstrate consistently high professional competence across classroom and parent interaction domains, with particular strengths in culturally responsive practice and daily living skill support. Two practice-level gaps—proactive safety and hygiene integration and structured IEP-linked parent communication—emerged as priority areas for training improvement within this program.

These findings should be understood as preliminary and program specific. They suggest that structured, culturally grounded diploma program training can support high professional performance in assistant teachers working with children with ASD in the UAE context, but replication with larger, multi-institutional samples incorporating formal interrater reliability measures is required before broader claims can be made. The measurement limitations of this study—particularly the absence of ICC statistics and the interpretive uncertainty associated with repeated SD values of 0.00—must be addressed in future evaluations.

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Authors' Contributions

Conceptualization: FH (lead), AA Alhumaidan (equal)
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Investigation: FNBM (lead), SANM (equal), AA Almenhali (equal)
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Data curation: HAJ (lead), SANM (supporting)
Formal analysis: FH (lead), FNBM (supporting)
Validation: FH, FNBM
Project administration: AA Alhumaidan (lead), HAJ (supporting)
Supervision: FH (lead), AA Alhumaidan (supporting)
Visualization: FH
Writing – original draft: FH (lead), FNBM (supporting)

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Writing – review & editing: FH, AA Alhumaidan, HAJ, FNBM, SANM, AA Almenhali

Conflicts of Interest

None declared.

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Abbreviations

ASD: autism spectrum disorder
CRP: culturally responsive pedagogy
ICC: intraclass correlation coefficient
IEP: individualized education plan
UAE: United Arab Emirates

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Expectant and New Mothers' Use of Facebook Private Groups to Learn About Infant Sleep and Feeding Practices: Descriptive Qualitative Study

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Abstract

Background: Sudden and unexpected infant death is a leading cause of postneonatal death in the United States. Following recommended infant care practices such as safe sleep and breastfeeding reduces the risk of sudden and unexpected infant death. Parents use social media to help them make decisions about infant care practices.

Objective: The objective of our qualitative study was to explore mothers' perspectives on the acceptability of Facebook private groups for providing education on infant care practices.

Methods: We conducted a descriptive qualitative study that recruited a purposeful sample of pregnant persons and mothers who recently gave birth; all were clients of the Special Supplemental Nutrition Program for Women, Infants, and Children in 1 of 2 states. We conducted in-depth interviews that were analyzed inductively through a systematic, iterative process using an interview guide. We asked participants about their perspectives regarding the use of Facebook private groups for learning about infant care practices, including sleep practices and breastfeeding. Data were collected until data sufficiency was reached.

Results: Of the 22 participants, 13 (59.1%) were Special Supplemental Nutrition Program for Women, Infants, and Children clients from Rhode Island, and 9 (40.9%) were from Virginia. While participants' use of Facebook in general varied, all either used Facebook private groups to obtain infant care practice guidance about safe sleep and breastfeeding or liked the idea of using specifically Facebook private groups to disseminate this information to pregnant persons and new parents. Participants reported using Facebook private groups for three main purposes: (1) information seeking, (2) the experience of engaging with Facebook private groups, and (3) social connectedness.

Conclusions: Facebook private groups were endorsed by the participants for providing mothers with information about infant care practices. Participants outlined their reasons for and experience with the use of Facebook private groups, which can inform effective use of the platform for educational interventions.

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KEYWORDS

social media; parenting; safe sleep; breastfeeding; qualitative; health behaviors

Introduction

Sudden and unexpected infant death (SUID), which includes sudden infant death syndrome, accidental suffocation and strangulation in bed, and ill-defined deaths, is a leading cause of infant mortality between 1 month and 1 year of age, accounting for approximately 3700 annual deaths in the United States in 2022 [1]. Black infants are more than twice as likely to die of SUID when compared to non-Hispanic White infants, and poverty remains an important risk factor [2]. Safe sleep practices are the only known way to protect against SUID. These practices include placing infants to sleep supine on a separate, firm, flat surface with no loose blankets or objects and room-sharing without bed-sharing. Despite widespread public

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health efforts to educate families on safe sleep practices and breastfeeding—behaviors that are crucial in reducing these deaths—the SUID rate in the United States has remained largely unchanged for over 20 years and may even be increasing most recently [3].

Parental decisions regarding sleep practices and breastfeeding are not based on knowledge of recommended practices from health care providers or other public health sources alone. Instead, mothers base many of their decisions about infant sleep and breastfeeding on information and advice from their social networks and increasingly on advice "crowdsourced" from others on the internet and/or social media [4]. Previous studies have shown that mothers want to weigh options for themselves, often trusting experiential advice from "people like me" more than evidence-based recommendations [5]. Consequently, social media now plays an important role in parenting decisions [6,7]. A recent study using 2021 Pew Research Center data found that the most popular social media platforms used by parents in the United States were YouTube (88%) and Facebook (79%) [8]. Mothers were especially likely to use Facebook, and 83% of the mothers who reported using Facebook did so daily [8].

Facebook private groups are communities people join based on common interests. They require moderator approval to view and participate in conversations. There are thousands of Facebook private groups for new or expectant parents based on city or neighborhood, profession, shared interests, or due dates. Facebook private groups have the option of having a moderator who can approve and remove posts and turn comments on or off. The moderators' degree of expertise and active moderation vary widely across groups. Given the nearly ubiquitous use of social media to guide parenting practices and the popularity of Facebook among mothers, we hypothesized that Facebook private groups could be leveraged to improve safe sleep and breastfeeding practices by creating large networks to promote safer norms for mothers with young infants. Thus, the objective of our qualitative study was to explore mothers' perspectives on the acceptability of Facebook private groups for providing education on infant care practices to inform the development of an intervention using this approach.

Methods

Design

We conducted a descriptive qualitative study [9,10] using a purposeful sample of pregnant persons and mothers with young infants to understand their perspectives on using Facebook private groups for education focused on safe sleep practices and breastfeeding. Understanding our target participant experience with Facebook private groups was the vital first step to developing an effective intervention using Facebook private groups to increase safe sleep behaviors and breastfeeding rates.

Ethical Considerations

Boston University served as the data coordinating center for this study, and their institutional review board deemed this study exempt (H-41548). The University of Virginia (2675), Columbia University Irving Medical Center (AAAT8775), and Washington University in St. Louis (202108141) participated in analysis of deidentified data, with the latter two also deeming the study exempt from review. Participants were provided with an information sheet, and all questions were answered by Boston University staff. Verbal consent was obtained prior to study enrollment. All participants received US $50 gift cards for taking part. Interviewees were assigned a participant number, and no personal identifying information was included in stored or analyzed transcriptions.

Sample

Clients of the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) who were pregnant or who recently gave birth were invited to participate in the study. All participants were at 27 weeks or more of gestation or had an infant younger than 6 months of age at the time of eligibility screening as they would have recent experience with using social media for information about infant care practices. To be eligible, participants also needed to be English speaking and own or have daily access to a Wi-Fi– or data-capable device on which they accessed social media. Participants did not need to use social media regularly or use Facebook to take part. Potential participants were excluded if they did not live or expect to live with their infant after birth or if the infant had or was expected to have a diagnosis that would impact infant care practices in a manner not compatible with study goals, including rare contraindications to breastfeeding or supine sleeping, such as use of medications contraindicated in breastfeeding, maternal HIV, or known spina bifida. Given the sensitive nature of these conditions, potential participants were asked whether their health care providers had advised that there was a contraindication to either practice rather than providing an exhaustive list of possible conditions. These eligibility criteria matched the criteria we intended to use in the larger intervention study.

WIC is an income-based program in the United States that provides supplemental nutrition vouchers for those who are pregnant or have dependents aged 5 years and under. WIC clients were chosen because the focus of our educational intervention was families who experience higher rates of SUID (eg, families who identified as being in a racial or ethnic minority group and/or with low income [11]). To be WIC eligible, one's gross income must be at or below 185% of the US Poverty Guidelines [12]; thus, WIC eligibility is an easily verifiable proxy for income that does not depend on self-report. Our goal was to develop an educational intervention for clients from WIC sites nationally to decrease SUID risk factors and increase protective factors, including breastfeeding, in this population. We chose qualitative methods to better understand the participant experience with Facebook private groups as this source of information was vital to aid in the development of the intervention.

QR codes with links to eligibility surveys were available in WIC offices via flyers, so they were available to all clients. Those who completed the survey and were eligible were contacted by study staff to complete the informed consent process and schedule interviews. All interested eligible participants who responded to scheduling calls took part.

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Interview Guide Development

The topics for the interview guide were developed based on literature reviews of studies using social media groups for medical interventions and studies looking at maternal decision-making on infant care practices. The team also looked at existing new parent Facebook private groups for common topics. The topic guide was piloted and refined as the interviews continued to ensure that intended topics were addressed (Multimedia Appendix 1).

Data Collection

We conducted in-depth semistructured interviews through videoconference from July 21, 2022, to February 1, 2023. Interviews were conducted in English by 2 trained interviewers (KB and CR). We used an interview guide asking participants about their perspectives regarding the use of Facebook private groups for learning about infant care practices, including infant sleep practices and breastfeeding. We used prompts to learn about any experiences they had with Facebook private groups, their thoughts about using the platform, and the trustworthiness of the information they received in such groups. Interviews lasted 30 to 60 minutes and were audiotaped and transcribed verbatim. Basic demographic and health data were collected during the consent process. Interviews were conducted until sufficient data were collected for the purposes of this study [13].

Data Analysis

We analyzed data through a systematic, iterative process of data collection and analysis to inductively create categories and then themes. Each transcript underwent multiple reviews by 2 investigators (ERC and RFC), who performed the early readings and initial and iterative coding followed by theme development and creation of a codebook. The other investigators were provided with the codebook and several transcripts to review as we developed iterations of the codebook based on ongoing conversations about the findings to reach consensus [14]. The Dedoose software (SocioCultural Research Consultants) supported the organization of the analytic process [15].

Results

Overview

We conducted 22 interviews with 13 (59.1%) WIC clients from Rhode Island and 9 (40.9%) from Virginia. The median age of participants was 28.5 (IQR 23-32) years; 90.9% (n=20) of the participants identified as female, 36.4% (n=8) identified as non-Hispanic White individuals, 27.3% (n=6) identified as non-Hispanic Black or African American individuals, and 31.8% (n=7) identified as Hispanic; and 22.7% (n=5) were pregnant with their first child at the time of the interview (Table 1). A total of 4.5% (n=1) of the participants identified as nonbinary. While participants' use of Facebook as a social media platform varied widely, all either used Facebook private groups to obtain safe sleep and breastfeeding information or liked the idea of specifically using Facebook private groups to disseminate this information to pregnant persons and new parents. They described a range of moderation practices in groups in which they were members, including moderators with expertise in topic areas and community volunteers. Participants reported using Facebook private groups for three main purposes: (1) information seeking, (2) the experience of engaging with Facebook private groups, and (3) social connectedness (Table 2). Illustrative quotes from each theme and subtheme can be found in Table 2.

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Table . Participant demographics (N=22).

Demographic	Participants
State of residence, n (%)	
Virginia	9 (40.9)
Rhode Island	13 (59.1)
Age (y), median (range)	28.5 (18.0-38.0)
Gender, n (%)	
Woman	20 (90.9)
Genderqueer	1 (4.5)
Nonbinary	1 (4.5)
Race and ethnicity, n (%)	
Non-Hispanic Black	6 (27.3)
Non-Hispanic White	8 (36.4)
Hispanic	7 (31.8)
Missing	1 (4.5)
Educational level, n (%)	
Lower than high school	2 (9.1)
High school graduate	4 (18.2)
Some college	9 (40.9)
College graduate	4 (18.2)
Postgraduate degree	3 (13.6)
Number of live births, n (%)	
None	5 (22.7)
1	7 (31.8)
≥2	10 (45.5)

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Table . Representative quotes from participants illustrating major themes and subthemes.

Themes and subthemes	Illustrative quotes
Information seeking	
Information quality and trustworthiness	• "I like to look at the comments [to decide if I trust something]. I like to see if anyone else has tried it already. That's why I realize I have to be on active Facebook groups and not just robots because I would want it to be where I see like if 100 moms tell me this works, I'm willing to try it....But I need to see that someone else was willing to give it a chance." [Quote 1; participant 17] • "I think Facebook is great because my husband uses Facebook...I used it the whole time I was pregnant for the groups of course. Much more easier to communicate with the different types of women who've been through similar situation like I have, and the security was a lot more trustworthy compared to Instagram who had a lot more bots from what I've noticed." [Quote 2; participant 17]
Accessibility of information	• "When I need a question, boom. Nobody has lives anymore, but that's not just pregnant people, that's people in general. So you can get a pretty quick response." [Quote 3; participant 12] • "Which is why I like Facebook groups because then you can go through and see the old posts and be like okay this is what I need right now. I don't want to go searching through the 15,000 pages of pamphlets that I have. Here's the information I need to know without a random Googling and having to try to trust what's there." [Quote 4; participant 20] • "Yes, where I did have to wait to be invited by one of the admins. It was very helpful because obviously there's like 30 or 40 of them. So it was very quick, and they asked relevant questions to make sure it wasn't just someone random trying to join in." [Quote 5; participant 17] • "It's good because everybody has a Facebook it's more like a nation-wide thing as to where if you do need the information it's easily found just by looking up certain groups." [Quote 6; participant 37]
Specific topics sought	• "I most got tips on how to prepare for breastfeeding and how to prepare myself when even breastfeeding does not work. It was a lot more better than truthfully what I got from my military hospital. So it gave me a bit more experience and I knew it was being done right because I've had a lot of people come and tell me this must not be your first child because you know how to properly hold the child because like most first time moms don't. I got a lot of great tips from that." [Quote 7; participant 17]
Experience of engaging with a Facebook group	
Feelings that come from participating	• "I don't know how to say it, but we get judged on the way we treat our babies because, especially like—and it's mostly other women like us that had kids before. So we are judged a lot and we are always doing stuff and people sometimes don't appreciate moms and we should be more appreciative." [Quote 8; participant 3] • "I feel like the closed groups have always been more polite, more well-mannered, you know, because there's always those people out there who are—have got to be rude and condescending and you know look down on people and they don't know the like everybody has their own situation, you know like there's just always one of those people there who has to be a negative Nancy." [Quote 9; participant 4] • "I feel moderation is more important than the actual content of the posts. So long as everything is moderated and it's not necessarily censored but it's done in the right mindset, then it's easier to get along with their group to appreciate what's going into it rather than it just being meme central and turning very quickly into something you don't want to engage in." [Quote 10; participant 13]

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Themes and subthemes	Illustrative quotes
Engagement with a Facebook group	• "I know there's a lot of people who don't feel comfortable um disclosing information, like something that they would feel ashamed of, you know, being a first-time mom and I feel like if you do feel ashamed of something that you don't know what's going on and you need the advice, I feel like having an anonymous post is perfect because then you can get the advice or experiences that you need without having to feel like you're being a bad mom or you know, being a bad parent in that sense." [Quote 11; participant 6]
Social connectedness	
Expanding social network	• "Well, one thing about going to Facebook for stuff like that is you'll get opinions from different people, from people all over actually. So it's not just geared to one type of population or something like that, but it would give opinions and thoughts of a variety of different people." [Quote 12; participant 10]
Community building	• "Yeah, I was definitely a lot lonelier when I had a newborn. I wasn't working either. So that was my only adult time was these other moms on the internet who were probably in the exact same phase that I was, but right now I can get out of the house, my kids are older, they're in school, they're independent. So I have a little more flexibility and freedom, especially with working. I can go into the office and have adult time." [Quote 13; participant 14] • "Everyone's going through the same thing at the same time. You're always talking to people who are either new moms or pregnant, trying to learn or trying to better themselves for their kids, which is the kind of environment you want to foster." [Quote 14; participant 13]

Information Seeking

Three subthemes were developed from descriptions of using Facebook private groups for information seeking: (1) quality and trustworthiness of the information; (2) accessibility of the information; and (3) ability to find information about specific topics, such as product information, parenting tips, tricks or hacks, and parenting styles or approaches.

Quality and Trustworthiness of the Information

Many participants noted that the information they received on Facebook private groups felt more trustworthy because it came from real people with similar experiences and the shared goal of being better parents (quote 1 from participant 17 in Table 2). They generally found that the information was both practical and honest. Some referred to trusting advice on specific questions they asked and on products others had used. However, others were more skeptical of any advice from social media, including from Facebook private groups, because they thought that they were likely based on information from, for example, bots or people who could personally gain from the advice they give (quote 2 from participant 17 in Table 2).

Accessibility of the Information

Participants liked the accessibility of Facebook private groups and often noted that they provided a venue where they could have their questions answered quickly at any time of day (quote 3 from participant 12 in Table 2). They also liked the searchability of the groups so they could find advice without actively asking (quote 4 from participant 20 in Table 2).

Some found that Facebook private groups, though closed, were still easily accessible without a long wait and liked that the vetting process provided some assurance about who was in the group (quote 5 from participant 17 in Table 2). Several participants also mentioned that many people already know about Facebook, which could facilitate quick access (quote 6 from participant 37 in Table 2).

Specific Topics Sought

Facebook private groups were viewed by participants as an easy way to ask specific questions to receive targeted responses. Parenting hacks, product recommendations, breastfeeding advice, and parenting styles were frequently referenced by participants as sought-out information on Facebook private groups. Pregnant persons also wanted to know whether symptoms they were feeling were experienced by others (quote 7 from participant 17 in Table 2).

The Experience of Engaging With Facebook Private Groups

The experience of participating in Facebook private groups played an important role in participants' willingness to use Facebook for a group whose primary objective was to provide education to parents, even if they did not otherwise use the platform. The 2 subthemes that were developed were feelings experienced while participating and different ways of engaging with such groups.

Feelings That Come From Participating in Facebook Private Groups

Participants frequently referenced negative feelings, most notably judgment and embarrassment, which can come from social media in general (quote 8 from participant 3 in Table 2), and felt that Facebook private groups provided more privacy

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and positive experiences with support rather than judgment, more honesty, and better social manners than nonprivate Facebook groups or other social media venues (quote 9 from participant 4 in Table 2). Thus, participants were interested in and sometimes actively sought Facebook private groups where they would feel more comfortable. They credited group moderation, screening of members, and the shared experience of members for this more favorable experience (quote 10 from participant 13 in Table 2).

Engagement With Facebook Private Groups

Participants liked that Facebook private groups offered the ability to engage in multiple ways. Some participants liked posting, whereas others preferred to only comment on others' posts or more passively read and "like" posts. Most felt that the ability to post anonymously created a safer space with more positive feelings (quote 11 from participant 6 in Table 2). Some participants also said that they preferred to engage with moderated groups so that the conversation remained civil.

Social Connectedness

Participants overwhelmingly felt that taking part in groups fostered social connectedness through the subthemes of community building and expanding social networks at a time that can be isolating.

Expanding Social Networks

Those participants who had used new parent groups or other affinity groups before reported that they were able to expand their social network and connect with other new parents. Participants also noted that, while parents in these groups share that they are all in a similar phase of life, because the groups are online, they are often more diverse than their personal social networks and, thus, could provide different ideas and perspectives from those of their families and close friends (quote 12 from participant 10 in Table 2).

Community Building

Shared experience was often cited in building a dynamic community in Facebook private groups. Participants described Facebook private group communities as providing support, understanding, and advice. Participants sought this type of community more at different times in their lives, with some describing needing it more with their first child, whereas others needed it more during later pregnancies due to the loss of a supportive parent or family member or moving away from previous supports (quote 13 from participant 14 in Table 2). Several participants noted the opportunity to build community around shared experiences (quote 15 from participant 13 in Table 2).

Discussion

Principal Findings

For this study, we set out to understand the perspectives of pregnant persons and new mothers regarding the use of Facebook private groups for learning about infant care practices, with a focus on those that reduce the risk of SUID, namely, safe sleep practices and breastfeeding. We discovered that, regardless of their feelings about using Facebook in general, participants expressed openness to and excitement about using Facebook private groups to learn about infant care practices. Many participants described Facebook private groups as providing trustworthy and easily accessible information and a more positive engagement experience compared to other social media and assisting in expanding their social networks. Furthermore, many felt that Facebook private groups created opportunities for social connectedness and support during a difficult transition period. Participants saw particular value in the shared experience and connectedness of the private group and its ongoing conversation. Despite reservations about Facebook in general, they expressed trust in the advice of other parents in Facebook private groups that are monitored over unmoderated material across social media.

Our findings on the acceptability of Facebook private groups for a parental health intervention are consistent with those of existing literature. Previous qualitative studies have primarily looked at the experience participants had in Facebook private groups or analyzed the transcripts of existing Facebook private groups. Groups have been viewed positively and described as a source of support and advice for parents with children with rare or challenging diagnoses, for childhood obesity prevention [6,16,17], for infant health information [18], for breastfeeding support [19], and for parents during the COVID-19 pandemic [20]. The themes that were generated through our study regarding why participants wanted to use Facebook private groups are also consistent with those found in previous literature on why new parents use Facebook private groups and the internet more broadly [7].

Our results also help further elucidate the reasons why we believe Facebook private groups facilitated by health care professionals have the potential to have a powerful impact on safe sleep and breastfeeding practices. Many of our participants acknowledged the postpartum period as a vulnerable time where they felt isolated and looked for easily accessible support and advice. Our participants described the support they received from closed groups as helping establish trust in the advice they received. While we hypothesized that they would come to Facebook private groups specifically for this peer support, the quality of moderation of the group was also valued by many participants who wanted to ensure that the advice was reputable. This is consistent with a study looking at Facebook private groups for parents with children with rare disorders, which found that 79% of participants would have liked a physician or medical professional to be in the group [21]. Thus, physician advice provided in a support group is likely to be both accepted and highly trusted.

Strengths of this study include sharing the perspectives of pregnant persons and mothers who are WIC clients, representing a group that is at high risk of SUID. We included participants from 2 cities. Similarly to all qualitative studies, our findings are not generalizable, and further research should explore the perceptions of caregivers in other demographic and geographic groups.

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Conclusions

Although their experiences with and opinions on Facebook vary, pregnant persons and mothers of young infants use and generally feel positive about Facebook private groups. Thus, these groups can serve as a useful platform for an intervention to encourage safe sleep and breastfeeding by providing education, support, and social connectedness during the postpartum period.

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Data Availability

Intellectual property and data generated under this project will be managed in accordance with both participating institutional and National Institutes of Health (NIH) policies, including the NIH Data Sharing Policy and Implementation Guidance of March 5, 2003, which was the policy guidance in effect when this project was funded. Materials generated under the project will be disseminated in accordance with participating institutional and NIH policies. Depending on such policies, materials may be transferred to others under the terms of a material transfer agreement. We have provided the scientific community with access to data collected during our prior studies, and this will continue with this study as well. This includes survey instruments and datasets. Researchers can contact our research staff for a request form that can be used to request access to the datasets and support for their use. Data will typically be made available to the public approximately 1 year after surveys are completed. Access to databases generated under the project will be available for educational, research, and nonprofit purposes. Such access will be provided using web-based applications as appropriate. Publication of data shall occur during the project, if appropriate, or at the end of the project, consistent with normal scientific practices. The final locked dataset will be stripped of all participant identifiers (including but not limited to name, date of birth, address, or phone number). This dataset will be available to the nonprofit community for noncommercial uses, provided that a data sharing agreement is reached and that the original creators of the dataset are able to collaborate in all secondary data analyses.

Authors' Contributions

Conceptualization: ERC (lead), RYM, MGP, FRH, AK
Data curation: EF (lead), KB
Formal analysis: ERC (equal), RFC (equal)
Funding acquisition: RYM (equal lead), MGP (equal lead), ERC (equal lead), FRH (supporting), RFC (supporting), AK (supporting)
Investigation: EF, KB
Methodology: ERC
Project administration: KB (lead), EF
Supervision: ERC (lead), RYM (support)
Validation: ERC, RFC (equal)
Writing – original draft: RFC
Writing – review & editing: ERC (lead), RYM, FRH, MGP, EF, KB, RFC, AK

Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview guide.
[DOCX File, 23 KB - pediatrics_v9i1e85640_app1.docx]

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Abbreviations

SUID: sudden and unexpected infant death
WIC: Special Supplemental Nutrition Program for Women, Infants, and Children

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Original Paper

A Social Media Intervention to Increase Caregiver Knowledge of Early Infant Communication: Multiple Methods Intervention Development and Pilot Study

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Abstract

Background: Greater caregiver knowledge of early language development may support more reciprocal interactions with infants and improved child language outcomes. Short-form video interventions on social media platforms like Instagram and TikTok could be a scalable, cost-effective way to increase caregiver knowledge.

Objective: The objective of this investigation is to describe the development and testing of a version of the BabyTok Project, a social media–based intervention for caregivers of very young infants under 3 months of age.

Methods: We used a multiple-method, pre-post quasi-experimental design to examine the feasibility, acceptability, and initial evidence of effectiveness of the BabyTok Project through a knowledge measure called the SPEAK-R (Survey of Parent/Provider Expectations and Knowledge–Research).

Results: Engagement metrics, participants' postintervention surveys, and feedback support the feasibility and acceptability of the intervention. Statistically significant scores on the SPEAK-R offer initial indications of change in caregiver knowledge.

Conclusions: The BabyTok Project has multiple demonstrations of its feasibility and acceptability and shows promise as a means to increase caregiver knowledge of early infant communication development and strategies to enhance children's learning. Interventions like the BabyTok Project could be a scalable way to promote optimal child language outcomes.

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KEYWORDS

parenting; infant; social media; language development; mHealth; early intervention

Introduction

Early Language Development

Infants are born interactional partners, and their earliest experiences with caregivers set their trajectory for language acquisition in the years that follow [1]. Infants who experience frequent, responsive, back-and-forth interactions go on to have a better understanding of language, larger spoken vocabularies, more complex grammar, and stronger reading, writing, social-emotional, and economic outcomes later in life [2-5]. The impact of these reciprocal exchanges is also visible in children's neuroanatomy [1,4,5]. Infants who experience more back-and-forth vocal turns with caregivers in the first year of life have denser white matter tracts in areas of the brain that are responsible for understanding and production of language, suggesting that the cumulative impact of early interactions begins in the first year of life [1]. For infants whose families experience economic hardship, responsive interactions serve as

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a protective factor against the wide-ranging negative neurodevelopmental consequences of poverty on early learning [6,7].

Promoting positive, responsive early interactions is a well-established way to improve children's language learning in communities that are experiencing poverty [8,9]. However, most interventions that aim to support caregivers to engage with their children are limited in two ways. First, many interventions begin later in toddlerhood rather than the earliest months of life [8]. Although these programs are still meaningful during toddlerhood, infants' brains develop networks that specialize in language from the very first days of life [1]. As such, promoting optimal child language learning should begin at or even prior to birth. Second, most interventions that aim to enhance the frequency and quality of infant-caregiver interactions use a coaching model in which a professional observes, guides, and gives feedback to caregivers. These interventions have a long history of evidence [10-12]. However, scaling preventative coaching models population-wide is difficult due to the cost of implementation [8], instability in funding, and variability in what home visiting programs operate in each state.

Light-Touch Interventions

Because coaching models are costly, researchers suggest the need for scalable, population-level interventions that increase caregiver knowledge of early language learning [8]. Compared to other areas of health sciences like smoking cessation [13], HIV prevention [14], or breastfeeding promotion [15], there have been relatively few investigations of mobile health efforts to promote optimal child language development. Research in this area is critical as approximately 30% of infants and toddlers whose families have low incomes are late talkers who may need ongoing and more intensive language interventions when they reach school [16]. One way to increase child language outcomes is to increase what caregivers know about early language learning [17]. Caregiver knowledge of early development is linked to more frequent and more responsive language interactions, so building caregiver knowledge is an important avenue for universal interventions at the population level [17]. Below, we highlight 2 mobile health, light-touch interventions to enhance caregiver knowledge and strategy use to promote their child's early language learning.

Háblame Bebé is a free Spanish-English mobile app designed to promote early bilingual language development among infants and toddlers by supporting parents to provide rich, engaging verbal input [18]. Early evaluations of the app indicate promising outcomes for enhancing parents' knowledge and language-supportive behaviors [18-20]. In a quasi-experimental study, researchers found that mothers who used the app increased the amount and quality of their language directed toward their children during play and shared reading [18]. Postintervention, participant mothers produced more total words, asked more questions, and demonstrated a stronger sense of pride and confidence in using Spanish with their children [18]. A subsequent randomized controlled trial assessed the app's impacts on both caregiver behaviors and early child language outcomes when implemented in real-world conditions without researchers' support to access and use the app [20]. Although the trial did not find statistically significant group differences in standardized child language scores, effect sizes favored the intervention group. Caregivers also reported high usability, acceptability, and satisfaction levels with the app as a light-touch intervention, highlighting its accessibility and cultural relevance [21].

Caregivers of infants in the United States widely use the internet social media platforms for information seeking about their child's health and development [22-25]. Unlike Háblame Bebé, which uses a standalone app, we created an intervention called the BabyTok Project to connect caregivers (eg, parents and infant/toddler teachers) [26,27] with evidence-based information via short-form videos on TikTok. Through initial testing, both sets of caregivers endorsed the intervention as feasible and acceptable, and caregivers reported that they learned new information that helped shape interactions with infants and toddlers in their care. These studies also provide information about engagement metrics for this type of intervention. While the 2025 investigation indicated positive directional change in caregiver knowledge, the gains were not statistically significant, perhaps due to the underpowered nature of the feasibility study and the short-term nature of the intervention. In the present iteration of the BabyTok Project, we extend the intervention to caregivers whose infants are under 3 months old to maximize the impact of responsive interactions with a larger sample size, and we lengthened the intervention to approximately 4 months.

Purpose of the Study

The purpose of this study was to describe the development of a social media–based intervention specific to the needs of caregivers of young infants (under 3 months) and to conduct a pre-post pilot test of the BabyTok Project to explore whether there are gains in caregivers' knowledge of early language development. We also aim to explore caregivers' perceptions of the intervention content and delivery to directly inform a larger-scale randomized controlled trial.

Methods

Study Design

This study used multiple methods, qualitative methods through focus groups during the development phase and a pre-post quasi-experimental design during the pilot, to determine feasibility and acceptance of the BabyTok Project, a 22-week intervention using social media to promote child language development. Data were collected to help evaluate user activity and engagement within the app, short-term effects on caregivers, and overall usability. Data were also used to support future adaptations and improvements to the intervention.

Intervention: The BabyTok Project

Content Development

Prior to the intervention, we created sample videos to share with focus groups to gain caregiver input before proceeding with full video development of the intervention. The fourth and fifth authors helped to design focus group protocols to learn more about how caregivers use social media, what types of content

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they search for related to their infants, and what makes a video catch and keep their attention. We also showed samples of the BabyTok Project videos to solicit feedback on style and content. Additionally, at the end of each focus group, we provided a list of video topic ideas and invited participants to share their opinions to help us understand more about what topics related to language and communication are most important to caregivers of infants. The focus group participants were recruited via an ad on Instagram, which ran for 4 weeks from mid-December 2023 to mid-January 2024. The ad used a URL code that sent potential participants to a Qualtrics form, which requested name and contact information. Those who gave their information were contacted via email and were asked the age of their infant and their caregiver status. Then, they were emailed a link to a Qualtrics survey, which included demographics and income-related questions. To be placed in a focus group, participants needed to be a caregiver of a child aged 0 to 6 months and qualify for social services such as Medicaid, housing assistance, TANF (Temporary Assistance to Needy Families), WIC (Women, Infants and Children), and/or food pantry/other goods. We conducted two focus groups with a total of 8 participants. The first focus group consisted of 3 participants who all reported being parents of infants, male, between the ages of 29 and 32 years, and Black or African American; 2 reported having a bachelor's degree and 1 an associate's degree; 2 reported living in an urban area and 1 reported living in a rural area. The reported income distribution among them was between US $40,000 and US $79,999. All 3 participants reported speaking English. The second focus group consisted of 5 participants who all reported being parents of infants, female, and between the ages of 24 and 32 years. Four participants reported being Black and 1 reported being Black and Hispanic/Latino; 1 reported having a bachelor's degree, 2 reported some college/associate degree, and 2 reported having a high school diploma; 3 reported living in a suburban area, 1 reported living in a rural area, and 1 reported living in a small town. The reported income distribution among them was wide, with reported earnings of US $20,000-29,999, US $30,000-39,999, US $70,000-79,999, and US $80,000+.

The groups were conducted via Zoom by the sixth author and were video- and audio-recorded. The third author and a trained undergraduate assistant attended the groups to help with any technical difficulties and to take notes. Participant responses were recorded via note-taking and read back to them at the end of each session to verify their answers. At the conclusion of the groups, one researcher synthesized the notes and asked for feedback from the other researchers on the team. The synthesized notes were also emailed to the participants for feedback to ensure that we described their opinions accurately. Opinions gathered from the focus groups regarding content they tend to watch and follow on social media indicated that the trustworthiness of content and content creators is of high importance. In addition, the focus groups discussed the importance of content being relatable and enjoyable to watch, with content that grabs your attention quickly described as preferable. The groups agreed that they scroll past content that does not have an immediate hook. When shown the sample videos, they overwhelmingly preferred videos with real caregivers and their babies. Participants also preferred videos with the speaker talking directly to the camera, videos with movement and some music but not too loud to be distracting, and videos with captions. The groups agreed that they enjoyed the educational content of the videos and that the information provided was valuable. Some critiques of the videos were that some were too fast and hard to follow, and the volume of background music was too loud. One focus group participant shared that some of the videos felt overproduced and more like an advertisement from a nongovernmental organization, and other focus group participants agreed. When asked for their opinions on topics they would like to see in future videos, participants were interested in information on children with delays and sign language for babies. This feedback from the focus groups was considered and integrated into the creation of the social media content for the intervention phase of the research. Participants were each emailed a US $50 virtual gift card at the conclusion of the focus groups.

Content Description

The project's fully developed content included 48 videos, each about 1 minute long, all posted on Instagram Reels. All videos were filmed and edited by a professional videographer, with the first author serving as the narrator. Each video featured the first author as well as B-roll clips of several families who volunteered to model for videos. The project also included 13 still posts with facts, affirmations, or questions as prompts to create a more natural, community feel, encouraging parents to engage, comment, and share as they would on a typical Instagram page. Three videos were also reposted as examples to illustrate concepts and activities discussed. Video content was created using the best available research on early language development and caregiver interactions [26,27]. The first video served as an introduction, guiding parents on what to expect during the study and introducing the first author's background as a speech-language pathologist, professor, researcher, and mother. The remaining videos covered the following topics: brain development, affirmations, early cues, routines, books, and specific strategies. For more detailed information on video content, see Table 1.

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Table 1. BabyTok Project content descriptions (n=64).

Topic	Posts/videos, n (%)	Purpose
Brain development	5 (8)	These videos teach caregivers about early brain development and how infants' brains are primed for learning language from birth.
Affirmations	5 (8)	Affirmation videos were shared to provide encouragement, confidence, and emotional support to caregivers.
Early cues	6 (9)	Babies communicate as soon as they are born through cries, fusses, and their movements. These videos help parents to recognize and interpret their baby's cues, give tips on how to respond, and boost their future communication skills.
Routines	4 (6)	Everyday routines help establish a sense of predictability that supports babies' learning. These videos help caregivers build routines by providing guidance about how to build in predictability around caregiving tasks, book sharing, and more.
Books	6 (9)	These videos highlight the benefits of reading even to young infants, and we provide tips on effective strategies like following children's attention/gaze and selecting engaging books for infants.
Specific strategies	14 (22)	These videos share ways caregivers can support language development through everyday interactions. They cover strategies like infant-directed speech (parentese), modeling language, using baby signs, and playtime tips to encourage tracking and reaching.
Myth busting	8 (13)	This section of videos addresses common concerns, developmental milestones, and misconceptions during a baby's first year, covering key topics like bilingualism and screen time.
Still posts	13 (20)	Still posts were used to provide announcements to participants, informative facts, affirmations, and question prompts to encourage participant engagement.
Reposts	3 (5)	TikTok reposts served as examples of previously discussed concepts (eg, signs to use or songs to sing) as well as sharing helpful tips from other parents. Reposts were also used to capture a greater demographic range of caregivers featured in the videos.

Fraud Prevention

Given the virtual nature of this study, we implemented a fraud prevention strategy to ensure data integrity and prevent masqueraders (individuals or bots who submit fraudulent responses) from participating in the study. The survey was completed on Qualtrics and received 308 responses. The first line of defense to prevent fraudulent responses was adding the Qualtrics Re-captcha feature to the initial 2-question prescreener. This feature did not detect all potential fraud. Therefore, to ensure that our participants were real individuals and to prevent ineligible participants from entering the study, we used a fraudulent response detection process, which included filtering out Qualtrics's identified bots and incomplete surveys, removing respondents with duplicate IP addresses and locations outside of the United States, and removing respondents who gave unintelligible or inappropriate answers to open-ended questions [28]. To provide extra verification, emails were sent with the following questions: (1) Are you a regular caregiver of a child? (2) If so, please provide the age of your child in months. If responses were inconsistent with survey data, these individuals were deemed ineligible to participate in the study.

Recruitment

Recruitment for this study began in the summer of 2024 through flyers that were distributed both in person and via email to local pediatric and obstetrics/gynecology clinics across the state of Florida. The flyer was also shared on social media platforms, including Instagram, TikTok, and Facebook. It featured a link and QR code that directed individuals to a survey containing 2 prescreening questions to verify caregiver eligibility. To be eligible, participants needed to either be pregnant and due on or before August 15, 2024, or have a child up to 3 months old, and qualify for social services such as Medicaid, housing assistance, TANF, WIC, and/or food pantry/other goods. Participants who were determined eligible were routed to a consent form to provide consent to the institutional review board–approved study. The recruitment period lasted 2 months.

Procedures

Once participants provided consent, they were sent an email requesting verification of their email address, cell phone number, Instagram handle, and their child's date of birth. After this information was verified for consistency with the demographic information, participants were sent a follow-up email that included links to the pretest measures, along with instructions for completing them. At this point, they were also asked to follow the study's Instagram page. Pretest measures included the SPEAK-R (Survey of Parent/Provider Expectations and Knowledge–Research) and demographic forms, which participants completed online via the links provided.

Once the pretest measures were completed and it was confirmed that all participants were following the social media page, researchers began sharing videos and still posts approximately 3 times per week. Participants were asked to watch and like posts to track content engagement. While commenting was encouraged, it was not prompted. Participants received reminders every other week via direct message through the Instagram app, email, or text messages from the research team to watch videos and like them. Following the intervention, participants completed the posttest measures, which included the SPEAK-R and a postintervention survey, all of which were completed online.

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Ethical Considerations

All participants provided implied consent for the institutional review board–approved study (Florida State University Study #00005223) through an online interest form with a waiver of documentation of consent. Participants received up to US $200 in gift cards as compensation. Compensation was distributed via email after pretest data collection (US $100) and the social media intervention and posttest data collection (US $100). All participants were assigned an alphanumeric code for all data files. One single Microsoft Excel file linked personal information to the code. The linking file and deidentified files are kept in an encrypted Microsoft Teams folder hosted by the university.

Measures

SPEAK-R

Similar to the prior BabyTok Project studies with infant/toddler teachers and caregivers of toddlers [26,27], the SPEAK-R was used as a tool to quantify changes in parents' perceptions of their understanding of early childhood language development. The SPEAK-R is a 22-item, self-administered questionnaire designed to assess knowledge of and beliefs about early childhood cognitive and language development [29]. The questionnaire consists of 4 multiple-choice items, 14 Likert scale items scored as *definitely true* (0) to *definitely not true* (4), and 4 Likert scale items reverse-scored as *definitely not true* (0) to *definitely true* (4). The questions focus on six topics: (1) bilingualism, (2) early exposure, (3) media use for child learning, (4) nature vs nurture, (5) sensitivity and responsiveness, and (6) talking and reading. The SPEAK survey was developed and tested on multiple population samples that included caregivers with low incomes [29]. During development, the SPEAK showed significant, positive correlations between scores and level of education, receptive language skills, and quality of language in the home environment [29]. During field testing, the SPEAK-R was proven reliable with a Cronbach α score of 0.92 [29]. The tool also has a 0.24 correlation (P<.001) with the 10-item version of the Knowledge of Infant Development Inventory (KIDI) as evidence of its concurrent validity [30]. We administered the SPEAK-R via an online survey at entry and after the 22-week intervention. The measure was gathered and scored using REDCap, and the data were imported into SPSS for analysis.

Instagram Engagement Metrics

For the purposes of this study, we define engagement as "specific interaction and usage patterns" [31] with the app. Prior to the study, we opted to use a private account to help maintain a level of confidentiality for participants. Private Instagram account owners do not have access to data metrics, called Instagram Insights, which track views, impressions, saves, shares, and watch-through rate [32]. To obtain data regarding the participants' use of the BabyTok Project intervention, participants were asked to "like" posts to indicate viewing. As such, these metrics do not reflect an "organic" pattern of liking, but rather, as an indication that they interacted with the content. Participants were not specifically asked to comment; however, we gathered data on comments per post and per participant as a measure of engagement with the intervention. Data were collected by reviewing each post and documenting the number of likes and comments per post and per participant. After the study was completed, we analyzed the total sum of likes and comments per post and the total sum of likes and comments per participant across the 22 weeks of the intervention and calculated the mean, SD, and range for each. Additionally, feedback regarding the intervention was analyzed by reviewing and coding individual comments for each post.

Caregiver Postsurvey

To analyze the acceptability and feasibility of the intervention, we administered an online survey using the Qualtrics platform after the completion of the intervention phase. The postsurvey consisted of 13 Likert scale questions with 5 possible answer choices ranging from *strongly agree* to *strongly disagree*, 1 multiple-choice question about the most helpful content, and 3 short-answer questions regarding takeaways from the content, feedback regarding the content or delivery, and input on future content. Answers to the Likert scale and multiple-choice questions were gathered and analyzed for patterns. Short-answer questions were gathered and analyzed for patterns and themes.

Quantitative Data Analysis

SPEAK-R

We used descriptive statistics (mean and SD) and a paired-samples t test in R to describe changes in caregivers' knowledge and beliefs about early childhood cognitive and language development as measured by the SPEAK-R. Cohen d was calculated for the paired-samples comparison by dividing the mean difference score by the standard deviation of the difference scores [33].

Instagram

Instagram data were collected using a simple count of likes and comments per video and per participant. We used a descriptive quantitative analysis to show the means and ranges of Instagram engagement metrics.

Qualitative Data Analysis

Instagram

Instagram comments were analyzed using the thematic analysis method prescribed by Brooks et al [34]. The second and third authors explored the data separately, and through an iterative process of meetings, constant comparisons, and continued data exploration, common and interesting themes emerged. Through consensus, the themes were labeled as codes, and at the conclusion of this analysis, a simple count of each code was collected to understand more about the engagement of the participants. Throughout this analysis process, the primary author was consulted to ensure the quality of data coding.

As with the previous BabyTok study [27], the data analysis team took several steps to ensure the trustworthiness of the data. To increase the trustworthiness of our findings, our approach included immersion with the data, independent coding with discrepancies resolved through consensus, debriefing with the primary author, and cross-checking for coding reliability [34]. To increase transferability, we provided definitions and several

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examples of participant comments. To ensure dependability of the data, we kept detailed records and an audit trail.

Caregiver Postsurvey

The responses to the short-answer questions in the postsurvey were also analyzed using the template analysis method described in Brooks et al [34]. The second and third authors followed the same process for analyzing the data that was followed for analyzing the Instagram comments. Throughout this process, the first author was consulted to ensure the quality of data coding. To ensure the trustworthiness of the data, we followed the same procedures outlined by Nowell et al [35] as described above in the qualitative analysis of the Instagram comments.

Results

Participants

After the verification and fraud prevention processes were completed, a total of 31 participants across the United States were included in the study. Among the participants, there were 27 mothers and 4 fathers. There were 15 participants in the 20-29 years age range, 15 in the 30-39 years age range, and 1 that was 40-49 years old. Of the total participants, 10 were White, 16 were Black, 2 were Hispanic/Latino, 2 were Hispanic/Latino-White, and 1 was Black, White, and Hispanic/Latino. All 31 participants spoke English, 4 spoke both English and Spanish, and 1 spoke both English and Yoruba. For more demographic information, see Table 2.

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Table 2. Participant demographic information (n=31).

Characteristics	Participants, n (%)
Relation to child	
Mother	27 (87)
Father	4 (13)
Age in years	
20-29	15 (48)
30-39	15 (48)
40-49	1 (3)
Race/ethnicity	
White	10 (32)
Black	16 (52)
Hispanic/Latino	2 (6)
Hispanic/Latino-White	2 (6)
Black, White, and Hispanic/Latino	1 (3)
Languages spoken	
English	31 (100)
English/Spanish	4 (13)
English/Yoruba	1 (3)
Educational level	
High school diploma or GED[a]	3 (10)
Some college	3 (10)
Associate degree (AA; AS)	5 (16)
Bachelor's degree (BA; BS)	16 (52)
Master's degree	3 (10)
Doctorate degree (PhD)	1 (3)
Estimated household income (in US$)	
Less than $10,000	1 (3)
$10,000-19,999	0 (0)
$20,000-29,999	3 (10)
$30,000-39,999	3 (10)
$40,000-49,999	5 (15)
$50,000-59,999	7 (23)
$60,000-69,999	4 (13)
$70,000-79,999	4 (13)
$80,000 or more	4 (13)

[a]Graduation Education Development.

Quantitative Results

SPEAK-R

Postintervention scores (mean 51.26, SD 12.52) were significantly higher than preintervention scores (mean 44.58, SD 11.37), t_{30}=4.54, *P*<.001, 95% CI 3.68-9.68, indicating an improvement in SPEAK-R knowledge scores. The effect size was large (*d*=0.82; Table 3).

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Table 3. Paired-samples t test for pre- and posttest scores (n=31)[a].

SPEAK-R	Mean (SD)
Pretest	44.58 (11.37)
Posttest	51.26 (12.52)
Difference	6.68 (8.18)

[a]t_{30}=4.54; *P*<.001; 95% CI 3.68-9.68; Cohen *d*=0.82.

Instagram Engagement

To ascertain which posts (videos and/or still posts) generated the most engagement, we examined the number of likes per post and the number of comments per post. Engagement rates were slightly higher for video content compared to still posts. On average, videos received 27 likes and 6 comments per post, compared to 24 likes and 5 comments per post for still posts. A video about postpartum depression and anxiety received the most likes, with all 31 participants liking the video. Three posts garnered 30 likes; they were a video about understanding infant cues, a video with ideas for communication activities during wake windows, and a video about how to respond when the cries of your baby are too much. Eleven posts received 29 likes, including but not limited to a video about what a baby's brain needs in the first few weeks, a video about strategies to calm a baby, a video about the myth of spoiling a baby through too much holding, a video about how to talk to a young infant, and a video about how to play with a young infant. Notably, videos that were posted toward the end of the 18-week intervention period received fewer (23) likes. These videos included 2 videos about babies and screen time and 2 videos about communicating with babies in a bilingual family. The post that received the least number of likes (20) was posted last and was a video titled "Things That Might Cause Concern in the First Year." On average, viewership of each post averaged 85% (26.48 likes out of a possible 31 likes); mean=26.48 likes per video, range=20-31, mode=27. The number of comments per post ranged from 0 to 20 (mean 5.69, mode 3, 4). The post with the greatest number of comments (20) was the video titled *You Can't Spoil a Baby*. A video about postpartum depression and anxiety had 16 comments, along with a video about understanding your baby's cues. The post with the fewest (0) comments was a video about communication skills to expect during the first year. Videos with 1 comment each included a video about research on routines for babies, a video about baby signs, a still post with a baby sign guide, and a video about how to read to a baby.

We also analyzed the number of likes per participant and the number of comments per participant. Participants were asked to like a post as confirmation that they engaged with the content; 13% (4 out of 31) of participants watched all video posts, and 84% (26 out of 31) of participants watched more than half of the videos (mean likes per participant=49.55, range=21-58, mode=57). The number of comments per participant was also gathered to understand more about participant engagement; mean=10.65, range=0-48, and mode=2. One participant engaged with 48 comments, 5 participants commented more than 20 times, and 5 participants did not comment at all throughout the course of the intervention.

Caregiver Postsurvey

Following the intervention phase, the postsurvey was administered to gather caregiver perspectives of the intervention (see Multimedia Appendix 1). Results showed that the statements most frequently agreed upon were "The information shared was interesting" (27/31 [87%] strongly agreed), "The information and language used were clear and easy to understand" (27/31 [87%] strongly agreed), and "The videos helped me feel confident that I can help my child's language learning" (27/31 [87%] strongly agreed). The statements with the lowest level of agreement were "Watching the videos changed my routines with my child" (16/31 [52%] strongly agreed; 9/31 [29%] agreed) and "I shared the videos with friends and family" (16/31 [52%] strongly agreed).

When asked, "What specific topics of videos did you find the most helpful or interesting?," the majority of caregivers (26/31, 84%) selected *baby gestures*, followed by *early cues* and *brain development* (23/31, 74%). The topic with the lowest number of votes was *shared attention* (13/31, 42%).

Qualitative Results

Participant Instagram Comments

Thematic Analysis

Through the qualitative data analysis process described in the Data Analysis section, initially 8 themes emerged: *venting*, *sharing*, *supporting each other*, *learning*, *practicing strategies*, *positive feedback*, *changes made*, and *questions*. At this stage, each of these themes was assigned a color, and each researcher separately coded the comments by highlighting them with the assigned color. After this initial coding process, the team met again to review each other's coding for discrepancies and to define the codes with more specificity. The team agreed that some changes to the codes were necessary to more clearly describe the data. Specifically, *venting* was renamed as *sharing a challenge*. *Sharing* was changed to *sharing positive experiences* and was defined more clearly as sharing about their babies' growth, milestones, and/or positive personal experiences but did not include discussing a challenge. *Learning*, *practicing strategies*, and *changes made* were merged under one code titled *learning through BabyTok*. The code titled *nonaligned/unclear intent* was added to label comments that did not match the topic of the video or post. Additionally, the code of *general comment* was added to describe a brief comment that expanded on the content topic. The resulting 8 themes are labeled and described in Table 4.

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Table 4. Themes from analysis of participant Instagram comments.

Theme	Definition	Example comment
Sharing positive experiences	Participants shared updates on their babies' growth, milestones, and/or positive personal experiences.	"I love talking to my baby and reading him my favorite books! He's only three months and is babbling SO much."
Sharing a challenge	Participants' comments were related to struggles and/or venting about challenges related to the baby or about being a caregiver.	"The first couple of weeks after postpartum I was alone and had to deal with the baby and myself. On one particular night she was crying non stop. I tried everything I could to try and comfort her but nothing helped and I cried with her...it felt like such a sad moment to me because I felt hopeless and without sleep."
Learning through BabyTok	Participants commented about learning something new, using a specific strategy, and/or making a specific change because of information learned from the videos.	"Through this page I've started to narrate what I do with my baby. If I'm making her a bottle, if I'm changing her, just making small talk, etc. and she understands and starts to coo which is very very cute! I like that she's able to distinguish my voice from others and starts to move around."
Supporting each other	Participants made comments that were supportive of other participants.	"I totally understand some days I feel like this as well. Keep pushing mama you got this."
Positive feedback	Participants made comments that were compliments, positive statements, and/or emoji related to the videos, posts, topics, and/or BabyTok in general.	"I love this ❤."
General comment	Participants made comments that were statements related to the content that expanded on the topic.	"Reading helps with cognitive growth, especially pictures."
Nonaligned/unclear intent	Participants' comments were unrelated, nonsensical, had unclear intent, and/or did not align with the content of the video or post.	"I can really relate to this." (This comment was in response to a TikTok video repost with Ms Rachel modeling baby signs.)
Questions	Participant comments were questions for the BabyTok facilitator.	"During my babies wake window I try doing tummy time but she flat out refuses to exercise or stay with her arms crossed for more than 5 minutes. Any tips or suggestions?"

Instagram comments findings based on Table 4 themes are described in more detail below. Additionally, key participant comments are included to help contextualize these results.

Sharing Positive Experiences

Throughout the intervention, participants shared positive experiences with each other, such as sharing about their babies' growth, milestones, and/or positive personal experiences related to caregiving of their baby. One participant shared the following about her baby when commenting on a video about understanding your baby's cues:

> *I've been experiencing this lately! My daughter just turned two months & she's really good at letting me know with her facial expressions when she's hungry or wants to be held so she can nap.*

Another participant commented the following on a video about free things to do in the community with the baby:

> *When we run errands I usually like to point stuff out & tell her what it is. Like if we're at the grocery store I'll say, this is an apple or we need beef. Just to have a little conversation with her & show the item.*

Sharing a Challenge

Participants shared comments related to the challenges faced as a caregiver of an infant. When responding to one video post about postpartum depression and anxiety, there were several participants who shared their struggles. One participant commented, "Most times i feel like I'm loosing myself ...postpartum stress is not really easy." On a video posted about wake window routines a participant commented, "Right now im so tired i talk to her and watch her sisters play. I'm exhausted lol not much energy I have..."

Learning

Participants made comments related to learning from the BabyTok Instagram page. One participant commented about changes she has made because of the BabyTok intervention:

> *Through this page I've started to narrate what I do with my baby. If I'm making her a bottle, if I'm changing her, just making small talk, etc. and she understands and starts to coo which is very very cute!*

Another participant commented that she plans to try a playtime strategy that was introduced in a video titled *Using Toys for Tracking*. Her comment was, "I'm going to start incorporating this during my babies wake time. thank you!"

Supporting Each Other

Participants also showed support for each other with comments like, "I totally understand some days I feel like this as well. Keep pushing mama you got this," and "Happy new week fellow moms!" Participants sometimes shared strategies directly with another participant to be helpful. One participant was worried about her baby getting a flat head due to always sleeping on one side, and another participant commented the following:

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> *Does she sleep facing a certain way? If so, you can try putting her head where her feet usually are. Then if she sleeps facing out the same way, she is now on her other side. (If that makes sense.) My niece also needed chiro and PT due to tight neck muscles on one side that led to her always wanting to face only one way.*

Positive Feedback

Participants provided positive feedback on the content and/or the BabyTok Project Instagram page in general with compliments, supportive statements, and/or emojis. One such comment was made on a video about reading with a baby at different times throughout the day. The participant wrote, "This project has really helped me and my newborn." Examples of other positive feedback comments that were made throughout the project were, "Thank you for sharing," "Interesting stuff," and "I love this ❤."

General Comment

Participants also made general comments that expanded on the content. For example, when commenting on a video about the benefits of reading books, a participant wrote, "Reading helps them with cognitive growth, especially pictures," and when commenting on a video about using wait time as a strategy, another participant stated, "Language is so important! Babies need that and also room to respond!"

Nonaligned or Unclear Intent

There were comments that were not aligned with the content or had unclear intent. One such comment was made on a video about free community routines. The participant's comment was, "I can relate." Another comment that was not aligned with the content was made on a video about the stress and anxiety that caregivers feel when babies cry for extended periods of time. The comment was, "Little miracles, there are such a joy."

Questions for BabyTok

Participants also asked questions in the comments for the BabyTok Project's facilitator, who was the first author. One such question was related to things to do with a baby during baby's wake window. The participant asked:

> *During my babies wake window I try doing tummy time but she flat out refuses to exercise or stay with her arms crossed for more than 5minutes. Any tips or suggestions?*

Another participant asked a question about a video that was posted about choosing books with real human faces to read to babies. The participant asked, "Could my baby enjoy this at two months?"

Caregiver Postsurvey

Thematic Analysis

Three open-ended questions were included in the caregiver postsurvey. They were "Please share any feedback or advice you have for us about the videos," "What was your main takeaway from the content posted," and "Please share what additional topics you might like information about in future videos." The main themes of *feedback and/or advice*, *main takeaways*, and *future videos* were derived from the questions in the survey. Through the template analysis process [10], the second and third authors individually studied the participant answers. The codes that emerged were *positive feedback*, *negative feedback*, *advice*, *empower*, *communication*, *strategy*, *informative*, *affirmation*, *change*, *postpartum*, *feeding*, *different ages/milestones*, and *delivery of content*. The two authors continued to analyze the data and met several times until consensus was reached. During this process, each author took notes about the coding process, thinking about the following questions: Did the codes fit well? Did new themes emerge? Did some codes overlap? Did the codes describe the data accurately? The main code of *future videos* was integrated into the *feedback/suggestions* code because there was crossover between the themes that emerged for each of these codes. Two main codes remained, and the subcodes for each main code were formalized and organized to more accurately describe the data. The code *main takeaway* was given the subcodes of *new information*, *empowering/affirming*, *strategy used/change made*, and *null/negative effects*. The main code, *feedback/suggestions*, was given the subcodes of *general positive statement*, *delivery of content*, *different ages/milestones*, *pregnancy and/or postpartum*, and *unrelated topics*. The themes along with their subthemes are described in Table 5.

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Table 5. Themes from analysis of postsurvey open-ended responses.

Theme	Definition	Example participant response
Main takeaway		
New information	Caregivers reported learning new information from viewing the BabyTok Project videos.	"Learning two languages at the same time helps the brain to develop better, contrary to popular opinion that it may hinder language development."
Empowering/affirming	Caregivers recognized their own impact on their baby and/or felt their parenting communications were making a difference.	"There is no such thing as a perfect parent. Also that you can take charge and help with the development of your baby."
Strategy used/change made	Caregivers mentioned using a specific strategy and/or making a specific change because of information learned from the videos.	"I stopped letting my baby have screen time."
Null effects	Caregiver responding with no comment or nothing learned from intervention.	"Nothing really."
Feedback/suggestions		
General statement	Any general positive comment related to the intervention as a whole.	"I love this segment and truly hope it continues. As a new mom it's just so helpful."
Delivery of content	Any comment with advice related to how the intervention was delivered and/or the platform used for the intervention.	"...it would be nice if specific days were set aside for posting and not just randomly any day."
Different ages/milestones	Caregiver suggestions that future videos include additional ages of development from during pregnancy to older childhood.	"I'd love to have the option for different chapters such as pregnancy through toddlerhood, elementary through middle school, etc."
Unrelated topics	Caregivers mentioned other topics not related to early language development and communicating with the baby such as feeding the baby, teething, helping baby learn to walk, siblings, activities with baby, etc.	"I'd love topics such as starting solids, teething, and even fun activities to do."
Null effects	Caregiver wrote N/A, no additional comment, not sure, or left the answer box blank.	"No additional comment."

Thematic analysis of the open-ended questions yielded key findings, which are described in detail below.

Main Takeaway

When answering the main takeaway question, participants gave answers showing that they learned new information. One participant answered by stating, "How my everyday interactions with my child is helping her learn and grow even if they feel small." Another participant stated, "It is really important to play and talk with my baby." Participants also described feeling empowered or affirmed. One participant wrote, "There is no such thing as a perfect parent. Also, that you can take charge and help with the development of your baby." Additionally, participants described strategies learned from the intervention or a change made as a result of the intervention. For example, one participant wrote, "I've stopped letting my baby have screen time." Another participant wrote, "I loved how you talked about building routines not schedules. The pressure that I lifted off of myself was huge. Routines are much easier to navigate with littles than schedules." There was one null response from a participant who answered the main takeaway question with the response, "nothing really."

Feedback/Suggestions

Participants were asked to share their feedback, advice, and ideas about future topics for the Babytok Project. Participants answered with general positive statements such as, "I love this segment and truly hope it continues. As a new mom it is just so helpful," and "The project was really helpful for my infant and I." Participants also answered with suggestions about content and delivery. One participant wrote, "Have them at a set time," and another wrote, "...it would be nice if the specific days were set aside for posting and not just randomly any day." Another participant answered with, "should do more videos." One participant wrote that they would like to see more representation in videos stating, "Include more videos featuring Dads, Grandparents, and other caregivers to promote diversity and representation in parenting roles." Participants also wrote that they would like videos in the future to include additional developmental ages and discuss developmental milestones. One participant wrote, "...going through all the stages of childhood would be a great direction for the page...creating a series or episodes for different stages would be great." Likewise, another participant wrote, "I'd like it to continue to cover toddler age or at least the first year..." Participants also wrote that they were interested in receiving more information during pregnancy, with one participant writing, "I'd love to have access to something like this during pregnancy so I can also be prepared before baby is born..." Participants were also interested in more information on postpartum health, teething, baby foods, common health issues in infants, and information on motor skills. There were several (14) null answers with participants giving answers such

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as N/A, no additional comment, or leaving the response box blank.

Discussion

BabyTok Project Iterations

This investigation builds evidence for the BabyTok Project social media intervention to support caregiver knowledge of early communication development. Caregivers of infants reported high levels of satisfaction with the intervention, and data from the quantitative measure indicate significant pre-to-post growth in caregiver knowledge of early child development, although these findings should be viewed in the context of the quasi-experimental design that does not have a control group. Given the correlation between caregiver knowledge of child development/language supporting strategies and the quality of very early interactions [17,32], this is a positive indication that light-touch interventions like the BabyTok Project may increase caregiver knowledge. Caregiver knowledge is known to mediate caregiver-child interactions, although a randomized controlled trial is needed to explore potential impacts of the BabyTok Project on real-time exchanges between infants and caregivers.

This iteration of the BabyTok Project began before 3 months of age and was longer than the toddler version of the BabyTok Project investigation with parents of toddlers (22 weeks compared to 8 weeks). These factors might explain the more sizeable increases in SPEAK-R scores in addition to the added statistical power achieved through a larger sample size. Although we did see decreases in engagement toward the end of the 22-week period, slightly longer interventions might be needed to ensure that caregivers are receiving enough of the content to increase their knowledge about early development.

Compared to other app-based interventions in which caregivers interact with in-app features and researchers, the BabyTok Project included a social element between caregivers in small groups. As we plan to expand and scale the project, we will retain the group nature of the intervention to encourage interactions between caregivers in the comments section on the videos. Because we monitor the comments, we are able to correct any false or misleading information that may appear. The benefit of this approach is that it enables caregivers to encourage one another, share ideas, and ask questions. Although it is not possible to disentangle the contribution of the "social" element apart from the content of the videos themselves, we believe it may be an important component that keeps parents engaged and that may build caregiver confidence by sharing information with one another. This approach does, however, complicate the available engagement metrics because watch time data are not available from private pages. Researchers who use social media platforms will need to balance the nuance of information available with privacy and confidentiality requirements of research.

Social media–based video content reaches caregivers on platforms like Instagram, on which they already spend time and search for information. Because social media–based interventions in this area are rare, we do not have many other contexts for comparison as it relates to the video watch rates and amount of engagement. Compared to our own prior work, however, this study had the highest percentage of videos watched, perhaps due to stronger implementation infrastructure with a research team member helping to distribute and follow up with participants every 2 weeks. This could be an important feature to ensure that the videos reach the intended audience, rather than relying on the algorithm alone to alert the users to new content. In fact, participants in past versions have noted that the algorithm did not return them to the page's content, so the direct messaging was essential. Contact with the research team also provided a checkpoint to make sure that participants were doing well, and in the future, it could also be an avenue to weave in a place for caregivers to ask questions about their child's learning/development if concerns arise, or even to promote the use of very early developmental screeners.

Implications for Other Caregiver-Focused Social Media Interventions

Participants in this study had several suggestions that are relevant to other social media–based studies outside of early language development. First, they recommended a predictable video release schedule so that they know when the videos are going to be posted (ie, Mondays, Wednesdays, and Fridays at 12 pm), although they did not specify preferred days and times for video distribution. Across studies, participants appreciated the direct messaging of content rather than relying on them to seek out the page or for the algorithm to deliver it. Participant feedback to include videos of multiple types of caregivers (ie, grandparents, aunts/uncles, and siblings) in the videos is also an important implication for other social media–based interventions for caregivers.

Limitations and Future Directions

Although the findings from this pilot study are promising, there are several limitations to note. Our pilot sample was small, and we did not verify the identity of the participants with a synchronous virtual meeting. We followed the bot and masquerader procedures described above, but verifying identities in a virtual meeting over Zoom would have been ideal and will be used in future investigations. First, it would enable us to ensure that the participants are caregivers of infants and not masqueraders on the internet. Second, it would enable us to meet and connect with participants in a more personal way that will be essential in a longer-duration randomized controlled trial that includes follow-up data collection and other measurements (ie, LENA [Language Environment Analysis] samples, observations, etc).

It is also important to note that our pool of participants had higher levels of education than one might expect from a low-income sample. This could indicate that caregivers with higher levels of education might have self-selected into the study. In addition, the pre-post quasi-experimental design precludes causal conclusions about the ability of the intervention to create change in caregiver knowledge. It is possible that caregivers gained information from other sources during the time they were in the study or that there was a testing effect from taking the SPEAK-R twice. It is also important to view the usage/engagement metrics within the context of the approach

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used in this study. The videos watched do not reflect the "organic" rate that we may have achieved with little researcher support and outreach. While we do not view this as a limitation, per se, we do view it as an important implementation feature that is key for social media interventions that use short-form videos. In addition, the measure used in this study, while not developed by the research team, does not appear to have external validation studies. Still, it is one of the only tools that assesses caregiver knowledge of early communication.

Conclusions

Multiple studies with different sets of caregivers endorse the BabyTok Project as a means to learn about children's early communication. Given the established feasibility and acceptability of the approach and preliminary evidence of changes in knowledge, future studies will examine whether the approach can enhance caregiver-child interactions during infancy and, as a result, if children whose parents received the intervention have stronger language outcomes than a control group. If future efficacy testing demonstrates positive changes in caregiver-child outcomes, the BabyTok Project and interventions like it could fill a persistent need for preventative, universal interventions to promote children's early language skills.

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Authors' Contributions

Conceptualization: MR, KD, AF
Formal analysis: FB, AJ, DLAS, AS
Funding acquisition: MR, AF, KD
Investigation: MR, AJ, FB
Methodology: MR, KD, AF
Project administration: AJ, FB
Protocol development: MR
Writing – original draft: MR (lead), AJ (supporting), FB (supporting)
Writing – reviewing and editing: MR (lead), AJ (supporting), FB (supporting)

Conflicts of Interest

None declared.

Multimedia Appendix 1
Postintervention feedback tables.
[DOCX File , 30 KB - pediatrics_v9i1e93171_app1.docx]

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Abbreviations

KIDI: Knowledge of Infant Development Inventory
LENA: Language Environment Analysis
SPEAK-R: Survey of Parent/Provider Expectations and Knowledge–Research
TANF: Temporary Assistance to Needy Families
WIC: Women, Infants, and Children

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Dental Health in Pediatric Patients With Different Types of Mucopolysaccharidosis: Retrospective Cross-Sectional Study

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Abstract

Background: Patients with mucopolysaccharidosis (MPS) appear to have an increased risk of developing dental disease.

Objective: This study aimed to evaluate the status of dental caries and dental anomalies among Chinese patients with different types of MPS.

Methods: This retrospective study analyzed a consecutive cohort of 102 pediatric patients with MPS who visited the Department of Stomatology at the Capital Center for Children's Health between August 2010 and August 2025. Eligible patients were defined as those with a confirmed diagnosis of MPS who were aged ≤14 years at the time of their dental visit and had complete dental examination records available. Dental caries and anomalies were assessed through clinical records and radiographic data.

Results: Dental caries were observed in 55.9% (57/102) of patients, and no statistically significant difference was observed across the MPS subtypes (*P*=.72). Deep dentinal caries (d4-6mft) were observed in 40.2% (41/102) of the participants and contributed most to the total decayed, missing, and filled teeth index score. The overall prevalence of dental anomalies was 32.4% (33/102), with a statistically significant difference among MPS subtypes (*P*=.005). Patients with MPS type IV had a significantly higher risk of dental anomalies compared to those with MPS type II (odds ratio 6.32, 95% CI 1.55 - 28.28; *P*=.01), after adjusting for age and gender.

Conclusions: The prevalence of dental anomalies differed significantly across MPS subtypes, while that of dental caries did not. These findings emphasize the need for early, targeted preventive care and tailored dental interventions to improve oral health outcomes in this population.

Trial Registration: Chinese Clinical Trial Registry ChiCTR2400090276; https://www.chictr.org.cn/showproj.html?proj=243687

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KEYWORDS

mucopolysaccharidosis; dental caries; dental anomalies; pediatrics; retrospective

Introduction

Mucopolysaccharidosis (MPS) is a group of inherited conditions involving metabolic dysfunction. Lysosomal enzyme deficiency leads to the accumulation of glycosaminoglycans (GAGs), resulting in systemic symptoms, and is categorized into 7 primary types (I [Hurler], II [Hunter], III [Sanfilippo], IV [Morquio], VI [Maroteaux-Lamy], VII [Sly], IX [Natowicz]) caused by the deficiency of 1 of 11 different enzymes. The inability to break down GAGs leads to their abnormal accumulation within various tissues and cells, progressively resulting in cellular dysfunction [1,2]. Globally, the estimated prevalence ranges from 1.04 to 4.8 per 100,000 live births [3-5]. In China, a study conducted across 21 provinces and municipalities between 2006 and 2012 reported that among 376 diagnosed cases of lysosomal storage diseases, MPS accounted for 50.5% (n=190 cases), with MPS type II (MPS-II) being the most common subtype, comprising 47.4% of all MPS cases [6].

Dental and craniofacial abnormalities were frequently reported in patients with MPS [7,8]. Common oral manifestations included macroglossia, anterior open bite, delayed eruption of teeth, cystic lesions, and temporomandibular joint abnormalities [9,10]. These patients also exhibited a higher susceptibility to dental caries, underscoring the need for preventive oral health measures. Meanwhile, due to the low prevalence of MPS and the fact that oral health issues are not among the life-threatening manifestations of the disease, patients rarely seek dental care voluntarily, which explains the current paucity of research on dental caries in this specific population. While previous studies on dental health in patients with MPS have primarily consisted of case reports, small case series, and small cohort studies, the

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overall oral health profile of these patients is poorly characterized.

Furthermore, MPS encompasses 7 distinct clinical subtypes, each exhibiting significant heterogeneity in systemic manifestations due to specific enzymatic deficiencies and the resultant accumulation of various GAGs (eg, dermatan sulfate, heparan sulfate, keratan sulfate, chondroitin sulfate, or hyaluronan) [11-14]. This systemic variability is likely reflected in oral health. For instance, the severe skeletal dysplasia, particularly prominent in MPS-IV, can lead to distinct craniofacial patterns, malocclusions, and potential impacts on tooth eruption and morphology [15]. Additionally, a Brazilian study involving 17 patients with either MPS-IV or VI found that enamel hypoplasia was observed exclusively in those with MPS-IV, while anterior open bite was present only in patients with MPS-VI [16]. Similarly, variations in the degree of soft tissue hyperplasia and the patient's capacity to maintain oral hygiene across different subtypes may influence caries risk. A UK single-center study reported a higher incidence of dental caries in patients with MPS-IV compared to the general population and other MPS groups [17]. Despite these plausible variations and growing international data, comprehensive and comparative analyses of oral phenotypes among MPS subtypes, particularly within the Chinese population, remain limited.

Therefore, based on electronic medical record data, this study investigated the prevalence of dental caries and dental anomalies among patients with different MPS subtypes and analyzed the correlation between dental anomalies and caries in patients with MPS to provide insights for improving preventive care and treatment strategies.

Methods

Ethical Considerations

This study was conducted in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement. The study was approved by the ethics review board of Capital Institute of Pediatrics (SHERLLM2024031) and was registered with the Chinese Clinical Trial Registry (ChiCTR2400090276). All study procedures were in strict compliance with the principles of the Declaration of Helsinki, and written informed consent was waived due to the retrospective nature of the study. To protect patient privacy, all data were anonymized and deidentified prior to analysis. Access to the original medical records was restricted to the research team, and no personally identifiable information (eg, names, medical record numbers, or exact dates) was extracted or reported.

Patients and Study Design

This retrospective cross-sectional study included pediatric patients diagnosed with MPS who visited the Department of Stomatology at the Capital Center for Children's Health between August 2010 and August 2025. This study used a convenience sampling method based on consecutive cases. The inclusion criteria were as follows: (1) a confirmed diagnosis of any subtype of MPS based on enzymatic or genetic testing, (2) age ≤14 years, and (3) availability of a complete dental examination record. Patients were excluded if they had concurrent major systemic conditions (unrelated to MPS) that could severely confound oral health status, such as uncontrolled diabetes, severe congenital heart disease, autoimmune diseases with oral manifestations, or a history of radiotherapy to the head and neck region. On the basis of these criteria, a total of 102 eligible patients were included in the final analysis.

The retrospective collection of electronic medical records was initiated after the study was registered on September 29, 2024. For patients who had multiple visits, only data from their first visit were included in the analysis. It should be noted that the hematology department of our single-center hospital is the largest MPS center in the country, and most patients visiting the stomatology department were referred for routine pretransplantation check-ups prior to stem cell transplantation, rather than presenting with specific oral problems. Therefore, although the data were derived from the stomatology department, the primary purpose of the patients' visits was stem cell transplantation, not specifically for oral issues. This indicates that the results of the oral examinations do not solely reflect the oral health of patients who actively seek treatment for oral problems in the stomatology department, thereby reducing the likelihood of selection bias to some extent. The findings of this study are more representative of the oral health status of patients with MPS, rather than being confined to those with severe oral problems.

Data Collection

The dental conditions of these patients were assessed by reviewing historical clinical records and radiographic data. Data were systematically extracted from oral health records, including demographic information (eg, age and gender), MPS subtype classifications, and comprehensive dental evaluations.

Dental anomalies were categorized into developmental (delayed or retained eruption, delayed tooth germ formation, delayed tooth development, and prolonged retention of primary teeth), morphological (conoid teeth, taurodontism, enamel hypoplasia, and microdontia), numerical (hypodontia and supernumerary teeth), positional (ectopic eruption, impaction, diastema, tooth inversion, and migration), and occlusal abnormalities (biprotrusion, crossbite, crowding, and spaced arches) [8]. Root developmental features (delayed formation, dilaceration, and elongated roots) and periodontal conditions (bone rarefaction and radiolucent lesions) were documented alongside dental follicle abnormalities.

Caries assessment used standardized diagnostic criteria through the International Caries Detection and Assessment System (ICDAS) [18] and the decayed, missing, and filled teeth index (dmft) [19]. All ICDAS codes were assigned based on standardized clinical intraoral visual examination. Lesion characteristics were recorded in terms of frequency (per-arch counts), anatomical distribution (maxillary or mandibular and anterior or posterior), and progression depth (ICDAS scores 1 - 6). All clinical examinations were performed by attending dentists as part of routine patient care over the study period. Consequently, multiple examiners were involved. While formal, prospective interexaminer calibration specific to this study was not feasible due to its retrospective design, the consistent use

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of the ICDAS and dmft criteria across the department provided a standardized framework for diagnosis and recording. In addition, a single primary investigator reviewed all original clinical notes. Any ambiguous, inconsistent, or missing entries were coded as “data missing” rather than inferred to avoid interpretation bias.

Statistical Analysis

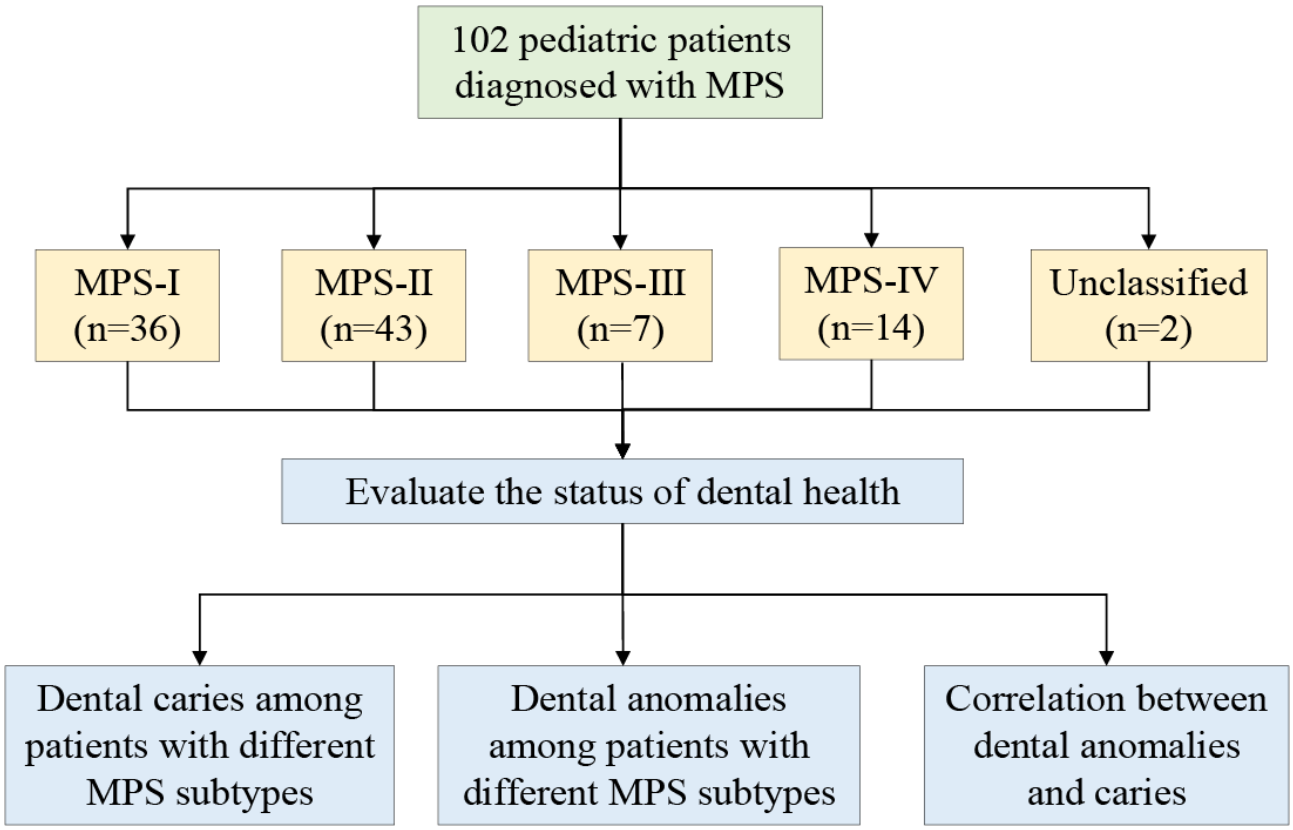
All statistical analyses were performed using R software (version 4.3.2; R Foundation for Statistical Computing). Continuous variables were described using mean (SD), while categorical variables were summarized using frequency (percentage). The normality of continuous variables was assessed using the Shapiro-Wilk test. Differences in the prevalence of dental caries and anomalies among MPS subtypes were analyzed with the chi-square or Fisher exact test. The Kruskal-Wallis test was used to compare the dmft index across subtypes. Where these tests revealed a statistically significant difference, post hoc pairwise comparisons were carried out to identify the specific pairs of subtypes that differed. Multivariable logistic regression was employed to evaluate the association between different MPS subtypes and dental health after adjusting for age and gender. Odds ratios (ORs) with 95% CIs were calculated to quantify effect sizes. A *P* value of less than .05 was considered statistically significant.

Results

Participant Characteristics

A total of 102 patients with MPS were included in this study (Figure 1), and their baseline demographic and clinical characteristics are presented in Table 1. Of these, 73.5% (75/102) were male, with a mean age of 4.8 (SD 2.6) years, ranging from 1 to 12.9 years. Regarding the age at diagnosis, 42.2% (43/102) of patients were aged 3 years or younger, 36.3% (37/102) were aged between 4 and 6 years, and 21.6% (22/102) were aged 7 years or older. MPS-II was the most common subtype (43/102, 42.2%), followed by MPS-I (36/102, 35.3%), while MPS-IV and MPS-III accounted for 13.7% (14/102) and 6.9% (7/102), respectively. Two cases (2/102, 2%) were unclassified. In terms of oral health status, the mean dmft index of the cohort was 2.7 (SD 3.4), with dental caries experience observed in 55.9% (57/102) of patients. Dental anomalies were detected in 32.4% (33/102) of the patients.

Figure 1. Research framework diagram. MPS: mucopolysaccharidosis.



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Table . Demographic and clinical characteristics of patients with mucopolysaccharidosis (MPS; N=102).

Characteristics	Values
Male, n (%)	75 (73.5)
Age (years), mean (SD; range)	4.8 (2.6; 1 - 12.9)
Age at diagnosis (years), n (%)	
≤3	43 (42.2)
4-6	37 (36.3)
≥7	22 (21.6)
MPS type, n (%)	
MPS-I	36 (35.3)
MPS-II	43 (42.2)
MPS-III	7 (6.9)
MPS-IV	14 (13.7)
Unclassified	2 (2)
Dental caries, n (%)	57 (55.9)
dmft[a] index, mean (SD)	2.7 (3.4)
Dental anomalies, n (%)	33 (32.4)

[a]dmft: decayed, missing, and filled teeth.

MPS Subtypes and Dental Caries

Table 2 presents the detailed characteristics of dental caries among patients with different MPS subtypes. There was no statistically significant difference observed across the MPS subtypes in dental caries (*P*=.72). Specifically, caries prevalence was 58.3% (21/36) in MPS-I, 51.2% (22/43) in MPS-II, 71.4% (5/7) in MPS-III, and 50% (7/14) in MPS-IV.

A total of 279 carious teeth were recorded. Patients with MPS-II had the highest number of carious teeth, followed by MPS-I, MPS-IV, and MPS-III. The majority of carious teeth were deciduous across all groups. By tooth type, molars were the most commonly affected, particularly in MPS-IV (35 carious molars among 7 patients) and MPS-II (66 carious molars among 22 patients). Carious lesions were more frequently observed in the maxillary teeth than in the mandibular teeth in all groups except MPS-IV.

For the dmft index, MPS-II showed the highest value (mean 5.68, SD 3.47), while MPS-III had the lowest (mean 2.40, SD 2.51). No statistically significant difference was observed among the 4 subtypes (*P*=.15). Further analysis of caries severity showed that the d4-6mft (deep dentinal lesions) were observed in 40.2% (41/102) of the participants and contributed the most to the total dmft score. Molar teeth had the highest mean dmft values in patients with MPS-IV (mean 5.00, SD 2.45), whereas patients with MPS-II exhibited the highest caries experience in maxillary teeth (mean 3.55, SD 1.99).

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Table . Dental caries in patients with different types of mucopolysaccharidosis (MPS).

Characteristics	MPS-I (n=36)	MPS-II (n=43)	MPS-III (n=7)	MPS-IV (n=14)	Unclassified (n=2)	*P* value[a]
Dental caries, n (%)	21 (58.3)	22 (51.2)	5 (71.4)	7 (50)	2 (100)	.72
Carious teeth, n[b]	94	126	24	37	5	—[c]
Carious deciduous teeth, n	94	125	19	37	5	—
Carious incisors	37	58	5	2	4	
Carious canines	5	1	1	0	0	
Carious molars	52	66	13	35	1	
Carious maxillary teeth	58	78	13	16	4	
Carious mandibular teeth	36	47	6	21	1	
dmft[d] index (n=57), mean (SD)	4.48 (3.14)	5.68 (3.47)	2.40 (2.51)	5.29 (2.56)	2.50 (2.12)	.15
d1-2mft	0.43 (1.21)	0.55 (1.26)	0 (0)	0 (0)	—	
d3mft	0.67 (1.85)	0.86 (1.55)	0.20 (0.45)	1.86 (1.46)	—	
d4-6mft	3.38 (3.34)	4.27 (3.65)	2.20 (2.68)	3.43 (3.31)	—	
Carious incisors dmft	1.76 (1.87)	2.64 (1.73)	0.60 (0.89)	0.29 (0.49)	—	
Carious canines dmft	0.24 (0.77)	0.05 (0.21)	0.20 (0.45)	0 (0)	—	
Carious molars dmft	2.43 (2.42)	3.09 (2.78)	2.60 (3.44)	5.00 (2.45)	—	
Carious maxillary teeth dmft	2.76 (2.30)	3.55 (1.99)	2.60 (2.41)	2.29 (1.89)	—	
Carious mandibular teeth dmft	1.71 (1.65)	2.55 (2.40)	1.20 (1.64)	3.00 (1.15)	—	

[a]Compared the differences among the 4 groups: MPS-I, MPS-II, MPS-III, and MPS-IV.

[b]Values represent cumulative counts of carious teeth. Percentages were not calculated because total tooth counts per group were not available.

[c]Not applicable.

[d]dmft: decayed, missing, and filled teeth.

MPS Subtypes and Dental Anomalies

Table 3 summarizes the prevalence and types of dental anomalies across different MPS subtypes. The overall prevalence of dental anomalies was 32.4% (33/102), with a statistically significant difference among MPS subtypes (*P*=.005). A post hoc analysis revealed a statistically significant difference between MPS-II and MPS-IV (*P*=.007). Patients with MPS-IV exhibited the highest prevalence of dental anomalies (9/14, 64.3%), followed by MPS-I (15/36, 41.7%), MPS-III (2/7, 28.6%), and MPS-II (7/43, 16.3%). No anomalies were detected in the 2 (100%) patients with unclassified MPS.

Table . Dental anomalies in patients with different types of mucopolysaccharidosis (MPS).

Characteristics	MPS-I (n=36), n (%)	MPS-II (n=43), n (%)	MPS-III (n=7), n (%)	MPS-IV (n=14), n (%)	Unclassified (n=2), n (%)	*P* value[a]
Total anomalies	15 (41.7)	7 (16.3)	2 (28.6)	9 (64.3)	0 (0)	.005
Developmental anomalies	9 (25)	3 (7)	1 (14.3)	2 (14.3)	0 (0)	—[b]
Morphological anomalies	3 (8.3)	3 (7)	0 (0)	4 (28.6)	0 (0)	—

[a]Compared the differences among the 4 groups: MPS-I, MPS-II, MPS-III, and MPS-IV.

[b]Not applicable.

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Developmental anomalies were the most common type observed in patients with MPS-I (9/36, 25%), while morphological anomalies were notably frequent in patients with MPS-IV (4/14, 28.6%). Patients with developmental anomalies primarily exhibited the following 4 manifestations: delayed or retained eruption, delayed tooth germ formation, delayed tooth development, and prolonged retention of primary teeth. Among these, delayed tooth germ formation occurred exclusively in patients with MPS-II, and delayed tooth development was only observed in patients with MPS-I and MPS-II. Only one 9-year-old patient (2.8%) with MPS-I presented with 3 types of developmental anomalies simultaneously, and all other patients (97.2%) exhibited only 1 type. Among patients with morphological anomalies, one 9-year-old patient with MPS-IV (14.3%) exhibited conoid teeth in 2 maxillary permanent molars, while all other cases (85.7%) presented with enamel hypoplasia.

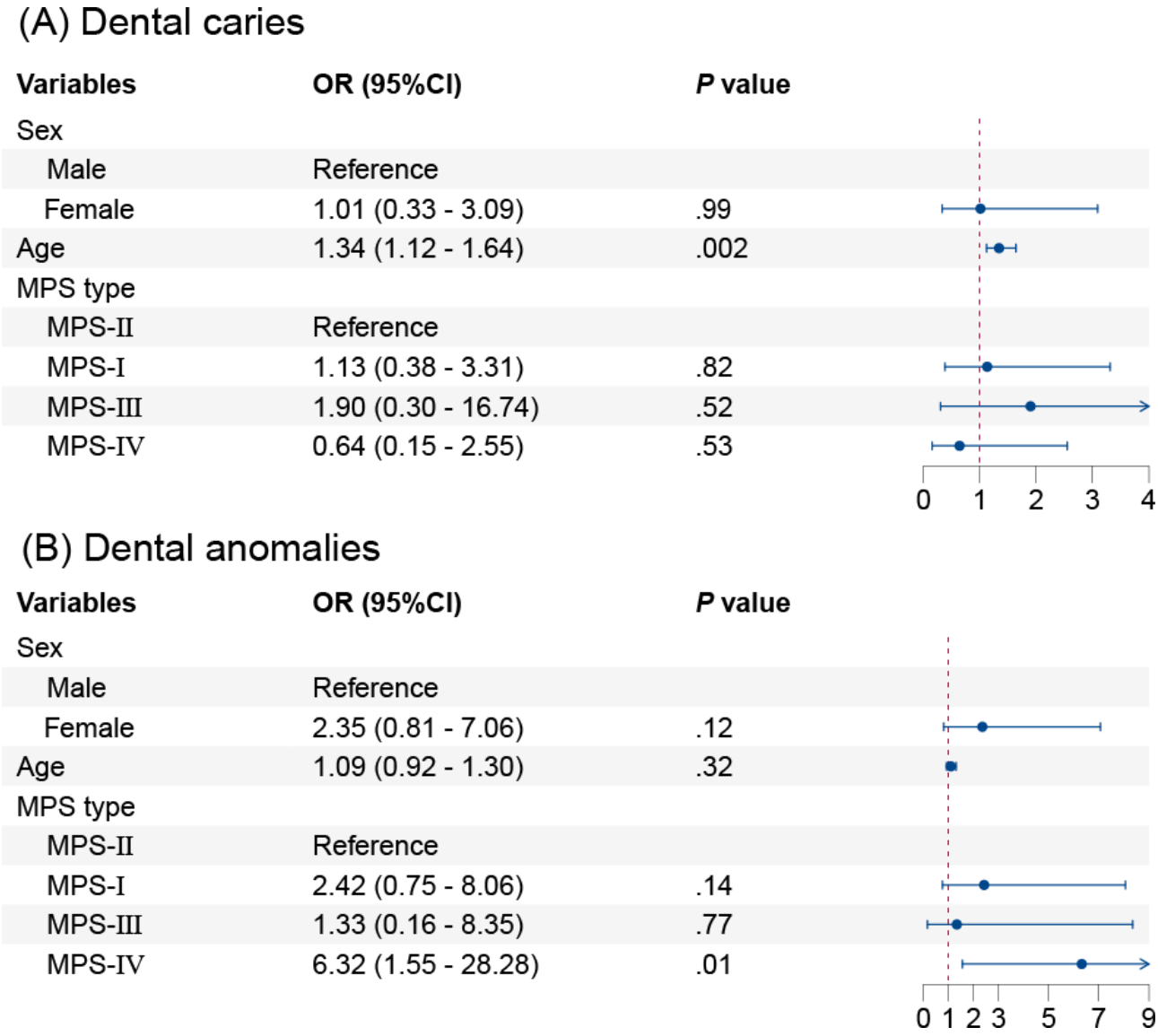
Numerical anomalies were observed only in patients with MPS-III (1/7, 14.3%) and MPS-IV (1/14, 7.1%). All patients with numerical anomalies exhibited missing teeth. Positional anomalies were present in patients with MPS-I (3/36, 8.3%) and MPS-III (1/7, 14.3%), whereas root anomalies were rare and detected in only 1 (2.3%) patient with MPS-II. Among all patients with positional anomalies, one case presented with an anterior crossbite, while the others exhibited malposition of unerupted teeth. The patient with root anomalies (MPS-II) showed root dilaceration. Bone anomalies were most prevalent in patients with MPS-I (7/36, 19.4%), and follicle anomalies were exclusively found in patients with MPS-I (2/36, 5.6%) and MPS-II (2/43, 4.7%). Patients with bone anomalies primarily presented with radiolucent bone lesions and condylar resorption. Those with follicle anomalies mainly exhibited large dental follicles.

Multivariable Analysis of the Association of MPS Subtypes With Dental Health

Multivariable logistic regression analysis was used to evaluate the association between MPS subtypes and dental health outcomes after adjusting for sex and age. Patients with MPS-II were the most prevalent and were therefore designated as the reference group. No significant association was observed between MPS subtypes and dental caries. In contrast, patients with MPS-IV had a significantly higher risk of dental anomalies compared to those with MPS-II (OR 6.32, 95% CI 1.55 - 28.28; *P*=.01; Figure 2).

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Figure 2. Multivariable analysis of the association of mucopolysaccharidosis (MPS) subtypes with dental health: (A) dental caries and (B) dental anomalies. OR: odds ratio.



Relationship Between Dental Anomalies and Dental Caries in Patients With MPS

The relationship between dental anomalies and dental caries in patients with MPS is presented in Table 4. No significant difference was observed in the prevalence of total dental anomalies between patients with and without caries (33.3% vs 31.1%; *P*=.81). Similarly, the presence of developmental anomalies was not significantly associated with dental caries (15.8% vs 13.3%; *P*=.73).

However, morphological anomalies were significantly less frequent in patients with dental caries compared to those without (3.5% vs 17.8%; *P*=.04), with an OR of 0.17 (95% CI 0.02 - 0.72). In contrast, bone anomalies were significantly more common among patients with caries (19.3% vs 2.2%; *P*=.008). The odds of having dental caries were approximately 10.5 times higher in patients with bone anomalies (95% CI 1.3 - 84.93).

Table . Relationship between dental anomalies and dental caries in patients with mucopolysaccharidosis.

Dental anomalies	Without dental caries (n=45), n (%)	With dental caries (n=57), n (%)	*P* value	OR[a] (95% CI)
Total anomalies	14 (31.1)	19 (33.3)	.81	1.11 (0.48 - 2.56)
Developmental anomalies	6 (13.3)	9 (15.8)	.73	1.22 (0.4 - 3.91)
Morphological anomalies	8 (17.8)	2 (3.5)	.04	0.17 (0.02 - 0.72)
Bone anomalies	1 (2.2)	11 (19.3)	.008	10.52 (1.3 - 84.93)

[a]OR: odds ratio.

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Discussion

This retrospective analysis of 102 pediatric patients with MPS in China revealed distinct oral health characteristics across MPS subtypes. The primary findings include an overall dental caries prevalence of 55.9% (57/102), with no significant differences among subtypes (*P*=.72). In contrast, dental anomalies were observed in 32.4% (33/102) of patients, showing significant subtype-specific variation (*P*=.005), with the highest prevalence in MPS-IV (9/14, 64.3%). Further analysis indicated that deep dentinal lesions (d4-6mft) contributed the most to the total dmft score, and molars were the most frequently affected teeth.

These findings are significant because they systematically characterize oral phenotypic variability among MPS subtypes in a Chinese pediatric population for the first time. The subtype-specific distribution of dental anomalies suggests that the underlying pathophysiology of MPS may differentially affect odontogenesis, while the relatively uniform caries prevalence indicates that common risk factors, such as impaired oral hygiene maintenance, may transcend subtype-specific differences. This understanding can assist clinicians in developing tailored oral health management strategies for different MPS subtypes.

Our findings align with and extend the existing body of evidence regarding oral manifestations in patients with MPS. The overall dental caries prevalence of 55.9% (57/102) observed in our cohort corresponds with previous reports of elevated caries experience in this population. For instance, a Brazilian cross-sectional study documented significantly higher caries rates among patients with MPS relative to unaffected individuals [20,21], while a study of Indian children reported increased caries indices in both deciduous and permanent dentitions in the MPS group compared to healthy controls [22]. Similarly, individuals with rare genetic disorders, including MPS, have been shown to possess a substantially elevated likelihood of developing dental caries [23]. Notably, our observation of a predominance of deep dentinal caries adds granularity to these earlier reports, suggesting that MPS-specific factors—such as enamel structural alterations, restricted mouth opening, and functional limitations—may predispose patients to more advanced carious lesions.

Regarding dental anomalies, our results corroborate the established understanding that such abnormalities are a frequent component of the MPS phenotype. Carneiro et al [8] highlighted a range of common radiographic findings in patients with MPS, including supernumerary teeth, peg-shaped teeth, taurodontism, tooth impaction, and dilated dental roots. This is consistent with the spectrum of anomalies identified in our cohort. Further supporting this pattern, Almeida-Barros et al [16] reported supernumerary teeth in 23.5% of patients with MPS-IV and MPS-VI, and another cross-sectional study noted a high frequency of cyst-like dental crypts, taurodontism, and tooth impaction among patients with MPS [21]. The convergence of these international findings underscores that dental anomalies are a core, recurrent feature across diverse MPS populations, likely stemming from the underlying disruption of craniofacial and dental development by GAG accumulation.

A key contribution of our study lies in the comparative analysis across MPS subtypes. We found no statistically significant difference in caries prevalence or the dmft index among subtypes, suggesting that universal risk factors, such as the profound challenges in maintaining oral hygiene common to all patients with MPS, may outweigh potential subtype-specific pathophysiological differences in caries susceptibility. This homogeneity contrasts with the distinct subtype-specific pattern observed for dental anomalies, particularly the significantly higher burden in patients with MPS-IV. This divergence indicates that while caries risk may be broadly elevated across MPS due to common functional limitations, the development of specific dental anomalies is more closely linked to the particular skeletal and developmental pathology of each subtype.

Although we attribute the subtype-specific differences in dental anomalies primarily to the severe skeletal dysplasia characteristic of MPS-IV, alternative explanations should be considered. Variability in medical management, such as the timing and availability of enzyme replacement therapy, across subtypes may indirectly influence oral and dental development. Additionally, differences in the average age at dental examination among subtypes could affect the detection rate of certain anomalies, particularly those associated with tooth eruption and development.

The clinical implications of this study are 3-fold. First, patients with MPS-IV should be prioritized for early and comprehensive screening of dental anomalies to allow for timely orthodontic intervention. Second, all patients with MPS require intensified caries prevention strategies, with particular emphasis on pit and fissure sealing of molars. Third, those subtypes with significant neurocognitive impairment, such as MPS-III, necessitate the development of adapted oral hygiene aids and caregiver-assisted protocols. These findings support the integration of standardized oral evaluation into the multidisciplinary management framework for MPS.

Several limitations warrant careful consideration. First, the retrospective design and extraction of dental data from historical clinical records introduce potential information bias. As multiple dentists conducted examinations over the 15-year study period without formal interexaminer calibration, variations in diagnostic thresholds and recording practices are possible. To mitigate this, a standardized data extraction protocol aligned with ICDAS criteria was applied by a single primary investigator. Nevertheless, such nondifferential misclassification would likely have biased effect estimates toward the null. Second, the sample size remained limited for some subtypes after stratification, potentially reducing statistical power. Third, the absence of a healthy control group precluded direct comparison with the general population. Finally, unmeasured confounders, such as dietary habits and detailed oral hygiene practices, could not be accounted for.

Future studies should prioritize prospective, multicenter designs with precalibrated examiners to ensure diagnostic consistency. Incorporating objective biomarkers, salivary microbiological analysis, and standardized imaging protocols would help elucidate the mechanisms underlying caries susceptibility and dental anomalies in MPS. Moreover, longitudinal studies are

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needed to evaluate the long-term effectiveness of subtype-specific preventive and therapeutic oral health interventions.

In conclusion, this study demonstrates that Chinese pediatric patients with MPS experience a substantial burden of dental caries and anomalies, with the latter showing marked subtype-specific variation. These findings underscore the necessity of subtype-tailored oral health strategies and the integration of structured dental assessment into routine MPS follow-up care to enable early detection and intervention.

Funding

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Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

MW designed the study and conceptualized the manuscript. RL collected the data. TX supported the statistical analysis. YW drafted the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

dmft: decayed, missing, and filled teeth index
GAG: glycosaminoglycan
ICDAS: International Caries Detection and Assessment System
MPS: mucopolysaccharidosis
OR: odds ratio
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

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Clostridium Abundance and Lower Weight-for-Age z Scores Among 6-Month-Old Infants: Nested Cross-Sectional Study

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Abstract

Background: The gut microbiota plays a crucial role in infant nutrition through its effects on energy metabolism, nutrient absorption, and immune regulation. However, evidence from Indonesian infants remains limited.

Objective: This study aimed to examine the association between genus-level gut microbiota abundance and weight-for-age *z* scores (WAZ) among 6-month-old infants in coastal Banggai District, Central Sulawesi, Indonesia.

Methods: We conducted a nested follow-up cross-sectional observational analysis of 88 six-month-old infants, including 42 (47.7%) who were born to mothers who were assigned to receive *Moringa oleifera* enriched with royal jelly group and 46 (52.3%) who were assigned to receive a multiple micronutrient supplement in a previous maternal supplementation trial. Maternal and infant characteristics were collected via structured interviews and standardized anthropometric measurements. WAZ was calculated using the World Health Organization Child Growth Standards, and underweight (WAZ <−2 SD) was reported as a secondary indicator. Stool samples were analyzed using genus-specific quantitative polymerase chain reaction to quantify *Bifidobacterium*, *Lactobacillus*, *Bacteroides*, *Clostridium*, and *Escherichia coli* (log_{10} colony-forming unit/mL). Associations between bacterial abundance and WAZ were assessed using multivariable linear regression adjusted for maternal supplementation allocation and relevant maternal, environmental, and infant covariates.

Results: The pooled mean WAZ was −0.47 (SD 1.09), and 8% (7/88) of the infants were underweight. The combined abundance of beneficial genera was higher than that of opportunistic bacteria (*E coli* and *Clostridium;* Wilcoxon signed-rank test; *P*=.002). Higher *Clostridium* abundance was inversely associated with WAZ (unadjusted β=−.094, 95% CI −0.173 to −0.015; *P*=.02; adjusted β=−.091, 95% CI −0.172 to −0.010; *P*=.03). No statistically significant associations were observed for *Bifidobacterium* (*P*=.13), *Lactobacillus* (*P*=.19), *Bacteroides* (*P*=.70), or *E coli* (*P*=.18) in adjusted models.

Conclusions: Among 6-month-old infants in coastal Central Sulawesi, higher genus-level *Clostridium* abundance was independently associated with lower WAZ. Given the cross-sectional design and genus-level quantitative polymerase chain reaction assessment, temporality and species-level mechanisms cannot be established. Longitudinal studies using more comprehensive microbiome profiling are warranted to clarify potential pathways linking gut microbiota and early-life growth.

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KEYWORDS

Clostridium; gut microbiota; weight-for-age z score; infants; Indonesia

Introduction

The growth of infants aged 0 to 6 months represents a critical period that is strongly influenced by nutritional status. One of the most sensitive indicators for assessing nutritional status is the weight-for-age *z* score (WAZ), where values below −2 SD are classified as underweight. Undernutrition, which may result from stunting, wasting, or both, is reflected by being underweight and contributes substantially to morbidity,

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mortality, and long-term developmental impairments in early life [1,2].

Globally, the prevalence of underweight among children under 5 has declined considerably over the past decades. According to the World Bank's World Development Indicators, derived from the Joint Child Malnutrition Estimates, the global prevalence has decreased from approximately 25% in the early 1990s to around 12% to 13% in recent years [3]. In Indonesia, the 2024 Indonesian Nutrition Status Survey reported a prevalence of 14.5%, showing a decline from the previous year but still above the national target [4]. At the regional level, disparities persist, with the 2023 Indonesian Health Survey reporting an underweight prevalence of 24.4% in Central Sulawesi and 22.7% in Banggai District [5]. This prevalence exceeds the World Health Organization (WHO) threshold for a high public health burden (20% - 29%), indicating a persistent challenge for child nutrition in these areas.

Although these figures illustrate the magnitude of the problem, understanding the underlying biological and environmental determinants remains essential. In addition to inadequate dietary intake and infectious diseases, recent scientific evidence has highlighted the critical role of the gut microbiota in shaping infant nutritional status. The gut microbiota influences energy metabolism, nutrient absorption, and immune regulation [6,7]. Emerging studies have shown that early-life variations in microbiota composition can affect linear growth and the risk of undernutrition [8]. Reviews have also emphasized the close link between microbial diversity, immune system maturation, and overall infant health [9,10].

Several studies have demonstrated associations between gut microbiota dysbiosis and growth impairment. Research in Bangladesh and Malawi found that children with growth faltering generally had lower levels of *Bifidobacterium* and *Lactobacillus*, along with a higher abundance of opportunistic bacteria such as *Enterobacteriaceae* [11-13]. Similarly, a study in Finland reported that probiotic supplementation could restore microbiota balance and promote infant growth [14]. However, evidence from Indonesia remains limited, particularly in coastal regions such as Central Sulawesi, where nutritional challenges and environmental exposures may influence early-life microbial colonization.

Moreover, most previous studies have primarily focused on stunting, while limited research has examined the association between gut microbiota balance and WAZ during early infancy. Therefore, this study aimed to examine the association between genus-level gut microbiota abundance and WAZ among 6-month-old infants in coastal Banggai District, Central Sulawesi, Indonesia.

Methods

Study Design and Setting

This study was a nested follow-up cross-sectional observational analysis of infants born to mothers who had previously participated in a randomized maternal supplementation trial conducted in coastal areas of Banggai District, Central Sulawesi, Indonesia, specifically in the rural subdistricts of Batui Selatan and Moilong. In the original trial, pregnant women were randomly assigned to receive either multiple micronutrient supplements (MMS) in accordance with national guidelines or *Moringa oleifera* enriched with royal jelly (MRJ) during pregnancy. Supplementation was provided from the second trimester until delivery (September 2023-June 2024).

This study used follow-up data from the infant cohort to examine the association between gut microbiota composition and infant nutritional status at 6 months of age, measured using WAZ. Because the infants originated from the previous maternal supplementation trial, the original supplementation allocation (MRJ vs MMS) was considered in the statistical analysis to account for potential confounding. This study did not evaluate the efficacy of the maternal supplementation intervention and did not involve new randomization or intervention during infancy. The original trial was not registered in a public trial registry; therefore, this manuscript is reported as a nested observational follow-up analysis rather than as a primary randomized trial report.

Follow-up data collection was conducted between August and December 2024 through household visits. Anthropometric measurements and questionnaire-based information on maternal, infant, and environmental characteristics were obtained, and infant fecal samples were collected for microbiota analysis. Laboratory analyses of the fecal samples were completed by April 2025 at a university-affiliated medical research center. Reporting followed the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guideline for cross-sectional studies because this manuscript reports a nested observational follow-up analysis rather than the primary outcomes of the original randomized trial (Checklist 1).

Participants

Infants included in this study were born to mothers who had participated in the original randomized controlled trial of maternal supplementation. In that trial, 160 pregnant women were randomly assigned to receive either the MRJ supplement—a daily capsule containing *M oleifera* leaf extract enriched with royal jelly—or a standard MMS in accordance with national guidelines. Supplementation was provided from the second trimester until delivery (September 2023-June 2024).

During the follow-up phase (August-December 2024), infants were assessed when they reached 6 months of age. The follow-up analysis focused specifically on infants at 6 months of age. Infants who had already exceeded 6 months of age at the time of follow-up or whose families had relocated outside the study area were not included in the analysis. Because the outcome assessment was restricted to infants aged 6 months, anthropometric measurements were not obtained for those who were not eligible for follow-up. A total of 88 infants met the inclusion criteria and were enrolled in this analysis (n=42, 47.7% from the MRJ group and n=46, 52.3% from the MMS group).

Ethical Considerations

This study was approved by the ethics committee of the Faculty of Public Health, Hasanuddin University (protocol code 281024093076; approval 3505/UN4.14.1/TP.02.02/2024).

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Written informed consent was obtained from all participants prior to enrollment.

Sample Size Considerations

The sample size for this nested follow-up analysis was determined by the number of infants who met the predefined eligibility criteria (assessment at 6 months of age) and were available during the follow-up period, rather than by an a priori sample size calculation for microbiota outcomes. To contextualize statistical power, a post hoc assessment indicates that with 88 participants and a 2-sided α level of .05, the study has approximately 80% power to detect a moderate association (equivalent to a correlation of r=0.30) in unadjusted analyses. We acknowledge that power may be lower in multivariable models after adjustment for multiple covariates; therefore, smaller associations may not have been detected, and nonsignificant findings for some genera should be interpreted cautiously.

Variables and Outcomes

The primary outcome was infant nutritional status assessed using WAZ based on the WHO Child Growth Standards (2006) and analyzed as a continuous variable. Underweight (WAZ<−2 SD) was defined and reported as a secondary descriptive indicator. The primary exposure variable was gut microbiota composition at 6 months of age, focusing on 5 bacterial genera: *Bifidobacterium*, *Lactobacillus*, *Bacteroides*, *Clostridium*, and *Escherichia coli*. Potential covariates included infant sex, birth weight, mode of delivery, maternal age and education, household socioeconomic status, breastfeeding practices, and the maternal supplementation group (MRJ or MMS).

Data Collection

Data were collected during home visits conducted by the research team in collaboration with trained enumerators. Structured questionnaires were administered to obtain information on maternal and infant characteristics, feeding practices, and sociodemographic factors. Following the interviews, anthropometric measurements of the infants were taken using calibrated equipment and standardized procedures, with assistance from the enumerators. In addition, fecal samples were collected from the infants for subsequent microbiota analysis.

Anthropometric Measurements

Anthropometric assessments were performed when infants reached 6 months of age. Weight was measured using a calibrated digital infant scale, and recumbent length was recorded as supplementary information. Measurements were taken twice; if discrepancies were detected, a third measurement was performed, and the mean of the 2 closest values was used in the analysis. WAZ values were calculated using WHO Anthro software (version 3.2.2), and underweight was defined as WAZ<−2 SD according to WHO standards.

Gut Microbiota Analysis

Fecal samples were stored at −20 °C and analyzed at the Hasanuddin University Medical Research Center. DNA was extracted using the Presto Stool DNA Extraction Kit (Geneaid Biotech Ltd) following the manufacturer's protocol. Quantitative analysis of gut microbiota was performed using quantitative polymerase chain reaction (qPCR) with genus-specific primers targeting *Bifidobacterium*, *Lactobacillus*, *Bacteroides*, *Clostridium*, and *E coli*. Results were expressed as $\log_{10}$ colony-forming units (CFU)/mL. Additional laboratory details for DNA extraction and genus-level qPCR procedures are provided in Multimedia Appendix 1.

Statistical Analysis

Data were analyzed using SPSS software (version 23; IBM Corp). Descriptive statistics were used to summarize maternal, infant, environmental, and microbiota characteristics. The Shapiro-Wilk test was applied to assess normality. Group comparisons between supplementation groups were performed using the chi-square test for categorical variables and the Mann-Whitney U test for continuous variables with nonnormal distributions. Paired differences in bacterial abundance within the same infants were assessed using the Wilcoxon signed-rank test. Associations between gut bacterial abundance ($\log_{10}$ CFU/mL) and WAZ were examined using multivariable linear regression models.

There were no missing data for variables included in the regression models; therefore, all regression analyses used n=88. Covariates were selected a priori based on biological plausibility and evidence from previous studies as potential confounders of the microbiota-growth relationship, including maternal supplementation group (MRJ vs MMS), maternal education, environmental health status, gestational age at birth, mode of delivery, infant illness history within the first 6 months, immunization status, exclusive breastfeeding, and birth weight category. To maintain parsimony given the modest sample size, we used this prespecified covariate set and fitted separate adjusted models for each bacterial genus (ie, without data-driven covariate selection procedures). Linear regression assumptions were evaluated using residual diagnostics for linearity and homoscedasticity and Q-Q plots for normality of residuals. Multicollinearity among covariates was assessed using variance inflation factors, and influential observations were examined using standardized residuals and the Cook distance. Model fit was summarized using R^2 and adjusted R^2. All tests were 2-tailed, and statistical significance was set at P<.05.

Results

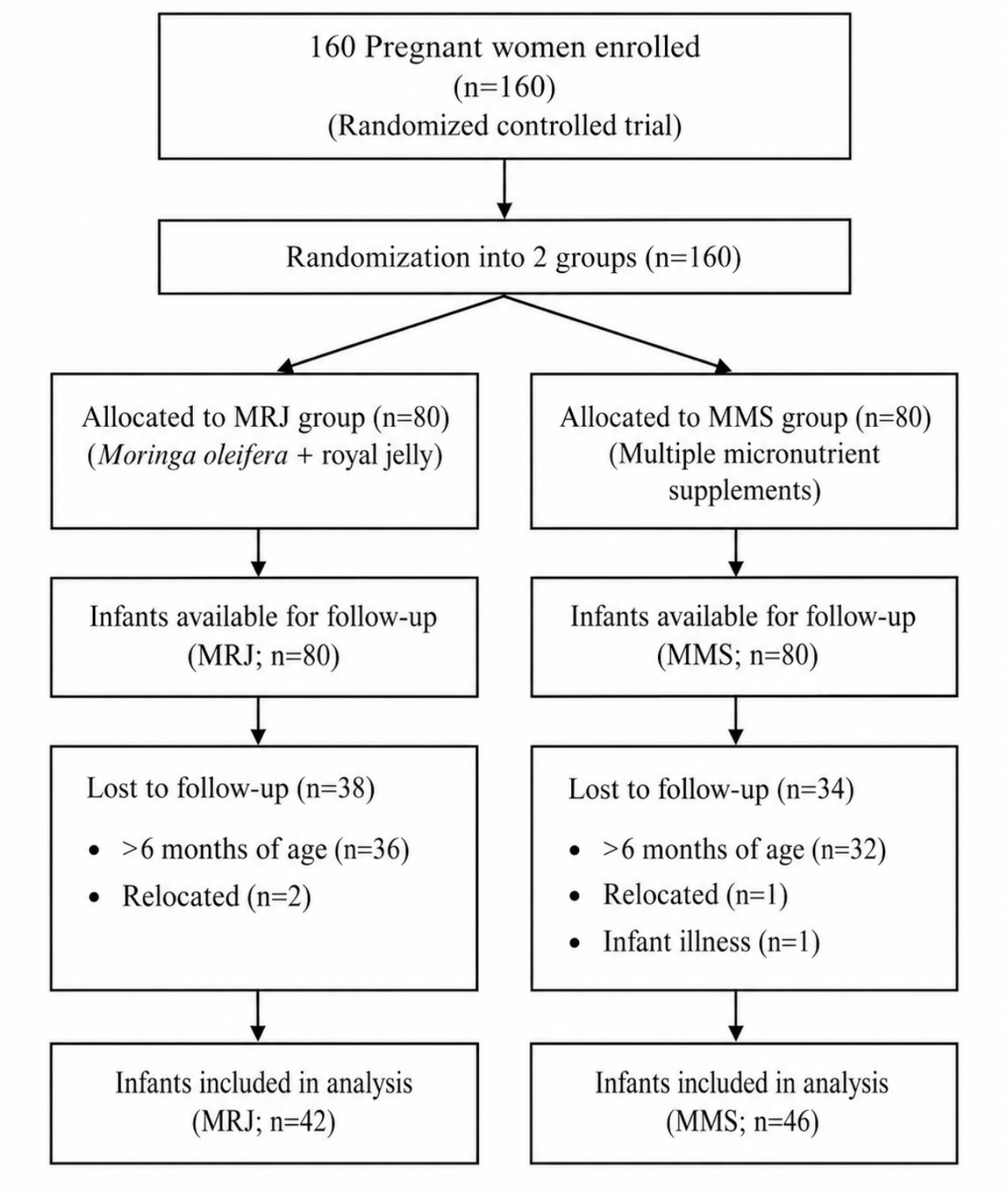
Characteristics of Study Participants

A detailed participant flow diagram is presented in Figure 1. A total of 88 six-month-old infants were included in the analysis (n=42, 47.7% MRJ and n=46, 52.3% MMS). Baseline household, maternal, and infant characteristics are summarized in Table 1. Maternal and paternal education were categorized as low (primary and junior secondary school) and high (senior secondary school or higher, including diploma and university). Most baseline characteristics were comparable between groups; however, the MRJ group had a higher proportion of fathers with low education than the MMS group (15/42, 35.7% vs 6/46, 13%; P=.01), and households in the MMS group more often reported a drinking water source within ≤10 m (12/46, 26.1% vs 3/42, 7.1%; P=.02). Infant sex distribution also differed

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between groups (male infants: 26/46, 56.5% in MMS vs 14/42, 33.3% in MRJ; *P*=.03). Anthropometric outcomes at 6 months were similar between groups, including WAZ (*P*=.63). Overall, mean WAZ in the pooled sample was −0.47 (SD 1.09), and 8% (7/88) were classified as underweight. These pooled data were used in subsequent analyses to examine associations between gut microbiota composition and growth outcomes.

Figure 1. Flow diagram of study participants. MMS: multiple micronutrient supplements; MRJ: *Moringa oleifera* enriched with royal jelly.



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Table . Characteristics of study participants.

Variables	MRJ[a] (n=42)	MMS[b] (n=46)	Total (n=88)	*P* value
Sociodemographic characteristics, n (%)				
Maternal education				.05[c]
Low	10 (23.8)	4 (8.7)	14 (15.9)	
High	32 (76.2)	42 (91.3)	74 (84.1)	
Paternal education				*.01* [c]
Low	15 (35.7)	6 (13)	21 (23.9)	
High	27 (64.3)	40 (87)	67 (76.1)	
Maternal occupation (unemployed)	32 (76.1)	35 (76.1)	67 (76.1)	.58[c]
Paternal occupation				.69[c]
Farmer	16 (38.1)	19 (41.3)	35 (39.8)	
Self-employed	7 (16.7)	4 (8.7)	11 (12.5)	
Household income <Banggai minimum wage	27 (64.3)	25 (54.3)	52 (59.1)	.34[c]
Environmental factors, n (%)				
Drinking water source ≤10 m	3 (7.1)	12 (26.1)	15 (17.0)	*.02*[c]
Adequate environmental sanitation	9 (21.4)	14 (30.4)	23 (26.1)	.24[c]
Maternal and perinatal characteristics, n (%)				
Infant sex				*.03*[c]
Male	14 (33.3)	26 (56.5)	40 (45.5)	
Female	28 (66.7)	20 (43.5)	48 (54.5)	
Preterm gestational age (<37 wk)	1 (2.4)	4 (8.7)	5 (5.7)	.20[c]
Delivery mode (C-section)	5 (11.9)	5 (10.9)	10 (11.4)	.57[c]
Maternal antibiotic use during pregnancy	12 (28.6)	15 (32.6)	27 (30.7)	.68[c]
Infant feeding practices, n (%)				
Early initiation of breastfeeding	17 (40.5)	23 (50)	40 (45.5)	.49[c]
Colostrum feeding	38 (90.5)	41 (89.1)	79 (89.8)	>.99[c]
Exclusive breastfeeding (0 - 6 months)	22 (52.4)	15 (32.6)	37 (42)	.09[c]
Still breastfeeding at 6 months	34 (81)	38 (82.6)	72 (81.8)	>.99[c]
Anthropometric characteristics				
Low birth weight (<2500 g), n (%)	2 (4.8)	5 (10.9)	7 (8)	.35[c]
Birth weight (kg), mean (SD)	3.21 (0.43)	3.13 (0.54)	3.17 (0.49)	.48[d]
Birth length (cm), mean (SD)	48.9 (1.26)	48.6 (1.90)	48.7 (1.60)	.52[d]
Infant weight at 6 months (kg), mean (SD)	7.14 (0.93)	7.28 (0.86)	7.22 (0.89)	.45[d]

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Variables	MRJ[a] (n=42)	MMS[b] (n=46)	Total (n=88)	*P* value
Infant length at 6 months (cm), mean (SD)	65.5 (2.5)	65.4 (3.3)	65.4 (2.9)	.79[d]
Weight-for-age *z* score, mean (SD)	−0.57 (1.12)	−0.36 (1.05)	−0.47 (1.09)	.63[d]
Underweight (weight-for-age *z* score <−2 SD), n (%)	4 (9.5)	3 (6.5)	7 (8)	.69[c]

[a]MRJ: *Moringa oleifera* enriched with royal jelly.

[b]MMS: multiple micronutrient supplements.

[c]Chi-square test.

[d]Mann-Whitney *U* test.

Gut Microbiota Composition and Distribution by Nutritional Status in 6-Month-Old Infants

The gut microbiota composition of 6-month-old infants is summarized in Table 2. Among the beneficial bacterial genera, *Lactobacillus* exhibited the highest mean concentration (mean 7.83, SD 1.75 log CFU/mL), followed by *Bifidobacterium* (mean 7.44, SD 1.88 log CFU/mL). The commensal genus *Bacteroides* was detected at comparable levels (mean 7.52, SD 1.82 log CFU/mL). In contrast, the mean concentrations of opportunistic bacteria were 8.03 (SD 1.43) log CFU/mL for *E coli* and 6.00 (SD 2.73) log CFU/mL for *Clostridium*. When grouped, the combined abundance of beneficial bacteria (*Bifidobacterium* and *Lactobacillus*) was significantly higher than that of opportunistic bacteria (*E coli* and *Clostridium;* mean 7.64, SD 1.36 vs mean 7.01, SD 1.82 log CFU/mL; Wilcoxon signed-rank test: *Z*=1204.5; *P*=.002).

Table . Gut microbiota composition of 6-month-old infants (n=88, log colony-forming unit [CFU]/mL).

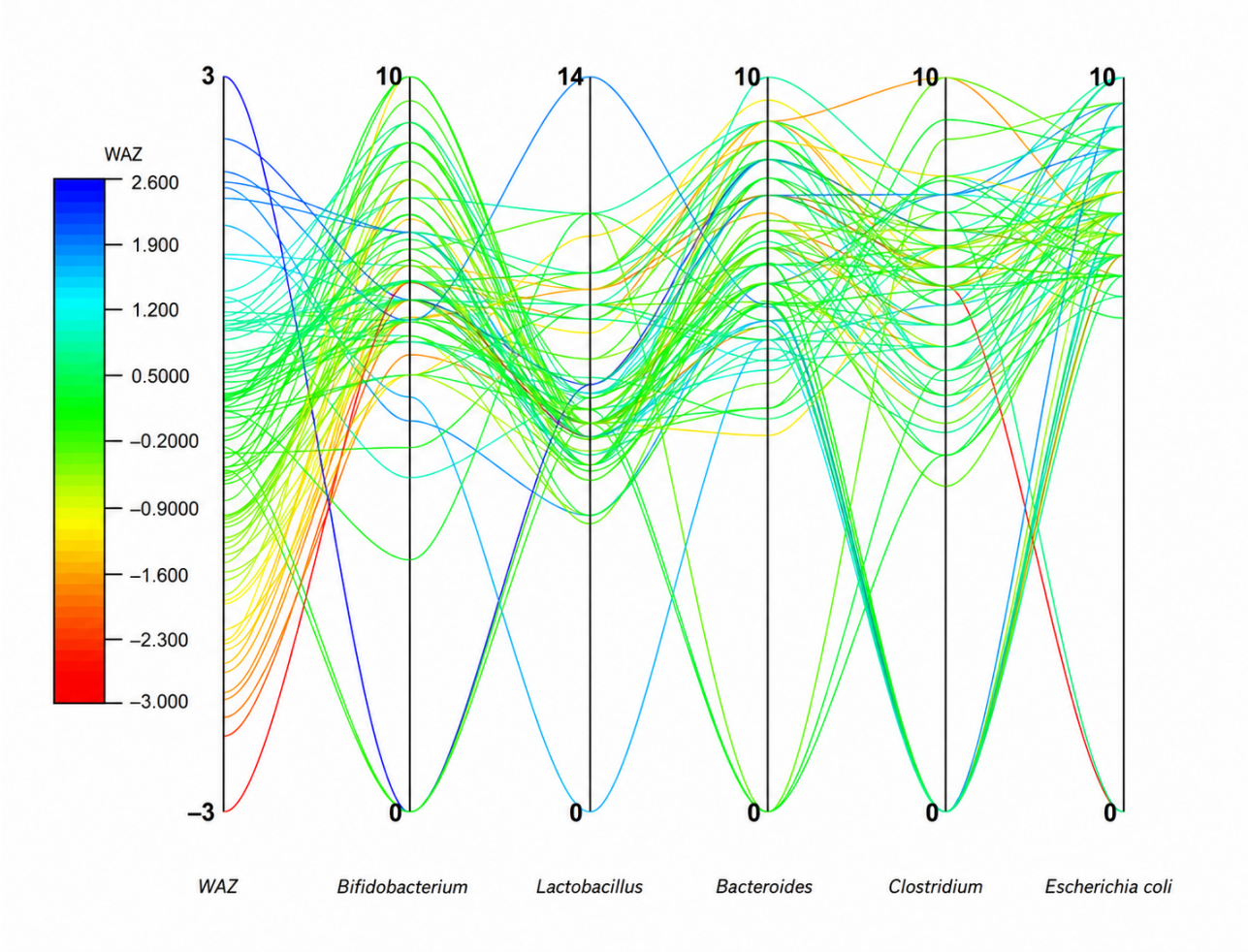
Gut microbiota	Values, mean (SD)	Values, median (IQR)
Bifidobacterium (beneficial)	7.44 (1.88)	7.69 (6.98 - 8.51)
Lactobacillus (beneficial)	7.83 (1.75)	7.78 (6.50 - 9.27)
Bacteroides (commensal)	7.52 (1.82)	7.54 (6.77 - 8.26)
Clostridium (opportunistic)	6.00 (2.73)	7.03 (5.55 - 8.12)
Escherichia coli (opportunistic)	8.03 (1.43)	7.84 (7.27 - 8.70)
Beneficial bacteria[a]	7.64 (1.36)	7.69 (6.98 - 8.51)
Opportunistic bacteria[a]	7.01 (1.82)	7.44 (5.89 - 8.12)

[a]Wilcoxon signed-rank test (beneficial vs opportunistic bacteria): *Z*=1204.5; *P*=.002.

Figure 2 illustrates the distribution of the 5 dominant bacterial genera (*Bifidobacterium*, *Lactobacillus*, *Bacteroides*, *Clostridium*, and *E coli*) according to infant nutritional status. Each line in the figure represents an individual infant, and the color gradient indicates WAZ, ranging from very low values (red, <–3 SD) to high values (blue, approaching 2 SD). Infants with lower WAZ demonstrated greater variability in microbial abundance, particularly for *Lactobacillus* and *Clostridium*. Conversely, infants with normal or higher WAZ values exhibited more uniform distribution patterns across the analyzed genera. These results indicate that underweight infants tended to present more heterogeneous gut microbiota profiles, whereas well-nourished infants showed a more balanced bacterial composition.

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Figure 2. Parallel coordinates plot of genus-level gut microbiota abundance (log_{10} colony-forming unit [CFU]/mL) and weight-for-age *z* scores (WAZ) in 6-month-old infants (n=88). Each line represents one infant. Line color indicates WAZ (red=lower WAZ; blue=higher WAZ; observed range −3.0 to 2.6). Vertical axes show WAZ and bacterial genus abundance measured by quantitative polymerase chain reaction.

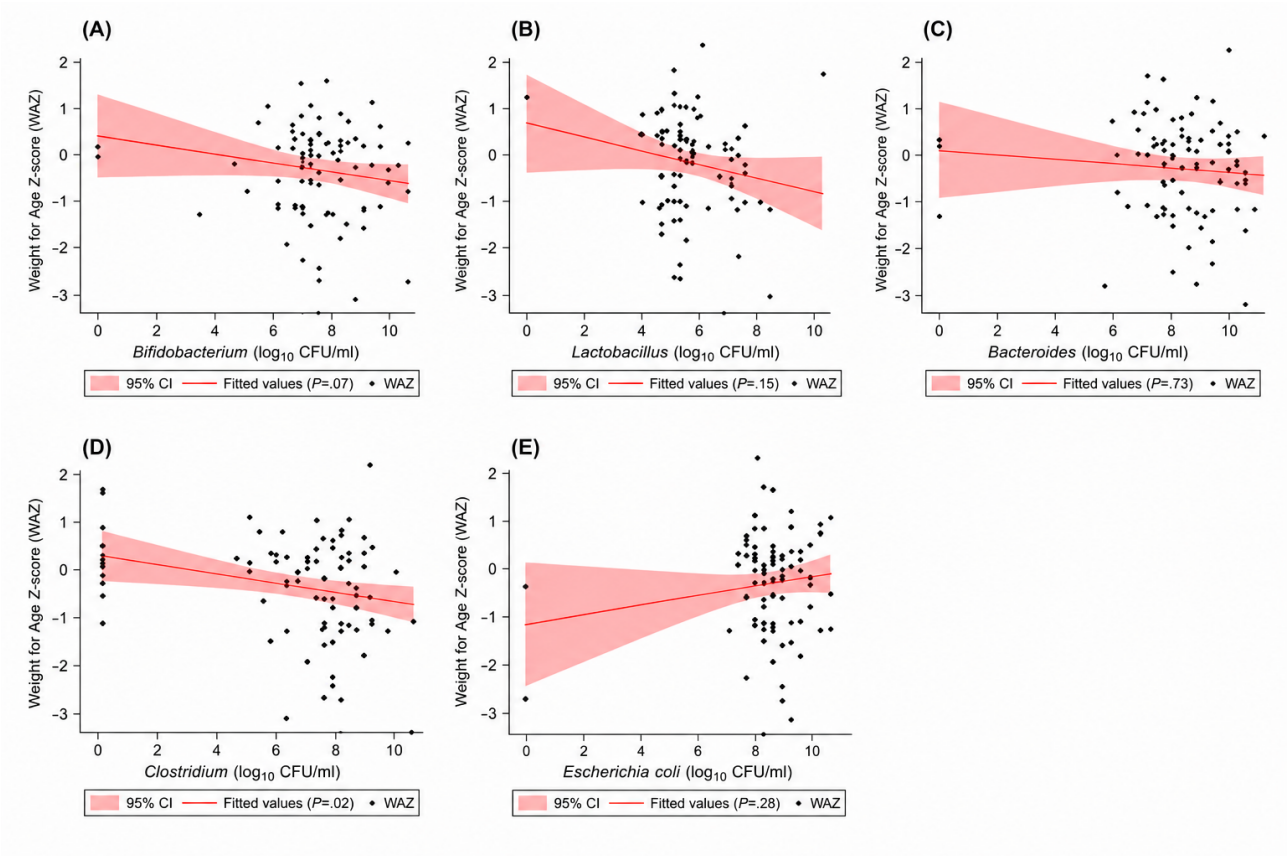


Association Between Gut Microbiota Genus and WAZ

The associations between gut microbiota composition and WAZ are illustrated in Figure 3. Overall, the regression patterns indicated a predominantly negative trend between bacterial abundance and WAZ across most genera. For *Bifidobacterium* (panel A) and *Lactobacillus* (panel B), the regression lines exhibited a slight downward slope, suggesting that higher levels of these bacteria were associated with lower WAZ; however, these associations were not statistically significant. *Bacteroides* (panel C) showed a nearly flat regression line, indicating a weak relationship with WAZ.

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Figure 3. Scatterplots showing unadjusted associations between genus-level bacterial abundance (log_{10} colony-forming unit [CFU]/mL) and weight-for-age *z* scores (WAZ) in 6-month-old infants (n=88). Each point represents one infant. The solid line shows the fitted linear relationship and the shaded area represents the 95% CI for the fitted line. Panels (A-E) correspond to *Bifidobacterium*, *Lactobacillus*, *Bacteroides*, *Clostridium*, and *Escherichia coli*, respectively.



In contrast, *Clostridium* (panel D) demonstrated a clear negative association, with a decreasing regression line, suggesting that greater *Clostridium* abundance was related to lower WAZ. For *E coli* (panel E), the regression line indicated a positive but nonsignificant trend, which should be interpreted with caution.

Table 3 summarizes the linear regression results examining the associations between bacterial genera and WAZ among 6-month-old infants. In the unadjusted model, none of the beneficial genera (*Bifidobacterium* and *Lactobacillus*) were significantly associated with WAZ, although both demonstrated a negative trend. Similarly, *Bacteroides* and *E coli* showed no significant associations. Conversely, *Clostridium* exhibited a significant negative association with WAZ (β=–.094, 95% CI –0.173 to –0.015; *P*=.02), indicating that higher *Clostridium* abundance was linked to lower weight-for-age status. This association remained significant in the adjusted model (β=–.091, 95% CI –0.172 to –0.010; *P*=.03) after controlling for maternal, perinatal, and environmental covariates. These findings indicate that higher *Clostridium* abundance was independently associated with lower WAZ, suggesting a potential link with early-life growth faltering.

Table . Association between gut microbiota genera and weight-for-age *z* scores (WAZ) in 6-month-old infants.

Genus	Model 1[a]		Model 2[b]	
	Unadjusted β (95% CI)	*P* value	Adjusted β (95% CI)	*P* value
Bifidobacterium	–0.105 (–0.220 to 0.010)	.07	–0.090 (–0.207 to 0.027)	.13
Lactobacillus	–0.091 (–0.215 to 0.033)	.15	–0.087 (–0.218 to 0.043)	.19
Bacteroides	–0.021 (–0.139 to 0.097)	.73	–0.024 (–0.149 to 0.101)	.70
Clostridium	–0.094 (–0.173 to –0.015)	.02[c]	–0.091 (–0.172 to –0.010)	.03[c]
Escherichia coli	0.083 (–0.067 to 0.233)	.28	0.110 (–0.051 to 0.271)	.18

[a]Model 1 (unadjusted): without confounding variables.

[b]Model 2 (adjusted): after controlling for confounding variables (maternal supplementation, maternal education, environmental health, gestational age, delivery process, infant illness history, immunization status, exclusive breastfeeding, and birth outcomes).

[c]*P*<.05.

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Discussion

Principal Findings

This study found a significant inverse association between *Clostridium* abundance and WAZ among 6-month-old infants living in coastal areas of Central Sulawesi, Indonesia. This finding indicates that higher abundance of opportunistic bacteria was associated with lower WAZ and may be a marker of early-life growth faltering. In contrast, *Bifidobacterium*, *Lactobacillus*, *Bacteroides*, and *E coli* were not significantly associated with WAZ in the adjusted models. Although infants from both maternal supplementation groups (MRJ and MMS) exhibited a relatively low prevalence of underweight (7/88, 8%), mild growth faltering persisted, indicating that postnatal influences such as feeding practices, environmental exposures, and gut microbiota composition likely continue to shape infant growth outcomes beyond prenatal nutritional interventions. Because the microbiota assessment in this study included only 5 bacterial genera quantified by genus-level qPCR, interpretations should be limited to genus-level associations. Recent systematic evidence supports a broader link between gut microbiota composition and child growth outcomes, including growth faltering and stunting, although findings vary across settings and methods [15], and recent reviews emphasize the intersection of undernutrition, microbiome development, and early child health outcomes [16].

The gut microbiota plays a critical role in nutrient metabolism, immune regulation, and intestinal homeostasis during infancy. In this study, beneficial genera such as *Bifidobacterium* and *Lactobacillus* were predominant, consistent with their established roles in carbohydrate fermentation, production of short-chain fatty acids, and support of mucosal immunity [15-17]. These genera are often enriched in breastfed infants and are linked to favorable nutritional outcomes. However, neither *Bifidobacterium* nor *Lactobacillus* demonstrated significant associations with WAZ in this cohort, which may reflect limited variability within a generally adequate range and/or limited power to detect smaller effect sizes. The nonsignificant association observed for *Bifidobacterium* should be interpreted with caution and does not necessarily indicate that this genus is not relevant to infant growth. *Bifidobacterium* is widely recognized as a key early-life gut colonizer involved in human milk oligosaccharide metabolism, short-chain fatty acid production, gut barrier maturation, and immune development [16,18]. Recent evidence also supports the role of *Bifidobacterium* in infant immune development and highlights species- and strain-specific functional differences, which may not be captured by genus-level qPCR assessment [18,19]. In this study, the lack of a significant association may therefore be partly explained by the modest sample size, limited between-infant variability, cross-sectional assessment at a single time point, and the inability to distinguish species- or strain-level variation.

In contrast, *Clostridium* exhibited a robust negative association with WAZ after adjusting for maternal, perinatal, and environmental factors, including maternal supplementation allocation. This aligns with previous studies reporting that differences in the abundance of opportunistic taxa are associated with impaired intestinal barrier function, low-grade inflammation, and decreased nutrient absorption efficiency [18-21]. Recent evidence further suggests that colonization during key developmental windows may be linked to microbiota-dependent shifts in growth and immunity during undernutrition [22]. However, because our microbiota assessment was conducted at the genus level using qPCR, the observed association reflects *Clostridium* at the genus level only; species-specific composition, pathogenicity, enterotoxin production, and functional activity cannot be inferred from these data. Accordingly, mechanistic interpretations should be made cautiously, and the findings should be interpreted as an association rather than evidence of causation. Similar findings from Indonesian and other low-resource populations have linked microbial dysbiosis, including increased *Clostridium* and reduced phylogenetic diversity, with growth faltering and stunting [19,22,23]. These observations underscore the relevance of gut microbiota composition as a determinant of infant growth and metabolic health. Recent studies from Indonesia also report gut microbiota differences between children with impaired growth and those with normal growth, including findings from East Nusa Tenggara, Aceh, and urban low-income settings, supporting the relevance of microbiota-growth relationships in diverse Indonesian contexts [20,24,25]. Consistent with this, recent work also reports that stunting can be associated with persistent and potentially transferable gut microbiome alterations [26].

The predominance of beneficial bacteria in this population, alongside the observed negative effect of *Clostridium*, highlights the delicate balance between protective and pathogenic microbial communities in early life. Maintaining this balance is influenced by breastfeeding, maternal diet, hygiene, and environmental exposures. Previous trials have demonstrated that supplementation with human milk oligosaccharides promotes the growth of *Bifidobacterium* while suppressing opportunistic bacteria, resulting in improved gut maturation and growth outcomes [22,27]. Similarly, meta-analyses have shown that infant formulas supplemented with prebiotics or synbiotics beneficially modify gut microbial profiles and improve feeding tolerance and growth [28]. Furthermore, transitions from exclusive breastfeeding to mixed or complementary feeding have been shown to alter microbial diversity and metabolic activity, influencing growth trajectories during infancy [29]. The interaction between nutrition, immunity (eg, secretory IgA), and microbiota composition supports the need for integrated interventions that sustain gut health and optimal growth [30].

From a public health perspective, these findings emphasize that gut microbiota composition is not merely a biological variable but a potentially modifiable correlate of child growth and nutrition [17,22]. The observed association between *Clostridium* abundance and lower WAZ suggests that environmental and behavioral factors influencing microbial colonization, such as hygiene, breastfeeding practices, and maternal nutrition, represent actionable targets for community-based interventions [12,16,31]. The predominance of *Bifidobacterium* and *Lactobacillus* in well-nourished infants further reinforces the importance of promoting exclusive breastfeeding and dietary

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diversity during lactation [32-34]. Incorporating probiotic and prebiotic strategies into maternal and child nutrition programs could enhance resilience against microbial dysbiosis and strengthen early-life growth outcomes [35,36].

Limitations

This study has several limitations. The cross-sectional design precludes causal inference, and temporality between gut microbiota composition and WAZ cannot be established. The modest sample size (n=88) may have limited statistical power to detect smaller associations, particularly in adjusted models; thus, nonsignificant findings should be interpreted cautiously. Because this analysis was nested within a prior randomized maternal supplementation trial, prenatal exposures—including supplementation adherence, maternal diet, and health during pregnancy—may have influenced infant gut microbiota through pathways not fully captured in the current models. Although supplementation allocation (MRJ vs MMS) was included as a covariate, residual confounding cannot be excluded. Maternal anthropometric data, including BMI at enrollment, were not available for this analysis and could not be adjusted for. Exclusive breastfeeding was included as a covariate; however, no dedicated subgroup analysis by breastfeeding status was conducted, and interpretations related to breastfeeding practices should therefore be made cautiously.

Furthermore, the use of qPCR quantification provides genus-level data and does not capture species-specific or functional microbial diversity. Future longitudinal studies using metagenomic and metabolomic approaches are warranted to elucidate the mechanistic pathways linking gut microbiota and early growth. Despite these limitations, this study provides locally relevant evidence from an understudied coastal population and highlights the potential role of *Clostridium* overabundance as a biomarker of growth faltering in early infancy.

Conclusions and Recommendations

In this study of 6-month-old infants from coastal areas of Central Sulawesi, Indonesia, *Clostridium* was the only bacterial genus independently and inversely associated with WAZ, even after controlling for maternal, perinatal, and environmental factors. In contrast, *Bifidobacterium*, *Lactobacillus*, *Bacteroides*, and *E coli* showed no significant associations with WAZ.

These findings indicate that higher *Clostridium* abundance is associated with lower WAZ and highlight the importance of maintaining a balanced gut microbiota for optimal infant nutrition. Future longitudinal studies should further examine how breastfeeding practices, maternal nutrition during pregnancy and lactation, and microbiota-supportive approaches may influence infant gut microbiota composition and growth outcomes in coastal and resource-limited settings.

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Data Availability

Data supporting the findings of this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
DNA extraction and quantitative polymerase chain reaction quantification of gut microbiota.
[DOCX File, 15 KB - pediatrics_v9i1e87452_app1.docx]

Checklist 1
STROBE statement.
[DOCX File, 21 KB - pediatrics_v9i1e87452_app2.docx]

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Abbreviations

CFU: colony-forming unit
MMS: multiple micronutrient supplements
MRJ: *Moringa oleifera* enriched with royal jelly
qPCR: quantitative polymerase chain reaction
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology
WAZ: weight-for-age *z* score
WHO: World Health Organization

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The Pattern and Characteristics of Childhood Unintentional Injuries in Abha Maternity and Children Hospital, KSA: Prospective Descriptive Study

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Abstract

Background: In Saudi Arabia, unintentional injuries among children represent a prevalent and significant public health issue and severe injuries are of the leading indications for hospitalization and impairments.

Objective: This study aimed to describe the pattern of unintentional trauma in children admitted to Abha Maternal and Children Hospital, South region of Saudi Arabia.

Methods: This study was a prospective descriptive, cross-sectional, hospital-based study, which was conducted in the Pediatric Intensive Care Unit, Maternity and Children's Hospital, Abha, Aseer region, Saudi Arabia. This is the central and main hospital in the region but not the only hospital receiving childhood injuries. The study period was from January 2023 to January 2024. Children's age groups were from 0 to 12 years old. All children in the study were admitted with a diagnosis of unintentional injuries, like RTAs (road traffic accidents), falls, and other home accidents. The study included 104 children and the data collected were analyzed using SPSS (version 27; IBM Corp). Appropriate statistical tests were used for the analysis and all tests were two tailed and probability $P \leq .05$ is considered significant.

Results: The sample size of the study was 104 children. The gender distribution was 35 females (33.7 %) and 69 males (66.3 %). The patients were recruited from 18 cities in the Aseer region. About half of the patients (49%) were aged 6 - 12 years. Road traffic accidents (RTA) represent the highest percentage of accidents, with 66 (63.5%) children, followed by falls from height with 38 (36.5%) patients. The most significant types of injuries were head and brain injuries 37 (35.6%), followed by chest and lung injuries 12 (11.5%). Most patients (n=62, 59.6%) remained admitted to the pediatric intensive care unit (PICU) for one to three days. Followed by three to seven days (27), then eight to 14 days (14). Head/brain axonal injury is also the most common injury associated with complications, followed by polytrauma.

Conclusions: Road traffic accidents are a significant cause of death and disability in Saudi Arabia for all age groups. A strong association existed between the PICU admission duration and the outcome (P=.02). Health and community institutes and governments should increase community education about the risks and consequences of RTA, strengthen traffic rules and laws, and punish violators.

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KEYWORDS

pattern; characteristics; unintentional injuries; children; complications

Introduction

Worldwide unintentional injuries contribute enormously to childhood mortality with nearly 1 million deaths per year in children and adolescents below 18 years [1]. Around 12% of the deaths due to injuries occur in children, the most common causative injuries of death in this age group are: road traffic accidents, drowning, burns, falls, and poisonings. Many of these mortalities are preventable [2]. In children and also the injuries largely contribute to child hood morbidity and can lead to severe occupational malfunctioning or non-functioning and/or social and psychological impairment [3]. There may be background

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risk in many cases [4]. Unfortunately, there is a paucity of data regarding trauma incidence and prevalence, specifically for Saudi Arabian children [5].

Injuries, especially unintentional injuries, are a leading cause of death among children and adolescents and a severe public health problem worldwide [6,7]. Unintentional injury is a disability that occurs under accidental circumstances [8]. The World Health Organization Report 2002 stated that injuries are the sixth leading cause of morbidity and mortality in childhood [9]. One of the most unintentional injuries in the world is road traffic accidents (RTA), which are the primary cause of unnatural deaths in the world and children, causing a loss of more than 260,000 lives in the 0 - 19-year age group annually [10] and a significant effect on the world's economy [11-13].

Investigations have shown that children and adolescents are most vulnerable to accidents. Due to physiological limitations, the growth process and behavioral characteristics (experience, need to test, explore, adventure, and risky behaviors) provide accident conditions for this group. Along with other environmental factors, for example, parents' low ecological safety levels and children's supervision and care have led to more severe and dangerous forms [14]. Every year, millions of children lose their lives because of preventable accidents. Burning, poisoning, falls, and trauma (accidents) are the four leading causes of mortality in children. Accidents represent 50% of all deaths among children, and one in every six children admitted to a children's hospital emergency department is related to accidents [15]. . Therefore, accidents are one of the leading health problems that continually threaten children's health [16]. This study was conducted due to limited data about the epidemiology of unintentional injuries among Saudi children and adolescents to increase the knowledge about the characteristics of these injuries for further appropriate intervention and to decrease the burden of such terrible events.

The study aimed to determine the pattern and clinical types of the unintentional injuries and trauma in children aged 0 - 12 years admitted to the PICU in Abha, Aseer region in KSA; together with determining of the short-term outcome and utilization need of the health facilities of the hospital including ICU admission and duration of hospital stay in this study group.

Methods

Study Design

This study is a prospective descriptive, review with follow up of children admitted with unintentional trauma since admission to the hospital and use of the pediatric intensive care unit database during the period of the study.

Study Setting

Pediatric Intensive Care Unit, Maternity and Children Hospital, Abha, Aseer region, Saudi Arabia.

Study Population and Sample

The study sample includes 104 of the children admitted with unintentional trauma to the Pediatric Intensive Care Unit, Maternity and Children Hospital (MCH), Abha. Fifteen to twenty pediatric patients were admitted to the pediatric department monthly due to unintentional injury.

Age group: From 0 to 12 years (because MCH receives pediatric patients up to 12 years)

Study period: January 2023–January 2024

Inclusion criteria: Any pediatric patient admitted with a diagnosis of unintentional injury, such as RTA, pedestrians, and falls

Exclusion criteria: Children with burns, poisoning, drowning, foreign bodies, and strangulation were excluded because these cases usually were admitted to other hospitals

Sample size: The formula used for calculation of sample size is:

n = (Z^2 * p * (1-p)) / d^2

Where:

n=sample size

Z=*z* score corresponding to the desired confidence level (eg, 1.96 for 95% CI)

p=expected prevalence or proportion (use 0.5 if unknown)

d=margin of error (eg, 0.05)

Sampling technique: Prospective review of the department database or Logbooks, as well as review of pediatric patients with a diagnosis of trauma

Data Analysis

Data were collected on a research data collection sheet and Data management and analysis were performed using SPSS (version 27.0; IBM Corp). Numerical data were summarized using medians and/or ranges. Categorical data were summarized as numbers and percentages. Estimates of the frequency were done using the numbers and percentages. χ^2 or Fisher tests were used to compare between the independent groups with respect to categorical data, as appropriate. Time to discharge was estimated using the Kaplan and Meier method. It was calculated from date of admission to date of discharge. Differences between the survival curves were assessed with the log-rank test. All tests were two-tailed and $P \leq .05$ is considered significant.

Study Recruitment

This included identifying and sourcing of the study population group according to the criteria of the study.

Ethical Considerations

The study was conducted in accordance with the Declaration of Helsinki and the research committee of Aseer Institutional Review Board, Directorate of Health Affairs, Aseer Region, Ministry of Health, Saudi Arabia, approved the study (REC 8-3-2023 dated 4/3/2023). Informed consent to participate was obtained from families (verbal approval) before being asked about the child. Privacy and confidentiality of the hospital data used was strictly kept and the data used was deidentified.

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Results

The current study included 104 pediatric patients. Ninety-nine patients were admitted to the PICU, three to the pediatric surgical ward under PICU team care, and two to the ER. More than two-thirds (n=69, 66.3%) of cases were males. Nearly half of the cases were aged 6 to 12 years (n=51, 49%). Most cases were of Saudi nationality (n=96, 92.3%). The patients were recruited from 18 cities in the Aseer region. Abha (n=53, 51%) and Khamis Mushet (n=17, 16.3%) had the highest percentage of patients, respectively. Most cases (n=99, 95.2%) had no past medical history. In contrast, a small proportion of patients had medical conditions, such as factor VIII deficiencies, global developmental delay, preterm birth with congenital heart disease, or nonspecific conditions. Road traffic accidents (RTA) represent the highest percentage of accidents, with 66 children representing 63.5%, followed by falls from height with 38 patients representing 36.5%, and both are notably more frequent in the 6 - 12 age group. Meanwhile, home accidents accounted for only 3 cases (2.9%) of all accidents. The most used method for transferring patients from the accident site to the nearest hospital was a red-crescent ambulance 47 (45.2%) patients, followed by a family car 46 (44.2%) patients.

More than one-third of patients arrived at MCH 6 - 10 hours after the first presentation 41 (39.4%), and nearly one-third at the first 2 hours 31 (29.8%). More than one-third of cases had head and brain injuries 37 (35.6%), followed by polytrauma (24%). More than half of patients 62 (59.6%) remained admitted to the PICU for [1-3] days, with a median length of stay of about two days, ranging from [1-24] days. Most patients 93 (89.4%) were transferred to the pediatric surgical ward (PSW) from the PICU. Only 6 (5.8%) patients were transferred to another hospital, and 5 (4.8%) patients died in the PICU due to severe injuries, such as multiple fractures and head/brain axonal injury. Most patients (n=89, 85.6%) were discharged from the hospital in improved and stable conditions (Table 1).

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Table . Clinical and hospital-related data.[a]

Variables	Values (N=104)
Time of presentation to MCH[b] after 1st presentation, n (%)	
First 2 hours	31 (29.8)
2 - 5 hours	2 (1.9)
6 - 10 hours	41 (39.4)
11 - 24 hours	18 (17.3)
24 - 72 hours	6 (5.8)
More than 72 hours	6 (5.8)
Diagnosis, n (%)	
Head/brain axonal injury	37 (35.6)
Polytrauma	25 (24)
Fracture skull	15 (14.4)
Chest/lung injury	12 (11.5)
Internal abdominal organ injury	7 (6.7)
Normal CT[c]	8 (7.7)
Needed surgical intervention, n (%)	
No	75 (72.1)
Yes	29 (27.9)
Destination of discharge from the PICU[d], n (%)	
Pediatric surgical ward	93 (89.4)
Other hospital	6 (5.8)
Died	5 (4.8)
Length of stay in PICU (days), n (%)	
1 - 3	62 (59.6)
4 - 7	27 (26)
8 - 14	15 (14.4)
Outcome, n (%)	
Improved	89 (85.6)
Complications, disabilities, and transfer	10 (9.6)
Died	5 (4.8)
Length of hospital stay (days), median (range)	2 (1-25)

[a]The percentage of the whole group discharge is taken out of the total number of 104 admitted children; while the percentage of discharge in the subgroups inside the table is taken in relation to the total of the same subgroup (e.g. age group).

[b]Maternity and Children's Hospital.

[c]CT: computed tomography.

[d]PICU: pediatric intensive care unit.

As shown in Table 2, most deaths (n=4/5, 80%) occur among females , and this was statistically significant (*P*=.04). However, there was no statistically significant difference in mortality concerning age, nationality, presence of past medical history, type of trauma, and diagnosis.

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Table . Mortality concerning different factors.

Variables	Alive (n=99), n (%)	Died (n=5), n (%)	*P* value
Age groups			.82
Less than 1 year	12 (12.1)	1 (20)	
1 - 5 years	38 (38.4)	2 (40)	
6 - 12 years	49 (49.5)	2 (40)	
Sex			.04
Female	31 (31.3)	4 (80)	
Male	68 (68.7)	1 (20)	
Nationality			≥.99
Saudi	91 (91.9)	5 (100)	
Non-Saudi	8 (8.1)	0 (0)	
Past medical history			≥.99
No	94 (94.9)	5 (100)	NA[a]
Yes	5 (5.1)	0 (0)	
Type of trauma			.65
Road traffic accident	62 (62.6)	4 (80)	
A fall from a height	37 (37.4)	1 (20)	
Diagnosis			.67
Chest/lung injury	12 (12.1)	0 (0)	
Polytrauma	22 (22.2)	3 (60)	
Fracture skull	15 (15.2)	0 (0)	
Head/brain axonal injury	35 (35.4)	2 (40)	
Internal abdominal organ injury	7 (7.1)	0 (0)	
Normal CT[b]	8 (8.1)	0 (0)	

[a]Not applicable.

[b]CT: computed tomography.

As shown in Table 3, the median time to discharge from the hospital was 2 days (Figure 1). The type of trauma significantly impacts time to discharge from the hospital. At one week, 34 out of 37 (93%) of patients who fell from a height were discharged, compared to 50 (81%) of patients who had a RTA. This difference was statistically significant (*P*=.41) (Figure 2). One child who sustained a severe RTA with multiple injuries and disability stayed in the hospital for an exceptional period of 25 days. Meanwhile, there was no statistically significant difference in time to discharge with age, gender, nationality, and diagnosis. The details of the injuries sustained by the children in the study group include the following:

1. Head/brain injuries: 37/104 (35.6%) children, of which 22 (21.2%) were associated with different degrees of brain hemorrhage (epidural, subdural , subarachnoid or intraparenchymal); 6 (5.77%) cases of brain injuries were associated with axonal injury, and 2 (1.9%) cases with fracture base of the skull. Skull fractures were found in 27 (26%) of the cases. Of these, 15 were isolated skull fractures without brain insult and most of them were single bone and nondisplaced with 4 (3.8%) depressed fractures and 3 (2.9%) multiple displaced fractures. A total of 8 cases (7.7%) of head trauma in the group show no abnormal computed tomography or magnetic resonance imaging findings
2. Lung injuries: In 12 (11.5%) cases with chest cage/lung trauma, 2 children (1.9%) had lung contusions, 2 (1.9%) had pneumothorax, 2 (1.9%) cases sustained pulmonary hemorrhage and 1 (0.96%) patient had surgical emphysema
3. Intraabdominal soft tissue organ injuries: 3 cases (2.9%) had splenic lacerations, 2 (1.9%) with liver injury and lacerations, 1 case (0.96%) with renal injury, and 1 case (0.96%) with direct arterial vascular injury
4. Multiple or major limb fractures: i5 cases (4.8%) of polytrauma were seen in the group

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Figure 1. Kaplan and Meier curve representing time to discharge for the whole group.

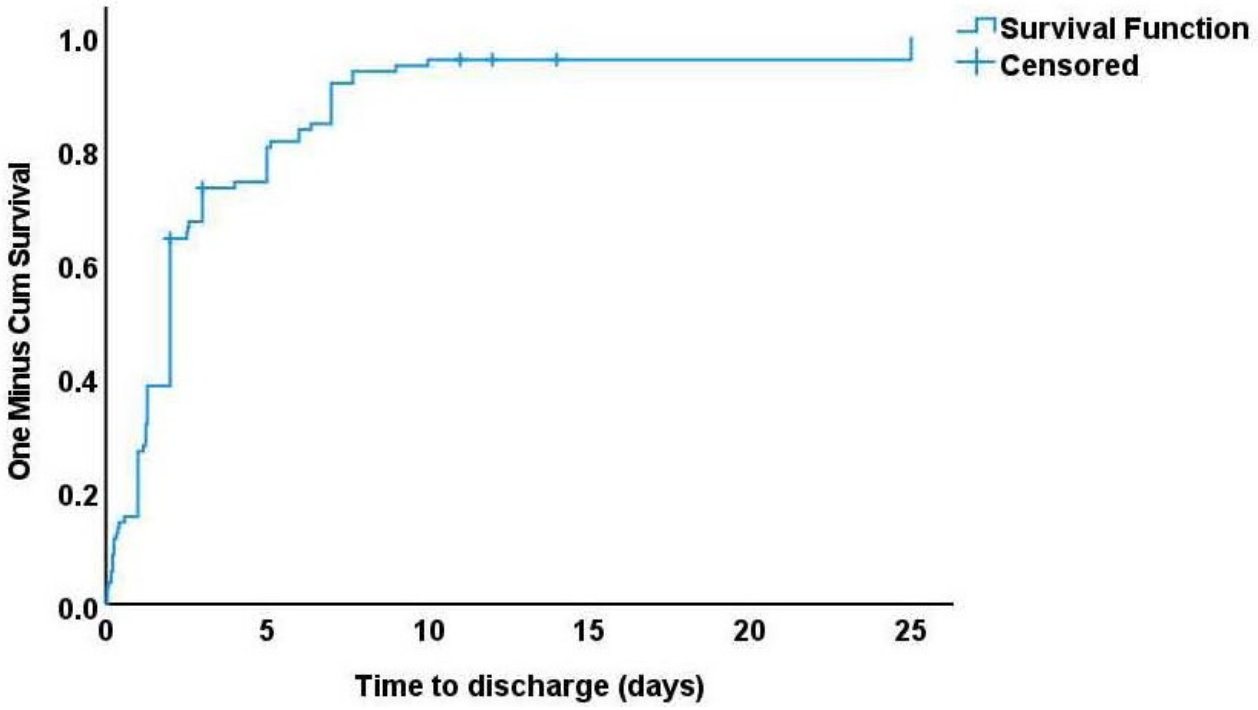
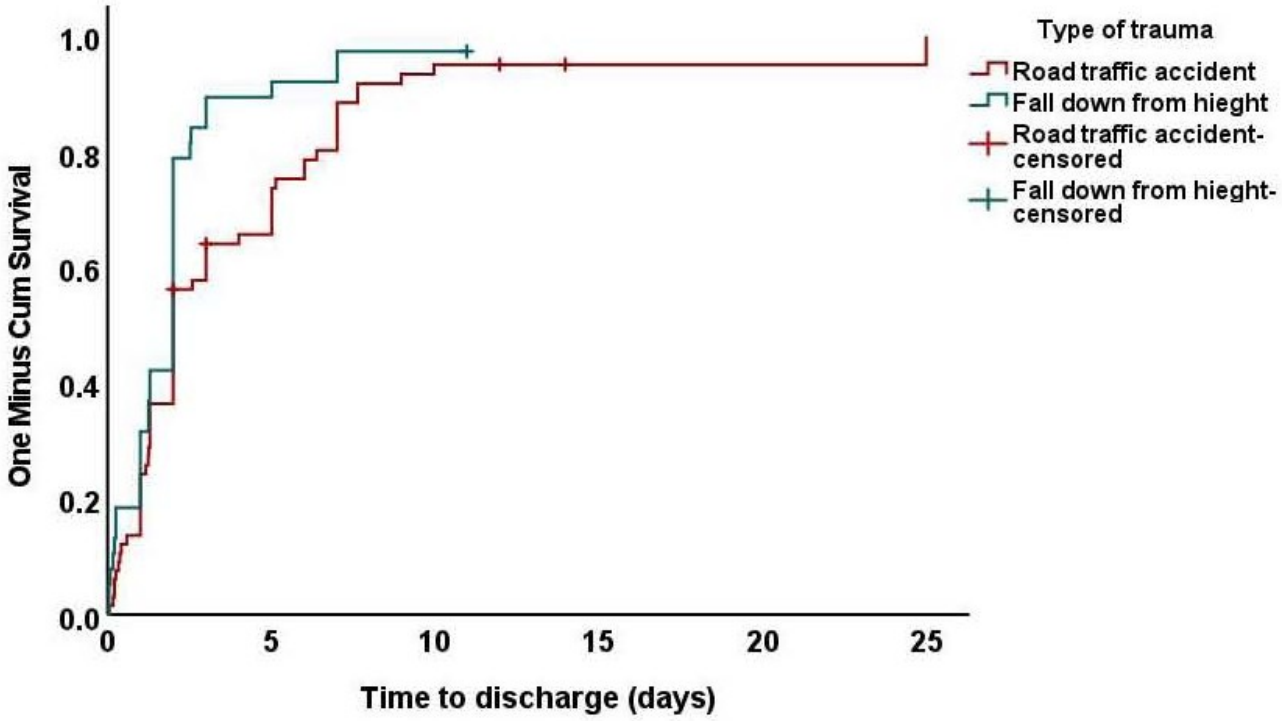


Figure 2. Kaplan and Meier curve representing time to discharge by type of trauma.



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Table . Time to discharge concerning different factors.

Factors	Discharged patients at 1 week	Median time of discharge (days)	*P* value
Whole group, median (range)	85 (86)	2	
Age groups, median (range)			.36
Less than 1 year	11 (93)	2	
1 - 5 y	37 (98)	2	
6 - 12 y	40 (81)	2	
Sex, median (range)			.90
Female	28 (91)	2	
Male	57 (84)	2	
Nationality, median (range)			.61
Saudi	76 (84)	2	
Non-Saudi	8 (100)	2	
Type of trauma, median (range)			.04
Road traffic accident	50 (81)	2	
A fall from a height	34 (93)	2	
Diagnosis, median (range)			.41
Chest/lung injury	12 (100)	2.5	
Polytrauma	19 (85)	2	
Fracture skull	15 (100)	2	
Head/brain axonal injury	28 (79)	2	
Internal abdominal organ injury	7 (100)	2	
Normal CT[a]	8 (100)	1.3	

[a]CT: computed tomography.

Most of the admitted children with different types of trauma improved with the treatment; some sustained complications or transferred and 5 died (Table 4).

Table . Outcome of each diagnosis.

	Chest/lung injury, n=12 (%)	Polytrauma, n=25 (%)	Fracture skull, n=15 (%)	Head/brain axonal injury, n=37 (%)	Internal abdominal organ injury, n=7 (%)	Normal CT, n=8 (%)	*P* value
Outcome							
Improved	11 (91.7)	18 (72)	15 (100)	30 (81.1)	7 (100)	8 (100)	NA[a]
Complications, disabilities, and transfer	1 (8.3)	4 (16)	0 (0)	5 (13.5)	0 (0)	0 (0)	
Died	0 (0)	3 (12)	0 (0)	2 (5.4)	0 (0)	0 (0)	

[a]NA: Not applicable

The hospital stay was significantly more extended among patients who died at the end compared to patients who improved (*P*=.02) (Table 5).

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Table . Time of arrival to hospital and length of hospital stay and their relation to patient outcome.

Time of arrival to hospital and length of hospital stay	Outcome			*P* value[a]
	Improved (n=89), (%)	Complications, disabilities, and transfer, (n=10), (%)	Died (n=5), (%)	
Time of presentation to MCH[b], median (range)				
First 2 hours	27 (30.3)	1 (10)	3 (60)	NA[c]
2 - 5 hours	1 (1.1)	1 (10)	0 (0)	
6 - 10 hours	34 (38.2)	6 (60)	1 (20)	
11 - 24 hours	16 (18)	1 (10)	1 (20)	
24 - 72 hours	6 (6.7)	0 (0)	0 (0)	
More than 72 hours	5 (5.6)	1 (10)	0 (0)	
Length of stay in PICU[d] (days), median (range)				
1 - 3	58 (65.2)	4 (40)	0 (0)	NA
4 - 7	22 (24.7)	3 (30)	2 (40)	
8 - 14	9 (10.1)	3 (30)	3 (60)	
Length of hospital stay (days), median (range)	2 (0 - 10)	2 (0.3 - 25)	11 (2 - 14)	.03

[a]*P*<.05 is considered significant.

[b]MCH: Maternity and Children's Hospital.

[c]NA: Not applicable.

[d]PICU: pediatric intensive care unit.

Discussion

Principal Findings

Unintentional injuries are accidents or mishaps that cause physical harm to a person. These can include falls, traffic accidents, burns, poisonings, drowning, and various other incidents. Over 900,000 deaths are reported annually due to unintentional injuries in the group of children and adolescents below the age of 18 years , representing 10% of all deaths worldwide [17].

The major findings in this study: of the 104 children with unintentional injuries admitted to Pediatric Intensive Care Unit, MCH, Abha, were as follows: A total of 69 (66.3 %) of patients were males, about half of the patients (n=51, 49%) were aged 6 - 12 years. Road traffic accidents (RTA) represent the highest percentage of accidents, with 66 (63.5%) children, followed by falls from height with 38 (36.5%) patients, The most significant types of injuries were head and brain injuries (n=37, 35.6%), followed by chest and lung injuries (n=27, 26.1%). Most patients (n=62, 59.6%) remained admitted to the PICU for one to three days. Followed by three to seven days in 27 patients (26%) then eight to 14 days in 15(14.1%). Head/brain axonal injury is also the most common injury associated with complications, followed by polytrauma. Overall, 89 (85.6%) patients improved and discharged with no sequelae, 10 (9.6%) were transferred to other units or develop disabilities and 5 patients (4.8%) died.

This study included 104 pediatric patients. Males dominated, accounting for 69 (66.3%) of the study population. This percentage is similar to that reported in studies conducted in Saudi Arabia [16,18,19]. Although there is male predominance, the rate of death was significantly higher (*P* value =.043) in females. Four female patients from the 31 admitted to the PICU died. Most patients were 6 - 12 years old, unlike in previous studies in China and the Netherlands, where age groups 1 - 3 predominated [20,21]. .

The commonly admitted age group in Saudi Arabia was 1 - 5 years [18,19]. This variation in our study can be attributed to RTA, the most common cause of unintentional injuries (representing 66.3% of the study population), followed by falls from heights. RTA has a high incidence in Saudi Arabia, with 81 percent of deaths due to road traffic accidents in the Ministry of Health hospitals, and 20% of the hospital beds occupied by traffic accident victims [22]. Falls represented a higher percentage in similar studies where the smaller age group dominated [16,18]. There is variation in the type of injury according to age group, where RTA predominates in the 6 to 12-year age group, while falling is more common in the younger age groups of 1-to 5-year-olds and less than one year. A study conducted in Makkah explained the higher incidence of falling as a cause of unintentional injuries in their research because of the predominance of the younger age group from one to five years. It attributed this to this age group's curious nature and immature judgment [18]. Another study stated that the incidence of falling decreases with increasing age [23]. The mechanism

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of injury can differ in different societies. Foreign body aspiration and suffocation were the most common admission causes leading to death in China, where RTA came in third place [17,20]. The incidence and type of unintentional trauma can be attributed to environmental factors, parental neglect, or maltreatment [17,24]. The most used method for transferring patients from the accident site to the nearest hospital was a red-crescent ambulance 47 (45.2%), followed by a family car 46 (44.2%). More than one-third of patients arrived at MCH 6 - 10 hours after the first presentation 41 (39.4%), and nearly one-third at the first 2 hours 31 (29.8%). Eighty-nine of patients (85.6%)were discharged from the hospital in an improved and stable condition. The mortality rate among the patients was comparatively low 5 patients (4.8%). This suggests that although some individuals exhibited injuries that were too grave to survive, the mortality rate remained regulated, possibly indicative of adequate medical care in most cases. The outcome was also good in other studies in Saudi Arabia, where the majority improved; however, the percentage of discharge with complications and disabilities was higher in different studies [18,19]. . The incidence of death was higher in patients with a longer duration of admission to the PICU. A strong association existed between the PICU admission duration and the outcome (P=.023).

The most significant types of injuries were head and brain injuries 37 (35.6 %), followed by polytrauma 22 (21.2%). Head and brain injuries and polytrauma carry a higher percentage of disabilities, complications, longer duration of admission, and death than other diagnoses. This result agrees with similar studies in Saudi Arabia [16,18] Similar results were also found in other countries [24].

Road traffic accidents are a significant cause of death and disability in Saudi Arabia for all age groups. Health and community institutes and governments should increase community education about the risks and consequences of RTA, strengthen traffic rules and laws, and punish violators. Expanding road safety measures to prevent head injuries is also important.

Limitations of Discussion

For more generalizations of the results and implications of this study; further elaboration of the problem on a wider basis is needed for this area of KSA to include all the hospitals in the region of Aseer

Conclusion and Implications

Many cases of the unintentional trauma in children in Aseer region in KSA are preventable by using measures to raise the population safety of the RTA as they represent a major type of injury in this region and also safety measures for decreasing the incidence of fall especially the area is a high altitude area in KSA.

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Data Availability

The datasets generated and/or analyzed during the current study are not publicly available but will be made available to qualified researchers subject to the terms of a data use agreement.

Authors' Contributions

Conceptualization: IMIES, NMTA, AEMM
Data processing: AAAA
Data retrieval: IAH, IB
Formal analysis: IMIES, NMTA, AEMM, IAH, IB, AAAA, SAAF, EMMM, MMMA
Methodology: IMIS, SAAF
Writing - original draft; IMIES, NMTA, AEMM
Writing - review and editing: IMIES, NMTA, AEMM, IAH, IB, AAAA, SAAF, EMMM, MMMA

Conflicts of Interest

None declared.

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Abbreviations

MCH: Maternity and Children Hospital
PICU: pediatric intensive care unit
RTA: road traffic accident

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Family Engagement in a Digital Intervention Targeting Risk for Anxiety in Parent-Child Dyads: Mixed Methods Study

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Abstract

Background: Digital health programs are increasingly important in the treatment and prevention of mental health problems in young children. However, suboptimal family engagement with a program may hamper its effectiveness. Family engagement in digital mental health programs is multifaceted and poorly understood, with ill-defined relationships among aspects of participation and program outcomes (ie, what constitutes *effective* engagement). Moreover, little is known about the barriers and facilitators to effectively engaging families at risk for anxiety, who may not be actively seeking treatment.

Objective: *Making Mistakes* is a novel, internet-based, cognitive behavioral preventive program for caregivers and their 5- to 7-year-old children, which aims to reduce the risk of anxiety by targeting family transmission of perfectionism or error sensitivity—that is, negative overreactivity to mistakes. This mixed methods study examined multiple facets of parent-and-child engagement in *Making Mistakes*, including adherence, cognitive and affective engagement, barriers, facilitators, and perceived outcomes associated with involvement.

Methods: A total of 87 dyads were included in a quantitative analysis of adherence to the program, including overall adherence and sustained engagement. Eighteen dyads completed qualitative interviews, which were subjected to a qualitative thematic analysis. Finally, a sample of *Making Mistakes* activity journals was qualitatively reviewed and synthesized.

Results: Parent and child adherence were strongly positively correlated (r_{85}=0.95). Dyads had low adherence to the weekly modules, which did not differ by intervention condition. Completion rates averaged 20%, with adherence declining over time. In contrast, qualitative data indicated high levels of investment in program content and topics, elucidated barriers and facilitators to program engagement, and highlighted numerous psychosocial benefits.

Conclusions: Engagement, operationalized as rote adherence to an intervention developer's criteria, may insufficiently capture the aspects of participation that are most meaningfully related to positive outcomes. Researchers and intervention developers should prioritize cognitive and affective aspects of engagement with program content, along with promoting and assessing behavioral engagement beyond adherence to program components. *Making Mistakes* shows promise as a low-cost, disseminable strategy to reduce intergenerational risk for anxiety. These findings have particular relevance for digital health programs focused on prevention, parent-child dyads, and anxiety and perfectionism.

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KEYWORDS

anxiety; mobile health; digital health; engagement; parenting intervention; prevention; perfectionism; single-session intervention; cognitive behavioral therapy; preschool; adherence; fidelity; eHealth; mHealth

Introduction

Engagement With Digital Health Programs

Despite the potential of digital health programs (DHPs) to prevent and treat mental health conditions in young children, DHPs have yet to make a significant mental health impact at scale. Many DHPs have faced suboptimal engagement [1], which also tends to decrease over time (ie, "the law of attrition") [2]. Engagement in DHPs is multifaceted, encompassing affective (eg, enjoyment), cognitive (eg, attention), and behavioral (eg, adherence to intervention prompts) components

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[3]. Moreover, interaction with a DHP's user interface is distinct from the enactment of the DHP's specific behavior change techniques, which is further distinguished from engagement in relevant health behavior changes [4]. Importantly, *effective* engagement is defined as the quantity and timing of energy investment into a stimulus or task that is required to bring about a desired outcome [3]. Understanding effective engagement across multiple dimensions is important to DHP development, dissemination, and evaluation.

Typical patterns of participation vary widely across DHPs, consumers, target conditions, and settings, and depend on how engagement is operationalized [5]. Thus, rather than assuming a rigid, "one-size-fits-all" approach, authors have called for research that focuses on the degree of improvement as a primary metric of engagement success while also exploring multifaceted patterns of involvement [5,6]. Meta-analytic work has shown that engagement in a DHP for mental health is positively associated with clinical improvement, regardless of the intervention focus or whether the intervention is guided or unguided [7]. In one anxiety-focused DHP, the *Unwinding Anxiety* mobile app, completing a higher proportion of modules, as well as specific behavior change techniques, was associated with greater improvements in mental health symptoms [8]. Few preventive, parent-mediated digital interventions for youth 7 years or younger have been rigorously evaluated [9]. Moreover, typical patterns of participation in these programs remain unstudied. Inclusion of consumer perspectives in intervention design, development, and dissemination may help to overcome challenges with program engagement, thereby enhancing outcomes [10]. Understanding consumer engagement in digital mental health interventions is critical, particularly for programs focused on young children.

In parent-mediated interventions, caregiver participation engagement (CPE) refers to active participation in a program, including follow-through with homework and behavior change plans [11]. A meta-analysis found that CPE in youth-focused prevention programs was associated with increases in positive parenting behaviors and decreases in child internalizing and externalizing symptoms [11]. Given that family engagement in mental health intervention programs continues to be a challenge [12], especially in prevention programs [13,14], and that the determinants of CPE are understudied [11], more attention is needed to identify the barriers and facilitators to effective involvement in family-focused behavioral health interventions.

Families With Elevated Error Sensitivity

In search of empirically informed targets for the prevention of anxiety, over 50 studies to date have linked higher error-related brain activity with anxiety, in both adult and pediatric samples [15-17]. This neural marker, the error-related negativity (ERN), is generated when mistakes are made on a task and can be recorded using an electroencephalogram. A larger ERN in children is related to higher anxiety. Furthermore, an elevated ERN in early childhood independently predicts the risk for clinical anxiety in later childhood [18]. The ERN has been associated with *error sensitivity*, or the tendency to react negatively to one's own mistakes [19]. Concern over making mistakes is also a hallmark of maladaptive perfectionism [20]. Given these findings, our research team developed an intervention that aims to impact the ERN by targeting overly negative responses to making mistakes (ie, behavioral error sensitivity or perfectionism) in young children [21].

Families high in error sensitivity or perfectionism may face unique challenges in engaging with preventive DHPs. Perfectionistic families may not always seek psychological services; thus, understanding engagement in non–treatment-seeking perfectionistic families is important, consistent with a *prevention* or health-promotion perspective [22]. According to the social expectations model, parents with unreasonably high expectations for their children may have an overcontrolling parenting style, thereby increasing the risk of maladaptive child perfectionism [23]. Moreover, the social learning model (also [23]) suggests that parents pass on perfectionistic behaviors to their children via modeling. These hypotheses are supported by meta-analytic research, which has revealed that parental self-oriented perfectionism, expectations, and criticism positively relate to child perfectionism [24]. Maladaptive perfectionism may result from child traits that dynamically interact with parental factors, such as harsh or critical communication, authoritarian or controlling parenting, psychological control, perfectionistic modeling, and excessive performance feedback focusing on error avoidance [25-31]. Furthermore, behavioral genetics has shown that perfectionism is moderately heritable, meaning perfectionistic families likely share genetic diatheses [20].

Few interventions have targeted perfectionism in youth [32,33] (see [34] for a cursory review). Parent-mediated interventions for perfectionism should target theorized intergenerational mechanisms of children's maladaptive perfectionism, such as setting excessively high standards, encouraging avoidance of mistakes, and modeling perfectionism [23,24,35]. Published recommendations on preventive interventions for perfectionism include adopting a positive psychology focus; providing a rationale and discussing risk; targeting maladaptive perfectionistic beliefs; providing cognitive reappraisal strategies; promoting a growth mindset, self-acceptance, and self-compassion; and engaging parents in reducing criticism, modeling calm responses to errors, and reiterating anti-perfectionistic messages [36].

Current Digital Health Intervention Program

In accordance with empirical findings, theory, and guidelines, a preventive DHP targeting error sensitivity in 5 - to 7-year-old child-parent dyads has shown pilot efficacy [21]. A randomized controlled trial (RCT) of an expanded version of this program is underway.

Mixed methods approaches can elucidate engagement and implementation outcomes in parent-mediated digital interventions (eg, [37-43]). However, little is known about program participation in error-sensitive families. Likewise, there is limited research on family engagement in preventive interventions for anxiety or on DHPs with children under the age of 7 years. Given the increasing importance of DHPs in preventing and treating pediatric mental illness, it is critical to understand *how* families participate in and benefit from these programs, the factors that facilitate participation, and the facets

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of involvement that contribute most to program success (ie, *effective* engagement). The findings will enhance the potential effectiveness and reach of DHPs by advancing knowledge of typical family participation in preventive DHPs, clarifying the relationship between engagement and program outcomes, and contributing to a deeper understanding of the factors that influence program participation.

In this study, we examine family participation in a preventive DHP targeting error sensitivity in young children and their parents. We delineate patterns of engagement with *Making Mistakes*, including adherence within dyads; perceptions of program outcomes; and cognitive, affective, and behavioral facets of engagement. We also explore facilitators and barriers to family involvement. The research questions are as follows: (1) To what degree do dyads engage in *Making Mistakes* with fidelity, including program adherence and enactment of content learned? (2) How is participation perceived to impact family functioning? (3) What are facilitators and barriers to family engagement? (4) How do qualitative descriptions of engagement contextualize quantitative findings? This study builds on the emerging body of parent-mediated and digital mental health interventions by using mixed methods to explore families' patterns of program participation. We incorporate robust qualitative methods to contextualize quantitative findings on program adherence and gain an in-depth understanding of participation. Understanding barriers and facilitators to engagement—and what constitutes *effective* engagement—may improve mental health outcomes for families by augmenting the impact of *Making Mistakes* and similar programs.

Methods

Recruitment and Participants

This mixed methods study included families who were randomized to the 3 active treatment arms of an ongoing RCT evaluating *Making Mistakes*, a web-based program targeting anxiety risk in 5‐ to 7-year-old children. Parent-child dyads were recruited from a community, nonclinical sample. In the larger study, dyads were interviewed about their experience, including program acceptability and appropriateness. Procedures and methods for the RCT can be found elsewhere ([34]; also see Multimedia Appendix 1).

Parent-child dyads were recruited for quantitative assessment as part of their participation in the larger RCT. Inclusion criteria were as follows: (1) elevated error sensitivity as measured by elevated scores on the Child Error Sensitivity Index, Child Error Sensitivity Index–Parent Report, or the Parent Sensitivity to Child Errors Index [19] and (2) completion of the baseline intervention module. Two dyads were excluded because they did not receive the weekly text message or email reminders as prescribed, due to clerical errors. An additional 7 dyads were excluded for not completing the entirety of the baseline intervention module, resulting in a final sample of 87 dyads for the quantitative assessment (n=30 with both parent *and* child in the active condition [P+/C+], 30 parent-active+child-control [P+/C–], and 27 child-active+parent-control [P–/C+]). Reported reasons for not completing the baseline module indicated barriers related to childcare requirements (ie, siblings), busy schedules, and factors potentially related to child age or developmental level (eg, child refusal to continue the study).

Families were eligible for qualitative interviews if they were randomized into 1 of 3 active intervention arms and completed at least a portion of the baseline module. The lead author (IAM) conducted all interviews, which were solicited across various phases of intervention completion. Random and convenience sampling were used for the first 10 interviewees. Strategic sampling was used for the remainder, which prioritized P+/C+ dyads. Sampling aimed to match or surpass the demographic diversity of the overall participant sample with respect to the timing of the interview vis-à-vis the phase of the study or intervention, race or ethnicity, gender and sexual orientation, and relationship status. Recruitment goals were based on data saturation, which often occurs between 10 and 17 interviews [44]. Data saturation was reached at 18 dyads (n=18 adults, 14 children). Additional information regarding qualitative data collection is reported elsewhere [45].

Ethical Considerations

Study procedures were approved by Florida State University's Institutional Review Board (STUDY00000605). Informed consent was obtained from parents, and assent was obtained from children. Participant information was kept private and confidential. We compensated participants with a US $25 gift card.

Study Design and Procedure

Overview

We used a qualitative-dominant, convergent mixed methods design [10,46] to elucidate family engagement in a preventive DHP targeting error sensitivity. The convergent design—wherein qualitative and quantitative data were collected during the same phase of the research process, analyzed separately, and integrated during interpretation—allowed us to gain a deeper understanding of effective family engagement. As a complement to the RCT's ongoing efficacy evaluation, this study focused on process-oriented features, implementation characteristics, and multidimensional indices of engagement [10]. The first author conducted the semistructured interviews both virtually and face-to-face in the lab setting. Interviews lasted, on average, 48 minutes and were audio-recorded and transcribed.

Intervention

Making Mistakes (described elsewhere in greater detail) [34] includes independently delivered child and parent modules. Child content included cognitive tools (eg, "mistakes are how we learn"; "mistakes can be funny"), listening to your "mistake buddy," and standing up to your "mistake bully," as well as behavioral components such as making mistakes on purpose (exposure) and challenging oneself to try hard things. Parent or caregiver modules similarly focused on exposure, encouraging "challenge-zone" child behavior, emphasizing effort over outcome, providing psychoeducation about error sensitivity, modeling positive reactions to mistakes, and responding positively to child mistakes. Furthermore, parent modules also included general positive parenting tools, such as the use of

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positive attention and one-on-one, child-led play (special time). Parents and children, respectively, completed the core intervention: a 45-minute baseline module, which was followed by 6 months of less than 5-minute video lessons, thrice monthly. Paper journal activities corresponded with the weekly content, and parents received weekly text and email reminders with links to access modules accompanied by brief messages to reinforce program content (eg, "You can encourage your child to do something challenging, even if they might make mistakes!"). Links were specific to each weekly video, and parents received 2 separate links (one for weekly parent content and one for child content). Participants "logged in" to each respective module by entering their study ID#, which was used to estimate rates of adherence. Thus, if both the parent and child content were accessed for a respective week, 2 separate ID "logins" were recorded.

Measures

Quantitative Measures: Adherence

Adherence was estimated via metadata extracted from the study website, which logged whether each respective module was accessed at any time between baseline and the 6-month follow-up assessment. If a particular module was associated with 2 or more logins for the same participant, only the first login was counted. As both conditions were housed on the same website, rates of condition contamination for the weekly modules were moderate; 1 active-condition parent (P+) accessed a control module, 2 P– parents accessed an active module, and 1 C– child accessed an active module. Given that all these participants had completed the correct initial (primary) module, they were included in the analyses. A summative measure of adherence was computed for parents and children, respectively, and the proportions of module adherence were calculated by dividing the total number of modules completed by 18. Parent and child adherence were then averaged to create a single adherence score. Finally, for sensitivity analyses, a composite variable was created for each of the 18 modules: whether any member of the dyad (including parent, child, or both) had logged into the respective module.

To characterize *sustained adherence*, a more sensitive metric of engagement, an additional variable was computed for parents and children, respectively: the number of *unique weeks* a participant logged in. Parent and child sustained adherence were averaged into a single score.

Qualitative Measures: Semistructured Interviews and Journal Entries

An interview guide [34] was developed for this study based on similar guides (eg, [40]). Interviews adhered to existing guidelines on semistructured interview research, including the use of fieldnotes and the incorporation of author positionality [47-50]. To further characterize patterns of CPE and child participation, a sample of paper journal entries was qualitatively reviewed. These included 32 journals photocopied following the baseline module (n=16) or returned at post treatment (n=16), including child (n=16) and parent journals (n=16). Patterns of engagement were reviewed holistically by the lead author (IAM), with a focus on the degree of completion, thoroughness and coherence of responses, common themes, and behavioral commitment language. The findings were integrated with qualitative and quantitative findings on engagement and fidelity.

Data Analyses

Adherence was reported descriptively for children and adults, including rates of overall and sustained adherence. A Welch's ANOVA examined differences in adherence by intervention condition. To interpret the qualitative data, a standard thematic analysis informed by the framework method was performed [51,52] using the NVivo software (version 12.7.0; by Lumivero). This study relied on a codebook generated for a prior study, and data preprocessing is described elsewhere in further detail [45]. Summarily, the analysis used a thematic framework [53], data familiarization, iterative development of a coding scheme and coding, double-coding and coauthor consensus building, recoding, development of a thematic matrix, and interpretation of data via the themes. The thematic matrix was developed using a combination of deductive and inductive processes. Rigor and trustworthiness were established through the use of previously published inquiry methods, strategic sampling methods to achieve a diversity of perspectives, triangulation of multiple data types, consultation, integration of author positionality, negative case analysis, and member checking [47,54].

Results

Overview

Our quantitative and qualitative results provided complementary insights. Although quantitative patterns revealed relatively low fidelity of adherence, this did not translate to poor engagement with the content. Importantly, barriers to high-fidelity participation were not always barriers to overall program success. Qualitative results highlighted diverse and idiosyncratic barriers and facilitators to engagement and suggested numerous positive outcomes of the program that, in turn, facilitated engagement.

Quantitative Findings

Demographics are summarized in Table 1; additional demographics of the qualitative sample are reported in Table S1 in Multimedia Appendix 1. Parent and child overall adherence were strongly positively correlated (r_{85}=0.946, 95% CI 0.919-0.965; P<.001). The overall rate of adherence to the weekly modules was approximately 20%, with substantial variability; indeed, 43.7% (n=38) of the parents and 44.8% (n=39) of the children did not log into any of the weekly modules. Parent and child sustained adherence were also strongly positively correlated (r_{85}=0.949, P<.001, 95% CI 0.923-0.966). Table 2 shows adherence by parent and child (see Table S2 in Multimedia Appendix 1 for analogous data within the qualitative sample). Furthermore, adherence declined over time (Figure 1).

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Table . Participant demographics (n=87).

Baseline characteristic	Full sample, n (%)	Interviewees, n (%)
Parent demographics		
Gender		
Woman	79 (90.8)	17 (94.4)
Man	7 (8)	1 (5.6)
Other	1 (1.1)	0 (0)
Education level		
Some high school	1 (1.1)	1 (5.6)
High school diploma or equivalent	4 (4.6)	0 (0)
Some college or 2-year degree	24 (27.6)	5 (27.8)
College degree	29 (33.3)	7 (38.9)
Graduate degree	29 (33.3)	5 (13.9)
Annual family income (US $)		
<10,000	2 (2.3)	1 (5.6)
10,000 - 25,000	6 (6.9)	1 (5.6)
25,000 - 40,000	10 (11.5)	2 (11.1)
40,000 - 75,000	28 (32.3)	9 (50)
>75,000	41 (47.1)	5 (27.8)
Race		
White	64 (73.6)	13 (72.2)
Black	15 (17.2)	3 (16.7)
Asian	1 (1.1)	0 (0)
Other	7 (8)	2 (11.1)
Ethnicity		
Not Hispanic or Latino	81 (93.1)	16 (88.9)
Hispanic or Latino	5 (6.9)	2 (11.1)
Relationship status[a]		
Married or remarried	61 (73.5)	13 (72.2)
Divorced, single	4 (4.8)	2 (11.1)
Single, never married	8 (9.6)	2 (11.1)
Long-term relationship	10 (12)	1 (5.6)
Child demographics		
Gender		
Girl	46 (52.9)	10 (55.6)
Boy	41 (47.1)	8 (44.4)
Race		
White	54 (62.1)	11 (61.1)
Black	15 (17.2)	3 (16.7)
Asian	1 (1.1)	0 (0)
Other	17 (19.5)	4 (22.2)
Ethnicity		
Not Hispanic or Latino	75 (86.2)	14 (83.3)
Hispanic or Latino	12 (13.8)	4 (16.7)

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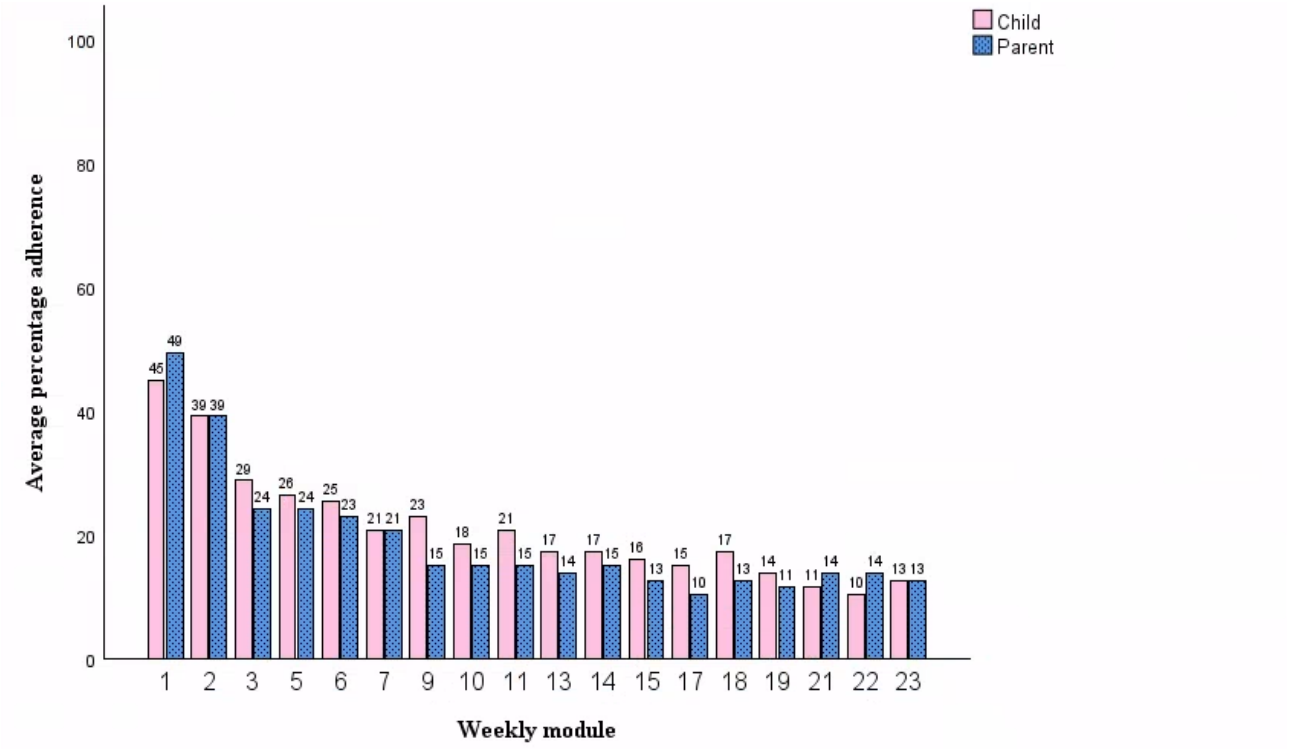
[a]n=83 for relationship status and parent age ($n_{missing}$=4). Full sample: mean parent age 36.6 (SD 6.0; range 22-52) years; mean child age 6.2 (SD 0.8; range 5-8) years. Interview sample: mean parent age 36.4 (SD 6.3; range 25-48); mean child age 6.2 (SD 0.9; range 5-8).

Table . Overall adherence rates and sustained adherence to the weekly modules (n=87 dyads)[a].

Dyad member	Number of unique weeks		Number of total modules		Percentage of total modules	
	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)
Parent	2.3 (3.7)	1 (0-2)	3.4 (5.2)	1 (0-4)	19 (29)	6 (0-22)
Child	2.2 (3.5)	1 (0-3)	3.8 (5.6)	1 (0-6)	21 (31)	6 (0-33)
Average	2.3 (3.5)	0.5 (0-2.5)	3.6 (5.3)	1 (0-6)	20 (30)	6 (0-33)

[a]Modules were delivered 3 out of 4 weeks, with assessments given every fourth week. Adherence ranged from 0 to 18 for number of modules completed (both parent and child); for unique weeks, it ranged from 0 to 14 (child) and 0 to 15 (parent).

Figure 1. Rates of parent and child adherence by weekly module. "Weekly module" refers to completion of the respective module at any time from baseline to 6-month follow-up.



ANOVA assumptions were not met (skewness=1.98; kurtosis=3.15; nonhomogeneity of variance). Thus, a Welch ANOVA, with Games-Howell post hoc comparisons, was used to test for differences in average sustained adherence (ie, number of unique active weeks) by intervention condition (P+/C+: mean 2.37, SD 3.48; P+/C–: mean 2.77, SD 4.26; P–/C+: mean 1.56, SD 2.54). The test was not significant ($F_{2,54.84}$=1.05, ω^2_random=−0.002, 95% CI −0.012 to 0.038; *P*=.36), indicating no differences in sustained adherence rates by condition. Post hoc comparisons revealed that sustained adherence in P+/C– was not significantly greater than in *P*+C+ (95% CI −2.02 to 2.82; *P*=.92, or P–/C+, 95% CI −1.01 to 3.43; *P*=.39); nor was there a difference between P–/C+ and *P*+C+ (95% CI −2.74 to 1.12; *P*=.57). (As a sensitivity analysis, we fit a population-averaged logistic model using generalized estimating equations with exchangeable working correlation to account for within-dyad dependence across weeks. The Condition × Week interaction was not significant (Wald χ^2_2=4.36; *P*=.11), indicating that completion trajectories across modules did not differ by condition. This result converged with the primary Welch ANOVA findings.)

Qualitative Themes

Overview

Table 3 shows a summary of qualitative themes and subthemes with example quotes. The themes titled (1) diverse family characteristics and needs and (2) program benefits are described in greater detail below. Patterns of journal completion revealed meaningful parental participation in the baseline intervention module. Journal review revealed detailed, specific written responses indicating deep cognitive and affective engagement with the content, as well as concrete behavioral intentions. A review of completed child journals indicated that some journal activities (eg, intentional misspelling tasks) were inappropriate for some younger children and that adult assistance facilitated journal completion. In addition, children's journal entries

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showed a mix of internally consistent responses (eg, endorsed positive self-talk such as "Everyone makes mistakes!" and did *not* endorse "trouble making mistakes"; ie, error sensitivity) and inconsistent responses (eg, circling *all* response options available, even when conflicting).

Table . Qualitative themes and subthemes with example quotes[a].

Theme and subtheme	Example quote
Diverse family characteristics and needs	
Broad applicability	"… she kind of fell into all the categories … being shy, being critical of herself … and like what other people thought, um, that fit her like a tee. Um, she has big feelings, deep feelings and... it resonated." (Parent 15)
Life circumstances and family structure	"I really have a desire to model trying new things, and putting myself out there, like being vulnerable to maybe not being great at first and, you know, working to get better … It's just so hard with kids and … I have four kids, [aged] seven and under." (Parent 4)
Program benefits	
Mindful parenting	"I'm, like, trying to be more mindful of it … Because I normally would overreact ... I feel like, 'Oh, my God, I'm such— like, 'I can't believe I did that'. (Parent 9)"
Ripple effects	"I tried to change the way I do things, which, honestly, it positively affects her … she's a lot more open, willing to talk and, um, you know, she doesn't get as … upset or anything, or have breakdowns and all." (Parent 6)
Improved parent-child relationship	"We have completely changed up everything [we do] in the house… If she did something wrong, we would say … 'is that a good choice?'… 'what are some better choices?' … 'because if you do this, this is what happens'... So now it's completely different … We redirect, and we talk about it and … actually figure—solve the problem." (Parent 6)

[a]Eighteen individual interviews were conducted with parent-child dyads, which were coded and subjected to a thematic analysis.

Diverse Family Characteristics and Needs

Overview

Families reported diverse barriers and facilitators to engagement. However, interviewees felt that *Making Mistakes* was broadly appropriate for their family and could offer at least *something* to other families. "I think it definitely should be a thing that, that's like, done by every parent" (Parent 12). Some respondents expressed that the program might be most useful for families of children with behavioral or emotional challenges, or overwhelmed parents in need of encouragement.

Facilitators and barriers to participation emerged with respect to both parent and child traits. Parental facilitators included a willingness to troubleshoot difficulties, along with perseverance in practicing strategies learned, even in the face of perceived failures or setbacks. Individual child differences also served as facilitators and barriers, such as attention span or ability to sit still, rambunctiousness, and tolerance of uncertainty. "My daughter is a planner. She doesn't like surprises … She's not great with … change … or transitions, so I kind of have to talk her through … her plan for the day" (Parent 15).

Broad Applicability

Children varied in their error sensitivity and other challenges. Some parents described moderate child error sensitivity, with bouts of low frustration tolerance. Others' children tended to actively approach challenges and had low error sensitivity. Still others described more significant behavioral or emotional challenges or expressed that their child perfectly fit the program's description of being highly error-sensitive (eg, shy, perfectionistic, avoids challenging tasks, or easily discouraged). Some parents felt their young children had not yet developed the "bad habits" of responding poorly to their own errors. Indeed, *Making Mistakes* content was suggested in some cases to be even more relevant to other children, including older siblings or others outside the home.

> *I also try to be mindful of it with my students … My niece and nephew, I'm like, "They need this …" He is going to be the type of kid that's at MIT, and he's gonna be like, real stressed out … and ready to like, [jump] off a bridge if something happens.* [Parent 9]

Interestingly, parents also varied in their own error sensitivity. Some communicated a desire to break cycles of "intergenerational trauma"—or maladaptive cognitions and behavior. Furthermore, some identified immense difficulty resisting the urge to correct their child's mistakes, with some equating mistakes with *failure*.

> *I used to not treat [mistakes] correctly … I am [no longer] … pushing him to, to do all the things perfect[ly], I think, you know mainly [Making Mistakes] was for me (chuckles)…* [Parent 18]

> *… the way I've been raised, is like, always, like push, and, you know, achieve, and kind of compared [myself to others] a lot too. So, mistakes are kind of … not looked upon well … I do just see a value in [the weekly activities], umm, for me personally.* [Parent 3]

Commonly, parents desired to engage their spouse or coparent in the content. "[My spouse is] a Veteran so … for him, it's

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separating that mindset of 'okay, this is not soldiers, this is a child'… he's still working on that … because he's very much sometimes in that military mindset" (Parent 6). Facilitators of parent and spousal or coparent participation emerged, including elevated parental error sensitivity, interest in learning about child development, a growth mindset, and favorable views of science; some postulated that younger and more "progressive" parents would find the intervention compelling. Despite heterogeneity in families' perceived problems, challenges, and circumstances, interviewees resoundingly felt *Making Mistakes* was applicable in some way.

Life Circumstances and Family Structure

Engagement was influenced by circumstances including family composition, busyness, employment status, and unpredictable or temporary stressors. However, no simple pattern of participation emerged; indeed, some with minimal circumstantial barriers engaged with low fidelity, and others with myriad external barriers were highly motivated to engage. Thus, engagement was dynamic, complex, and influenced by multiple factors. Specific barriers included single parenthood, excessive childcare demands (especially having multiple young children), busy family schedules, and a desire to avoid overfilling their child's plate. Busyness decreased adherence to the program.

Temporary circumstances dynamically impacted interest or ability to engage in *Making Mistakes*, including moving or job loss (barriers); resolution of a problem such as bullying, leading to a reduction in child psychosocial problems (decreased motivation to engage); or having an infant child, which led to higher perceived program relevance yet more barriers to actual participation. Overall, family or household structure, employment, and busyness were viewed as barriers, with short-term stressors (eg, moving, newborn care, child bullying) also contributing to the ability and motivation to participate. However, life circumstances, along with perceived child problems, only explained a portion of the variation in program engagement.

Program Benefits

Overview

Dyads consistently expressed that their family had benefited in some way from *Making Mistakes*, which, in turn, facilitated participation fidelity. Cognitive and behavioral change came from the repeated implementation of strategies including reframing mistakes, modeling positive reactions, and responding positively to children's mistakes. Parents described positive changes in the intervention targets (ie, child error sensitivity) as well as in their own error sensitivity, parent-child communication, and family emotional health. Cognitive changes (eg, increased awareness, modified beliefs about mistakes) were framed as leading to behavioral changes in parents and their children, as well as in other family members or individuals outside of the family. Interviewees also evidenced internalization of program concepts and strategies. For example, some parents struggled to recall specific program-related changes until the strategies were cued, after which they expressed strongly positive feelings toward the content.

> *[This program] put a name to [encouraging her to do hard things] and kind of highlighted and reminded me … to suggest those things and … explain that to her … I do remember thinking about those things, and being like, "that is extremely good information …" [Special time] is something I was not doing before, um, and then I kind of forgot that … this program was the one that kind of like, turned that light on.* [Parent 4]

Children struggled to identify changes; however, some described internalized cognitive strategies, such as listening to their "mistake buddy," often with helpful scripts. For some, perceived benefits included reduced performance anxiety and perfectionism, increased positive goal-setting and bravery, and improved attentiveness and self-regulation abilities.

> *Before, I tried not to make mistakes that mu- a lot, which I, which I did. And now it's, and now I know that it's okay to make mistakes. So, so, it's just fine for me… I messed up and I was like, "it's okay!".* [Child 12]

Mindful Parenting

Interviewees gained increased awareness of their impact on their children through a combination of psychoeducation on error sensitivity and being urged to pay more attention to their own behavior and their child's psyche.

> *I wondered why my son gets so angry. And ... [now I understand he gets angry when] he make[s] a mistake, or [when I punish him], stuff like that* [Parent 14]

Parents also gained an understanding of their children's developmental level, as well as naturalistic opportunities to reinforce healthy concepts.

Mindfulness also facilitated resisting the urge to correct or preempt children's mistakes. This reduction in "autopilot parenting" seemed to stem from increased awareness of parents' own behavior, improved frustration tolerance, and tolerance for child messiness. "I would say I've learned to be a little bit more patienter [sic]" (Parent 10). Mindfulness also led to more developmentally appropriate expectations of their children, which deemphasized perfection and outcomes, instead emphasizing effort and the "big picture." Respondents learned to pause before responding, when they would recall program concepts and respond accordingly. Interestingly, parents also highlighted a behavioral outcome not explicitly taught: correcting their own negative responses to mistakes.

> *I'll tell … all my kids like, "Mommy made a mistake," or "Mommy behaved really poorly. I was, uh, I was upset and I, I said a bad word and that was not nice …" Them knowing that I'm not perfect … it gives them the opportunity to not be perfect, too.* [Parent 4]

Ripple Effects

Indirect effects included reciprocal positive influences between child and parent behavior, changes in parents' own error sensitivity, and reported benefits to siblings or family members. "I think she did definitely gain some self-confidence, um, for

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sure ... she does really well with the, with the positive reinforcement and praise and … one-on-one time …" (Parent 17). For some dyads, positive family changes were spurred by the child. For instance, parents intentionally reinforced children's *Making Mistakes* content, and some children reminded their parents and siblings to respond positively to mistakes. In addition, a family noted that their child's increased emotional vocabulary facilitated their ability to support him appropriately.

Parents learned to be kinder to themselves, which stemmed from modeling positive reactions to their own mistakes and from frequent, small reminders. "It kind of helped me to get my patience back in line and it, you know, kind of let me realize too, that, 'okay, you're Mommy, but you're not perfect; you're gonna make mistakes, too'" (Parent 10). Positive changes extended to other children and caregivers, as well. Indeed, *Making Mistakes* provided a rationale for parents to encourage coparents to be more mistake-friendly. Most interestingly, program content spread beyond dyads' immediate family, including the workplace, schools, extended family, and friends.

> *I would say something that's like, "Oh my God, I'm such an idiot, I left this out overnight." And she's like, "No, Mom, no negative self-talk" … I'll say something like, "Do you know what this is?" … she'll be like, "An overreaction?" … I think she even told my mom, like, "That's the mistake bully" (laughing).* [Parent 9]

> *… her brother, um, who is autistic and does not cope well with failure, and doing poorly, and making mistakes … she immediately took those ideas home, and does not just say them when she makes mistakes, she's helping to express them to him as well.* [Parent 16]

Improved Parent-Child Relationship

Interviewees also described improved parent-child functioning. This included more positive communication and quality time, more openness, and fewer negative disciplinary methods, as well as explanations provided to children in slower and simpler language, leading to reduced conflict and frustration. Parents replaced harsh and less effective discipline, such as spanking or yelling, with more effective and gentler methods, such as talking things through and using positive reinforcement.

> *We really [reduced his punishments], because in the past we used to say, "you are not going to play with … your Legos," or "you're not going to watch TV, you're not to go to the park." And, now we're being more relaxed with, with him [and only removing video-game privileges] … because it was [too much punishment] for him.* [Parent 18]

These changes led to children more openly discussing their mistakes with parents. "[She's more open about] how she feels… there not being like this fear cloud that, you know, (chuckles) 'Mom's gonna get upset', or 'Mom's gonna shut down'…" (Parent 6).

Families described myriad benefits from their participation. Improvements were noted as receiving helpful tips, which led to more aware and intentional parenting, in turn leading to improved child behavioral and emotional functioning. While respondents generally felt *Making Mistakes* positively impacted their lives, some families described more profound positive results that dramatically improved family functioning and child emotional health.

Discussion

Principal Findings

This study examined participation fidelity, family involvement, perceived outcomes, and barriers and facilitators to engagement in a web-based anxiety prevention program in parent-child dyads. Qualitative and quantitative data showed high levels of engagement in the initial module, albeit low levels of DHP adherence over the 6-month intervention period. Barriers and facilitators included competing demands and program credibility, respectively. Perceived benefits emerged as a key facilitator, resulting from engagement spanning cognitive, affective, and behavioral domains.

Engagement Barriers and Facilitators

Participants completed, on average, one-fifth of the weekly modules, with engagement dropping off over time; however, the modal dyad completed zero weekly modules. Online video and paper journal completion generally coincided, though more families completed the videos, and a few completed journals without the videos. In contrast to the weekly modules, in-lab engagement in the baseline module activities was high. Differences in lab versus home participation align with research demonstrating the utility of human facilitation in promoting DHP usage [55]. DHPs often face low adherence, which may limit therapeutic benefits [56]. Additional work should clarify the relative importance of—and strategies to optimize—different levels of digital engagement, including mechanical program usage, cognitive engagement with program notifications, and behavioral enactment of nondigital tasks resulting from the program [3]. Our findings suggest that this type of DHP may have a strong impact when integrated with human facilitators at the outset, followed by software-delivered engagement strategies tailored to the individual family's needs. Future research should determine the optimal forms of involvement needed to attain program benefits [57].

Numerous barriers and facilitators to family engagement were identified. Facilitators included programmatic factors, such as teaching specific content and strategies, rationale provision (ie, psychoeducation on error sensitivity), mobile-friendliness and navigability, regular reminders with repeated exposure to the content, participation in the in-lab baseline module, and approaching *Making Mistakes* as a shared family activity. Facilitators also included family characteristics, such as child enthusiasm for learning; perceived relevance to child *or* parent based on program descriptions of traits associated with error sensitivity (eg, shy, sensitive, socially anxious, reactive); belief in the program's potential and interest in child psychology and parenting improvement; personal negative experiences with high error sensitivity; and buy-in from co-caregivers. Indeed, the broad applicability of *Making Mistakes* appeared to be a key driver of parent participants' affective engagement, or

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emotional investment, with the program, which facilitated behavioral change. Moreover, early improvements in family functioning facilitated buy-in and continued engagement. Facilitators overlapped with those found in previous research, including perceived need, appealing content and delivery, openness to prevention and health promotion approaches, individual motivation and interest, and increased insight into health [38,58]. Our findings on facilitators and barriers shed light on potentially important factors influencing CPE within a DHP [11]. Additional strategies, such as personalization and gamification, may enhance overall program adherence and efficacy.

Both program-related and family-related barriers were identified. Regarding program-specific barriers, some families cited issues related to poor customizability of content and delivery, too many steps to access the content, repetitive or overly simple content, intervention dose (ie, weekly) perceived as daunting, and insufficient incentives to complete the weekly activities. Family-level barriers consisted of low perceived relevance due to parent or child traits; multiple competing demands, especially work and childcare; single-parent status; and temporary stressors, such as moving, separation, or child psychosocial stressors. Barriers overlapped with those found in previous research (eg, [38,42]), including childcare demands, employment, low perceived need, difficulty with program navigability, and perceived burdensomeness. Many barriers were potentially related to social determinants of health and the limited sophistication of the program; therefore, just-in-time adaptive interventions could be developed to equitably address error sensitivity in at-risk families [59]. Of note, the sample only included study completers or partial completers, and thus barriers to initial participation were not captured (eg, see [60]). Overall, barriers and facilitators aligned with those predicted by the health belief model and the theory of planned behavior—such as perceived costs, threats, attitudes, and subjective norms—consistent with research demonstrating support for these models in parenting intervention engagement [61]. These findings also add to the growing body of evidence on engagement in youth mental health services [62,63]. However, the development and testing of theories of family engagement in DHPs will be needed to address barriers and optimize facilitators.

Program Outcomes

Abundant positive changes were highlighted via qualitative interviews. Commonly cited outcomes included direct intervention targets—including parent sensitivity to child errors and child error sensitivity—though broad changes to parenting and parent-child functioning were also described. Changes to beliefs or thinking (eg, reframing mistakes, increased parenting awareness) seemed to reflect evidence of cognitive engagement. These mental shifts were described as preceding behavioral changes. In addition, improvements in child emotional functioning appeared to be driven by changes in parental behavior, although perceived impacts were bidirectional. Participants described additional unanticipated outcomes, including benefits to siblings, other caregivers, friends, family, and community members. Indeed, these descriptions of wide-ranging improvements appeared to reflect a high level of behavioral engagement with *Making Mistakes*, even despite low rates of adherence to the weekly modules.

This apparent discrepancy—that is, abundant perceived positive outcomes and descriptions of strategies enacted, despite low weekly adherence—merits further attention. The findings support distinctions among aspects of behavioral engagement, such as using a DHP's interface, enacting specific techniques learned, and making broader changes to health behaviors [4]. It is possible that the initial in-lab intervention module was an adequate dose for many participants, and subsequent program interfacing was not necessary for broader enactment of concepts learned. Alternatively, the simple weekly reminder texts and emails may have spurred continued improvements, even for those who did not complete the activities. The findings extend the literature on CPE within a DHP, suggesting that cognitive and affective engagement, as well as more "downstream" indices of behavioral engagement, may be more important than traditional metrics of DHP *adherence*. To better understand what constitutes *effective* CPE [3,11], future research may directly compare different behavioral engagement strategies and explicitly link them to outcomes of interest.

Qualitatively, families also commented on the positive impact of study involvement, including participation in dyadic games during the lab, as well as routine outcomes monitoring via error-sensitivity measures [34]. Future research should clarify the relative importance of such nonspecific program components, including measurement and observation procedures. Indeed, given the known benefits of measurement-based care in youth mental health services [64] as well as the potential for observer effects or reactivity in parent-child interaction research [65], participant reports of program-related changes to functioning should be interpreted cautiously.

Enhancements to program design and structure may help to overcome common program-related barriers to participation. Beyond well-established DHP design recommendations, such as customizable reminders and intervention frequency, gamification, human facilitation, ease of access, and appealing content and delivery (eg, [66-68]), this study suggests several additional strategies that may enhance engagement. Participants responded well to psychoeducation about *error sensitivity*, including its causes and consequences, which increased the perceived relevance of the program. Additionally, DHPs and caregiver-mediated programs may be enhanced through options to engage cocaregivers in the program. Moreover, the findings suggested that offering the initial in-lab module, along with parent-child games, and the opportunity to approach the program as a dyadic activity may have facilitated program engagement. Finally, regular reminders (nudges), including periodic assessments, may have driven family investment even in the absence of repeated doses of the intervention content. These potential strategies should be empirically validated in future research.

This study has multiple strengths, including integrated qualitative and quantitative data; demonstration of qualitative rigor and trustworthiness; inclusion of young children in data collection; multiple novel foci (ie, DHPs for 5 to - 7-year-olds,

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error sensitivity, preventive parent-child program development); intervention targets derived from a neural marker of anxiety; multiple operationalizations of adherence; and a critical focus on multiple aspects of engagement, a common pitfall of DHPs and of caregiver-mediated interventions [56].

This study must also be interpreted in light of several limitations. Both intervention conditions were housed on the same website, and thus, a few participants accessed a video from the other condition. Thus, analyses focused on rates of adherence by condition should be interpreted with some caution. In addition, our measures of behavioral engagement were somewhat limited, including overall adherence and sustained engagement. Future research should incorporate more dynamic and multidimensional metrics, such as the amount of time spent with the intervention or implementing strategies learned; explore temporal patterns of program participation; or use ecological momentary assessment methods to capture behavioral, cognitive, and affective engagement over time. In addition, though diverse perspectives were represented among the qualitative interviews, external validity is limited by the sample's makeup: mostly White, highly educated, multi-parent homes with relatively high household income. Thus, the results may not be fully generalizable to marginalized families facing additional participation barriers. Future studies must examine *Making Mistakes* engagement in diverse samples.

Conclusion

Preventive programs for young children and families may yield broad-ranging benefits, including transdiagnostic impacts beyond specific intervention targets. Our findings highlight the importance of qualitative assessment in trials of preventive programs and contribute to the sparse literature on prevention programs for young children [69]. The findings also contribute to the broader literature on perfectionism interventions for young people [36], digital health interventions [9,66] including those for preschool anxiety [70,71], and parent-based interventions for young children [72,73].

These findings support further evaluation of a low-intensity preventive intervention, *Making Mistakes*, which shows promise in promoting positive change within error-sensitive families. *Making Mistakes* included a single-session intervention (see [74]) in tandem with brief reminders or nudge interventions [75]. Future iterations of *Making Mistakes* or similar programs could benefit from further tailoring for very young or preliterate children, including the use of verbal recordings instead of written practice assignments. Finally, to meet the diverse needs of families with elevated error sensitivity (see [31]), *modular* DHPs could be developed to prioritize family preferences and accommodate additional areas of concern to the family [76]. Future research should evaluate the long-term impact of *Making Mistakes* and elucidate family engagement in diverse populations. Importantly, family-focused developmental models of perfectionism, including the social expectations, social learning, and anxious rearing models [23,24,31], should guide efforts to develop and implement engaging digital mental health interventions to prevent the development of pediatric anxiety disorders and cultivate resilience in families.

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Generative artificial intelligence tools, including ChatGPT by OpenAI and VA GPT by the Department of Veterans Affairs, were used in the development and editing of code for some quantitative analyses as well as in the preliminary interpretation of select statistical output. The authors take full responsibility for the accuracy, originality, and integrity of all manuscript content.

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Data Availability

The datasets generated and analyzed during this study are not yet publicly available due to the ongoing status of the broader randomized controlled trial. Upon completion of the randomized controlled trial, a portion of the deidentified data underlying this paper will be made publicly available.

Conflicts of Interest

None declared.

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Multimedia Appendix 1
Supplemental data and access to Making Mistakes program.
[DOCX File, 31 KB - pediatrics_v9i1e79898_app1.docx]

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Abbreviations

CPE: caregiver participation engagement
DHP: digital health program
ERN: error-related negativity
RCT: randomized controlled trial

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Online Information About Cardiac Neurodevelopment: Mixed Methods Study

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Abstract

Background: Infants with complex heart disease often have delayed development, learning difficulties, and mental health problems as they grow older. Their parents and other caregivers engage in online health information–seeking behavior to understand and support their children's health and development.

Objective: In this study, we analyze the presence, nature, and presentation of information about neurodevelopment on the websites of congenital cardiac surgical programs in the United States.

Methods: We used a mixed methods approach, specifically a convergent design. We correlated the presence and presentation of information about neurodevelopment on each program's website with state-level and program-specific factors extracted from multiple publicly available databases. Quantitative analysis methods included descriptive analyses, Student *t* tests, Pearson chi-square test, and multivariate logistic regression analysis, all performed using SPSS (IBM Corp). Qualitative methods included both inductive and deductive content analysis.

Results: Only 39% (50/129) of programs provided any information about neurodevelopment online. High surgical volume correlated with the presence of online information (P<.001). Websites were written at an average 7th to 10th grade reading level, and fewer than 5% of websites had information in a language other than English. Two semantic clusters of website format, content, and element selection were identified, reflecting distinct approaches to adult learners. Program websites clustered into "sage on the stage" and "guide on the side" formats. Few websites incorporated features caregivers previously identified as useful, with only 6% including the four most helpful features.

Conclusions: We highlight the paucity of accessible caregiver-oriented information about neurodevelopment on congenital cardiac surgical programs' websites in the United States and characterize two primary website models. The lack of information may negatively impact caregiver understanding of and engagement with neurodevelopmental services for their child with a congenital heart defect. Future research should explore the impact of each website model on caregiver understanding of and engagement with neurodevelopmental services, as well as the generalizability of these findings to other domains of pediatric subspecialty care.

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KEYWORDS

heart defects, congenital; neurodevelopment; online health information seeking; digital media; pediatric hospital; caregiver; qualitative research; cardiac surgery; quality of life; OHIS

Introduction

Congenital heart disease (CHD) is the most common type of birth defect, affecting nearly 1% of babies born in the United States every year [1]. Survival has improved with advances in medical and surgical management [2]. As survival has improved, neurodevelopmental impairments have emerged as the predominant morbidity for neonatal heart surgery. Such

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impairments in gross motor skills, executive functioning, and mental health are considered one of the primary determinants of quality of life across the patient's lifespan [3-5]. Many of these impairments are amenable to treatment; however, many children do not receive appropriate screening, with parent and other caregiver understanding one likely barrier to screening [6,7].

Parents and other caregivers (grandparents, foster parents, etc) of children with CHD prefer more information than pediatric cardiologists provide, particularly about their child's future quality of life [8]. As with other patients and caregivers, they fill their knowledge gaps using online health information-seeking behaviors [9-13]. Websites rival health care professionals as the most common source of information caregivers use to learn about their child's heart condition (72% - 92% compared with 77% - 92%, respectively), with 30% of those caregivers reporting the use of hospital websites [11,12]. While most parents report searching for information about their child's cardiac condition (88%), many also search for information about long-term outcomes (73%) and challenges associated with CHD (59%) [11]. A handful of studies have evaluated online information about congenital heart defects, but no previous studies have evaluated congenital cardiac surgical program websites, either overall or for information specifically related to the neurodevelopmental impacts of CHD [14,15]. It is unclear if currently available information is adequate to inform caregiver understanding of the need for and engagement with neurodevelopmental supports for their child.

This study analyzes the information about neurodevelopment available on the websites of congenital cardiac surgical programs in the United States. Given heterogeneity in both congenital cardiac surgical outcomes and health care funding and delivery across the United States, we hypothesized that center-specific factors as well as state-level sociodemographic variables would predict the presence, reliability, and models of information provided on these websites.

Methods

Sample Selection

A total sample of all US congenital cardiology surgical programs was defined using the 2021 - 2022 Congenital Cardiology Today directory. Given the impact of funding, politics, and values on institutional priorities and behaviors, a database containing program-specific and state-level characteristics of each program was created. Metrics reflecting the size and robustness of each congenital cardiac surgical program, sociodemographic characteristics of the children in the state being served by each program, and each state's investment in the health and education of children, all extracted from publicly available data, were included in this database (Table 1).

Websites for each congenital cardiac surgical program with information on cardiac neurodevelopment were identified between June and October 2022 using a two-step strategy. First, congenital cardiac surgical program websites were identified. Second, each website was queried for information on neurodevelopment. All web searches described below were conducted by an undergraduate researcher from the Midwest with no prior exposure to the topics of pediatric cardiology or cardiac neurodevelopment.

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Table . Publicly available data sources used to identify program-specific and state-level characteristics.

Data source	Data extracted
Congenital Cardiology Today Directory (2021 - 2022)+ program websites	
	Program size (cardiologists [n])
STS[a] Public Reporting Database 2015 - 2018	
	Surgical cases (n)
	STAT[b] 4+5 cases (%)
	Overall observed/expected mortality
FREIDA[c] 2022	
	Presence of a pediatrics residency program
	Presence of a pediatric cardiology fellowship program
US Census 2020	
	State population who are BIPOC[d] (%)
	State population that is Hispanic/Latino (%)
ACS[e] 2016 - 2019	
	State unemployment rate
	Children in the state living in poverty (%)
	Children in the state without insurance (%)
	Children in the state on Medicaid (%)
Kaiser Family Foundation Reporting 2019	
	Whether or not a state had accepted Medicaid expansion
National Center for Education Statistics 2019	
	State-level student-teacher ratio in K-12 classrooms
IDEA[f] Part B Child Count and Educational Environments Report 2019 - 2020	
	Students in K-12 classrooms with an IEP[g] (%)

[a]STS: Society of Thoracic Surgeons.

[b]STAT: Society of Thoracic Surgeons–European Association for Cardio-Thoracic Surgery.

[c]FREIDA: Fellowship and Residency Interactive Electronic Database.

[d]BIPOC: biracial or people of color.

[e]ACS: American Community Survey.

[f]IDEA: Individuals with Disabilities Education Act.

[g]IEP: individualized education plan.

Website Identification

To maximize search results, a two-pronged approach was used to find congenital cardiac surgical program websites. First, the websites listed in the Congenital Cardiology Today directory were visited. If the listed website was specific to the congenital heart program at that institution, the URL was saved and the splash page was saved as HTML. If the listed website was an institutional website not specific to the congenital heart program, the institutional website search bar was queried sequentially for nontechnical keywords: “heart,” “heart defect,” “heart surgery,” “congenital heart defect,” “pediatric cardiology,” and “cardiac defect.” English language terms were chosen as this is the official language of the country in which all programs were located. Approximating the strategy used by individuals searching for health information online, the first 10 results of each search were reviewed [16]. If a congenital heart program website was found, the URL was saved and the splash page was saved as HTML. This search strategy generated a repository of institutional congenital heart program websites.

Neurodevelopmental Information Identification

Overview

Each congenital cardiac surgical program website was then searched for information about neurodevelopment. Once again, a two-pronged approach was used, this time to allow for the evaluation of internal and external search engine optimization. First, all previously identified congenital cardiac surgical program websites were reviewed to identify the presence of any information related to neurodevelopment. Second, a Google

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(Google LLC) search was performed to identify information about cardiac neurodevelopment on the institutional website. The webpages identified using this process formed the units of analysis for subsequent qualitative analysis.

Institutional Website Search

Each congenital cardiology program website, regardless of whether it was identified through the *Congenital Cardiology Today* directory or via a search of the institutional website, was reviewed to identify any information about neurodevelopment. Search terms were preselected and included "development," "neurodevelopment," "neuropsychology," and "brain." If no mention was found on review of each website, the websites were searched using Command-F and through the site search bar on the institutional website. The first 10 results of each search were reviewed [16]. If information about cardiac neurodevelopment was identified, the URL was saved, the splash page was saved as HTML, and all text and images were scraped and archived in the archived qualitative data analysis software Dedoose (Sociocultural Research Consultants, 2022).

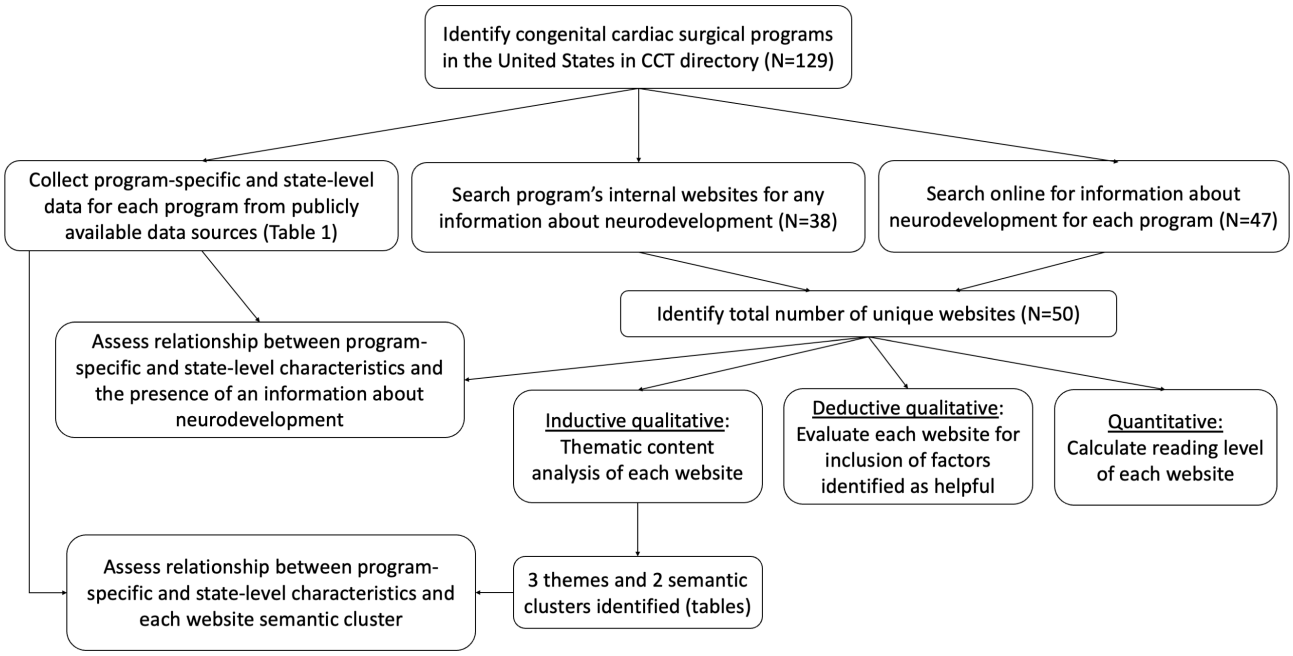
Google Search

A Google search for each program's name as listed in the Congenital Cardiology Today directory, in conjunction with preselected keywords, was performed. To maximize search results, keywords were selected based on the verbiage found on the websites of institutions with program websites and included "neurodevelopment," "cardiac psychology," "neurodevelopmental follow-up," and "cardiac neurodevelopment." The first 10 results of each search were reviewed [16]. If a program website was found, the URL was saved, the splash page was saved as HTML, and all text and images were archived as described above.

Mixed Methodology

A convergent mixed methods design was used with parallel quantitative and qualitative analyses, each informing the other (Figure 1) [17]. The central research question was: "How do congenital cardiac surgical programs in the United States communicate information about cardiac neurodevelopment online?" We also asked the subquestion: "Which program-specific and state-level factors impact how this communication occurs?" Results are reported following the Standards for Reporting Qualitative Research [18].

Figure 1. Study design overview. CCT: Congenital Cardiology Today.



Quantitative Analysis

A total population sample requires no inferential statistical analysis because descriptive analysis captures the full population. However, given imperfections in all sampling techniques, univariate and multivariate analysis of program-specific and state-level characteristics correlating with the presence of information about neurodevelopment on congenital cardiac surgical program websites were performed using chi-square tests, *t* tests for the equivalence of the means, and multivariate logistic regression analysis. The program-specific and state-level characteristics are listed in Table 1. For multivariate analysis, surgical programs were binned into even thirds based on surgical volume, with cut points at 125 cases and 270 cases per year, and based on surgical complexity with cut points at <21.75% Society of Thoracic Surgeons–European Association for Cardio-Thoracic Surgery 4+5 cases and >26.75% Society of Thoracic Surgeons–European Association for Cardio-Thoracic Surgery 4+5 cases. Program size was binarized, with larger programs being defined as those with at least 20 cardiologists. Two-sided significance was defined as $P<.05$, and all analyses were performed with SPSS (version 28).

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Qualitative Analysis

Inductive Content Analysis

Inductive content analysis of the archived websites was performed between July 2022 and October 2023. This data-driven strategy involves approaching the data without an a priori code book. Instead, a code book is constructed as the data is reviewed in an effort to "remain open to new discoveries" [19]. Codes emerged as the team collaboratively examined the archived websites and created analytic memos documenting their analysis and coding structure. In this fully crossed design, all websites were coded by each coder.

The aims of this analysis were two-fold: (1) to identify semantic clusters based on the types and modalities of information shared on this diverse group of websites; and (2) to situate these clusters within the intersecting geographic, academic, medical, social, and interpersonal spaces occupied by congenital cardiac surgical programs within the United States [20].

Positionality and Reflexivity

The four primary coders have expertise in health equity (DC), psychology (GC), medical anthropology (KRO), and pediatric cardiology (JBA). One is the parent of a child with CHD (JBA). One has studied CHD at two heart centers in the Midwest, one in the urban Pacific Northwest, and one in the urban South (KRO). Two were undergraduate students with no previous exposure to CHD at the time of this study (DC and GC). This study grew out of one author's experience seeking information online about her son's heart defect and its long-term implications (JBA).

Deductive Content Analysis

Language Accessibility

The readability of each website was calculated using multiple measures, including the Flesch-Kincaid readability test, SMOG (Simplified Measure of Gobbledygook) index, and Gunning Fog [21].

Caregiver Utility

Each website was coded for the presence of the top four features preferred by parents of children with CHD [11]. These features include (1) a combination of words, pictures, and videos; (2) descriptions of current research; (3) patient stories; and (4) links to additional websites.

Transparency and Reliability

The transparency and reliability of each website were calculated using JAMA (Journal of the American Medical Association) benchmarks, a streamlined tool to assess "the quality of medical information on the internet" [22]. JAMA benchmarks uses four criteria: authorship, attribution, disclosure, and currency. Scores range from 0 to 4.

Results

Sample

All 129 congenital cardiac surgical programs in the United States listed in the Congenital Cardiology Today Directory were analyzed (Table 2). Only 50 (39%) programs included information about cardiac neurodevelopment on their program website. This information could be found by searching within the program website for 38 programs and via a Google search for 47 programs.

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Table . Program-specific and state-level characteristics of all US congenital cardiac surgical programs.

Characteristic	Values
Programs, n (%)	
US programs in the Congenital Cardiology Today Directory	129
Neurodevelopmental information findable on Google	47 (36)
Neurodevelopmental information findable on program website	38 (30)
Neurodevelopmental information findable by either method	50 (39)
Program-specific characteristics	
Contributed to STS[a] database, n (%)	91 (70)
Pediatric residency program, n (%)	106 (82)
Pediatric cardiology fellowship, n (%)	65 (50)
Number of surgical cases (over 4 years), mean (SD)	899 (671)
STAT[b] 4+5 cases (%), mean (SD)	24 (6)
Observed/expected mortality, mean (SD)	1 (0.5)
State-level characteristics	
BIPOC[c] (%), mean (SD)	38 (14)
Hispanic/Latino (%), mean (SD)	19 (13)
Unemployment rate, mean (SD)	5 (1)
Children in poverty (%), mean (SD)	18 (4)
Children uninsured, (%) mean (SD)	5 (2)
Children on Medicaid (%), mean (SD)	38 (6
Accepted Medicaid expansion, n (%)	95 (74)
Student to teacher ratio, mean (SD)	16 (3)
Students served by IDEA[d] (%), mean (SD)	13 (2)

[a]STS: Society of Thoracic Surgeons.

[b]STAT: Society of Thoracic Surgeons–European Association for Cardio-Thoracic Surgery.

[c]BIPOC: biracial or person of color.

[d]IDEA: Individuals with Disabilities Education Act.

Quantitative Analysis

Five congenital cardiac surgical program–specific factors, and no state-level factors, correlated with the presence of information about neurodevelopment on surgical program websites (Table 3). Only surgical volume retained significance after multivariate analysis: programs averaging more than 270 surgical cases a year were significantly more likely than lower-volume programs to post information about neurodevelopment on their website (P<.001; Table 4).

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Table . Program-specific and state-level characteristics correlated with the presence of online information about neurodevelopment (univariate analysis).

Characteristic	Values (*df*)	*P* value
Program-specific characteristics		
Contributed to STS[c] database	12.602 (1)[a]	<.001
Pediatric residency program	9.299 (1)[a]	.002
Pediatric cardiology fellowship	27.448 (1)[a]	<.001
Number of surgical cases (over 4 years)	−6.221 (89)[b]	<.001
STAT[f] 4+5 cases (%)	−2.415 (89)[b]	.009
Observed/expected mortality	1.421 (89)[b]	.08
State-level characteristics		
BIPOC[d] (%)	0.824 (127)[b]	.21
Hispanic/Latino (%)	1.323 (127)[b]	.09
Unemployment rate	0.249 (127)[b]	.40
Children in poverty (%)	−0.684 (127)[b]	.25
Children uninsured (%)	0.261 (127)[b]	.40
Children on Medicaid (%)	0.876 (127)[b]	.19
Accepted Medicaid expansion	0.332 (1)[a]	.55
Student to teacher ratio	−0.210 (127)[b]	.42
Students served by IDEA[e] (%)	0.694 (125)[b]	.25

[a]Chi-squared test used to evaluate binary variables.

[b]*t* test for the equivalence of the mean used to evaluate continuous variables.

[c]STS: Society of Thoracic Surgeons.

[d]BIPOC: biracial or person of color.

[e]IDEA: Individuals with Disabilities Education Act.

[f]STAT: Society of Thoracic Surgeons–European Association for Cardio-Thoracic Surgery.

Table . Factors correlated with the presence of information about neurodevelopment on program websites (multivariate analysis).

Program-specific characteristics	Odds ratio (95% CI)	*P* value
Pediatric Cardiology Fellowship Program present	1.1 (0.30-4.40)	.86
Pediatrics residency program present	11.8 (0.80-178)	.07
Surgical volume[a]		
Lowest tertile	Reference	Reference
Middle tertile	3.4 (0.67-17.17)	.14
Highest tertile	65.3 (8.0-531.40)	<.001
Risk category[a]		
Lowest tertile of high-risk cases	Reference	Reference
Middle tertile of high-risk cases	0.5 (0.09-2.54)	.40
Highest tertile of high-risk cases	0.3 (0.056-1.75)	.19

[a]In multivariate analysis, only surgical volume significantly correlated with the presence of online information about neurodevelopment. Society of Thoracic Surgeons participation was excluded due to collinearity with surgical volume and surgical complexity. Programs were stratified into tertiles by ’15-’18 surgical volume and percent Society of Thoracic Surgeons–European Association for Cardio-Thoracic Surgery 4+5 cases. Highest annual surgical volume >270 cases; lowest <125 cases. Highest surgical complexity/risk of mortality >26.75% Society of Thoracic Surgeons–European Association for Cardio-Thoracic Surgery 4+5 cases; lowest <21.75% Society of Thoracic Surgeons–European Association for Cardio-Thoracic Surgery 4+5 cases.

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Qualitative Analysis

Sample Overview

The final dataset for qualitative analysis comprised 48 websites containing text, images, and videos. Data from one program were corrupted in the archival process, and one program had inadequate information for coding. Website content included information about neurodevelopment, the process for screening, and supports available at the individual institution, descriptions of research into the field, patient and family experiences, and links to external resources. The nature, amount, richness, and technicality of this information varied between programs.

Inductive Content Analysis

Three Cross-Cutting Functions

Taken in its entirety, the content and formatting of each website served three functions: (1) to convey information, (2) to form a connection with the reader, and (3) to establish the competence of the program. The information conveyed, the connection formed, and the emphasis on competence varied from site to site. Most websites described how CHD can alter children's physical, mental, and social development. However, while some focused on how clinicians can help, others focused on the impact of these challenges on the child's quality of life. Similarly, two primary strategies to connect with the reader emerged from the data: some websites used a formal, technical tone to establish authority, while others used a more collaborative style, sharing simplified, practical information. To establish competence, some websites referred to recommendations from organizations such as the Cardiac Neurodevelopmental Outcome Collaborative, American Heart Association, and the National Pediatric Cardiac Quality Improvement Collaborative, while others shared patient stories and testimonials [23].

Two Semantic Clusters

Differences across websites in terms of information conveyed, connection formed, emphasis on competence, and formatting formed the basis of two semantic clusters (Table 5). These two clusters parallel two previously described theories of adult learning and reflect the conceptualization of the institution as either a sage on the stage or a guide on the side [24]. The combined content and formatting used by websites in the first cluster emphasized the value of the services and expertise offered by the sponsoring institution, positioning their respective program as a sage on the stage. The features of the websites in the second cluster emphasized caregivers as partners in their children's development, positioning their programs as guides on the side. Websites that clustered around the sage on the stage model focused on institutional expertise and communicated "who we are and what we do," while those that more strongly reflected the guide on the side model focused on addressing children's needs in partnership with parents or other caregivers and were more effective at sharing "what your child needs and how we can help."

Table . Two semantic clusters were defined by the differential presentation and relative emphases of each website on the congenital cardiac surgical programs' competence, connection to the patient, and services offered.

Function and format	Sage on the stage	Guide on the side
Convey information	Clinician focused: • Centers on the clinician's role • Focuses on technical aspects of clinic visits • Describes research output	Child focused: • Centers on the child's needs • Focuses on practical details of clinic visits • Describes toll of CHD[a] on the entire family
Connect with the reader	Authoritative: • Specialized language and jargon • Technical images and illustrations • Headshots of providers • Emphasizes partnerships with other medical professionals • Shares recommendations from professional organizations	Collaborative: • Plain language • Simplified images and illustrations • Candid pictures of patients and providers • Emphasizes partnership with children and their caregivers • Shares patient stories • Social media links • Requests for donations • Describes patient participation in research
Establish competence	Formal validation: • Awards and certifications listed • Scope and experience of program and providers emphasized	Anecdotal evidence: • Patient testimonials
Format	Formal: • Third person language • Passive voice • Serif fonts, taller than wide • Few or no pictures or videos	Informal: • First or second person language • Active voice • Sans-serif fonts, wider than tall • Pictures and/or videos included

[a]CHD: congenital heart disease.

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Sage on the Stage

Websites conforming to the sage on the stage model reflected an authoritative stance (Table 6). Introductory phrases tended to describe services offered by their programs, with a subsequent description of the neurodevelopmental challenges faced by children with CHD. In this way, they centered the institution, not the child. Institutional resources and expertise were emphasized by highlighting staffing, multidisciplinary collaboration, and specialization, as well as by using more technical images and formal typography.

Websites were more likely to use third-person and passive voice to describe both the challenges faced by children with cardiac concerns and the institution's services. While this created a sense of impartiality, it also distanced the author from the reader and weakened the reader's connection to the institution. Families and children were presented as the beneficiaries of partnerships between medical professionals and were described as the participants of, rather than collaborators in, research endeavors.

These features combined to create expert-centered websites, with children as the objects of their expertise, and characterized parents and other caregivers as assistants in their children's care.

Table . Examples of features associated with the sage on the stage websites.

Function and format	Feature description	Examples
Convey informatin	• Centers on the clinician's role • Focus on technical aspects of clinic visits • Describes research output	• The follow-up program, "tracks, monitors and manages the development of children with congenital heart disease who undergo surgical intervention as infants." • "Hammersmith Infant Screen and Bayley Developmental Scales." • "Conduct a range of translational and basic science research." • "Description of research of QI projects in cardiac neurodevelopment."
Connect with the reader: authoritative	• Picture: headshots of providers • Images: technical • Language: specialized/jargon • Partnership: with medical professionals • Appeals to authority	• Cross-sectional image of a 3D rendering of a heart. • "Impaired visual-spatial and visuo-motor skills." • "We partner with each family's local pediatrician to develop a transparent approach to care." • "The American Heart Association and American Academy of Pediatrics recommend that all children with complex congenital heart disease receive regular developmental monitoring."
Establish competence	• Awards and certifications listed • Scope and experience of program and providers emphasized	• "US News and World Report Best Children's Hospitals for Cardiology & Heart Surgery 2022 - 2023 logo. • American Nurses Credentialing Center Magnet Recognition logo. • "As a world leader in pediatric cardiac care." • "We're recognized across the country for establishing the first cardiac developmental follow-up program in the nation." • "The best care in the region for children with heart disease." • "Renowned experts." • "Revolutionary treatments." • "Team includes experts in physical and occupational therapy, speech therapy, a registered dietician, neuropsychologist, and pediatricians. A social worker is also available to support families."
Format: formal	• Third-person language • Passive voice • Font: serif, taller than wide • Few or no pictures or videos	• The heart center, "is dedicated to providing comprehensive care to all of our patients, including monitoring and treatment for any neurodevelopmental disabilities."

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Guide on the Side

Websites conforming to the guide on the side model addressed parents and other caregivers directly, using first- and second-person language, and described them as an active part of the team, collaborating with medical professionals to promote their child's success (Table 7). They used plain language and defined technical terminology or jargon as it occurred.

Table . Examples of features associated with guide on the side websites.

Function and format	Feature description	Examples
Convey information	• Centers on the child • Focuses on practical details: insurance coverage, finding parking, paperwork involved, duration of visits, clinic phone numbers, links to online appointment desks, email addresses for coordinators • Describes patient participation in research • Toll of CHD[a] on the whole family	• "Your child's first visit to the Cardiac Neurodevelopmental Clinic involves a thorough screening by providers from many different medical services. Each is an expert in a specific area of pediatric growth and development. This exam will take about 3 hours." • "Some families have found it helpful to bring snacks, drinks, toys or books to occupy their children during the appointment." • "Having a child with a serious heart condition…may leave you with a jumble of thoughts and feelings, including anger and grief….any and all thoughts or feelings you experience during this time are normal."
Connect with the reader: collaborative	• Pictures: candid pictures and videos of patients and providers • Images: simplified • Language: plain • Partnership: with families • Patient stories • Social media links • Requests for donations • Research: invitation to participate	• Image of a female health care provider in a medical setting sharing a teddy bear dressed in scrubs with a girl in a wheelchair. • Image of a female nurse providing hands-on care to a female infant following open-heart surgery in an intensive care setting. • "Neurodevelopment is a term that describes how our brains grow and form connections that direct our function and behaviors." • Links to Facebook (Meta), SnapChat (Meta), Twitter (formerly known as Twitter; X Corp), LinkedIn (Meta), Instagram (Meta), and YouTube (Google LLC) accounts. • "We'll be right by your side providing care." • "Together, we will decide if any other support or programs can help your child." • "If families and children are willing, voluntary participation in clinical research studies remains the cornerstone of the process."
Establish competence	• Patient testimonials	• "Website section: "Stories to Inspire." • Stories about children at home with their families.
Format	• First/second person language • Active voice • Font: sans-serif, wider than tall • Pictures or videos included	• "We look forward to partnering with you to help your child reach their fullest potential." • We will refer you to "specialists in your community who can help your baby reach key developmental milestones, such as walking and talking."

[a]CHD: congenital heart disease.

Visual and verbal storytelling provided another mechanism for demonstrating mutual respect and building personal connections. Candid images of providers interacting with children in both inpatient and outpatient settings powerfully illustrated the relationships that can develop between children and their medical team. They also highlighted the approachability of these providers. Written accounts of children's challenges and successes invited the reader to imagine what the best possible outcome for their child might look like and reminded them that they are not alone on their journey. Solicitations for donations or research participation similarly invited readers to partner with the institution to further the work of caring for children with CHD in developmentally appropriate ways.

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These features combined to create websites that were patient-centered, respected caregiver authority, and promoted collaboration in the care of children with CHD.

Degree of Conformity

Few websites reflected a single pattern; rather, combinations of various elements on each website conformed more or less closely to one or the other. About half (25/48, 52%) of program websites conformed most closely to a guide on the side model, 40% (19/48) of them reflected a sage on the stage model, and 8% (4/48) of them had overlapping features of both. Websites from larger programs (≥20 cardiologists) were statistically more likely to follow a guide on the side model (20/28 vs 5/16, χ^2_1=6.7, *P*=.01). No other program- or state-level characteristics correlated with a program conforming to one vs the other learning model.

Deductive Qualitative Analysis

Language Accessibility

All but two program websites were written above a 6th-grade reading level, with an average reading level between the 7th and 10th grade (Flesch-Kincaid mean 9.9, SD 2.4, Gunning Fog mean 9.0, SD 2.9, SMOG index mean 7.6, SD 1.9). Only two websites had information in a language other than English. Both offered information in Spanish.

Caregiver Utility

No more than one-third of websites included any one of the individual website features that most parents of children with CHD identified as useful. Only three program websites included all four features (Table 8).

Table . Inclusion of website features parents find useful.

Characteristic	Values, n (%)
A combination of words, pictures, and video	5 (10)
Descriptions of current research	16 (33)
Patient stories	16 (33)
Links to additional websites	16 (33)
All features	3 (6)

Transparency and Reliability

Of the 48 programs with codable data, the average JAMA benchmarks score was 1.5/4. Only four websites listed any authors, all of whom were authors for attached or embedded files, not for the main website. While nearly all programs included a copyright date on their website, only 1 program included information on when the website was most recently updated, with 3 other programs including the publication dates of attached or embedded files. A total of 15 programs cited sources for statements made on their website.

Discussion

Principal Findings

This study outlines the current paucity of information about neurodevelopment shared online by congenital cardiac surgical programs, identifies barriers to parents and other caregivers accessing that information, and identifies two website models corresponding to two models of adult learning.

Comparison With Prior Work

Overview

Despite the potential neurodevelopmental impacts of CHD, children's receipt of developmentally supportive care is inconsistent, and both short- and long-term outcomes remain variable [6,7,25-27]. Many factors associated with children receiving neurodevelopmental follow-up (hospital-initiated scheduling, antenatal diagnosis, and longer postoperative length of stay) suggest that caregiver understanding facilitates receipt of this care. Increased parent and caregiver education may improve follow-up with anticipated positive downstream impacts on patient outcomes [6]. Given caregivers' reliance on online sources of health information and their documented use of congenital cardiac surgical program websites, these sites may be one venue to provide such education.

Limited Searchable Information About Cardiac Neurodevelopment

Parents and other caregivers of children with CHD report that online resources help them better understand their child's diagnosis and the information from their child's health care team. However, approximately a quarter of parents note that information about their child's cardiac diagnosis is difficult to find online [11]. This study expands upon this parental observation, finding that only 39% (50/129) of congenital cardiac surgical programs in the United States include any information about one of the biggest contributors to these children's quality of life, the neurodevelopmental sequelae of CHD, on their institutional websites. Due to poor search engine optimization, this information was difficult to find, with only 38 programs having information that could be found by a search of their institutional website and 47 having information that could be found via a Google search.

This lack of searchable information is troubling, as more than a third (39%) of parents and other caregivers report using websites, not their child's health care provider, as their primary source of information about their child's heart condition [12]. These numbers are higher for caregivers of patients on public insurance (45%) and caregivers with less than a high school education (48%). These children from socioeconomically disadvantaged backgrounds, whose parents and other caregivers rely more on online sources of information, are the same children who experience higher rates of mortality, longer lengths

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of stay, and higher medical costs following cardiac surgery [25-27]. This suggests a disproportionate impact of this missing information on those children already at risk for worse outcomes.

Language and Literacy Barriers

Parents and other caregivers face additional challenges accessing information, even when it is included on congenital cardiac surgical program websites. In this study, all but two program websites were written above a 6th-grade reading level, with an average reading level between the 7th and 10th grade. In addition, despite nearly 20% of US adults being foreign-born, many of whom speak English as a second language, in this study, only two congenital cardiac surgical program websites offered information in a language other than English [28].

Lower socioeconomic status, lower educational attainment, and speaking English as a second language are all associated with both lower literacy and lower health literacy [28,29]. Lower health literacy is associated with worse health outcomes in both children and adults [30-32]. No studies have explored the relationship between parent or other caregiver health literacy and outcomes following childhood cardiac surgery. However, children who live in lower-income neighborhoods, further from a specialized congenital cardiac surgical center, and who have public (as opposed to private) insurance have higher rates of mortality, longer lengths of stay, and higher medical costs following cardiac surgery [25-27]. This suggests that health literacy may be one of the mediators of health outcomes in these children and supports the American Heart Association recommendation that all health care communication be "accessible at any level of health literacy" [33].

Many medical organizations offer guidance on health care communication, for both print and online materials. The Joint Commission recommends that health care organizations know "the language needs and literacy levels of the population and community served" [34]. Practical recommendations can be found in the Health Literacy Universal Precautions Toolkit, created by the Agency for Healthcare Research and Quality [35]. Recommendations include having staff members skilled in assessing, selecting, and creating written materials that are easy to act on; obtaining patient feedback on written materials; routinely assessing whether written materials are easy to understand; and providing materials in the preferred language of the patients cared for.

The use of features that parents and other caregivers of children with CHD have previously identified as useful may also improve comprehension for parents and other caregivers with limited health literacy. These features include using a combination of words, pictures, and videos; sharing patient stories; and sharing summaries of recent research [11]. These features were infrequently found on the websites reviewed in this study, with each feature being found on no more than a third of the websites visited, and only three websites including all four features.

Sage on the Stage and Guide on the Side

Most surprisingly, we identified two semantic website clusters corresponding to two established adult educational models: the sage on the stage and the guide on the side. Those websites adhering to the sage on the stage model emphasized institutional expertise, reflecting an authoritarian and patriarchal stance toward patients and their loved ones. Those conforming more closely to the guide on the side model emphasized parental partnership and centered the patient and family experience with humility and empathy, reflecting a family-centered model of care.

Educational researchers continue to debate the relative merits of each model in promoting adult learning [24,36]. It remains to be seen if one, the other, or a combination of both models is most palatable to the parents and other caregivers of children with CHD and whether such differences impact parental follow-up adherence, parental stress, and child developmental outcomes.

Recommendations for Congenital Cardiac Program Website Development

Congenital cardiac surgical program websites have the potential to improve parents' and other caregivers' understanding of their child's unique developmental and mental health needs. This study reveals a lack of relevant information on surgical program websites, poor search engine optimization, language barriers, and a lack of features preferred by parents. To improve website effectiveness, there are several steps website developers can take (Textbox 1). These include the following: (1) including content about the developmental and mental health impacts of CHD; (2) performing internal and external search engine optimization; (3) removing language barriers by limiting jargon, using plain language, and providing information in their patients' preferred languages; (4) including more features that caregivers find useful; and (5) including links to local resources. These simple changes could increase the impact of existing websites by helping caregivers recognize the anticipated neurodevelopmental sequelae of their child's CHD and access services to support their child's development.

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Textbox 1. Recommendations for website developers.

1. Include information about neurodevelopment.
2. Perform internal and external search engine optimization (use metadata tags such as “cardiac neurodevelopment,” “development,” “ADHD,” and “neuropsychology”).
3. Write website content at a level that parents and patients can understand (sixth-grade reading level or below with active voice, no jargon, short paragraphs, and simple illustrations).
4. Provide information in the languages spoken by patients and their caregivers.
5. Include website features that parents of children with CHD find useful (a combination of words, pictures, and videos; descriptions of current research; patient stories; and links to additional resources).
6. Include links to local, community-based resources.

Additional improvement could be realized by institutional application of the principles underpinning the guide on the side model—empathy, humility, and collaboration—through the process of human-centered design [37]. By seeking out and incorporating parent and other caregiver perspectives at all stages of website development, institutions could identify the preferred model of content delivery (sage on the stage vs guide on the side) for patients and families in their catchment area and develop strategies for cognitive alignment. Centering the parents and other caregivers of children with CHD will allow for optimized delivery of accessible, impactful, and usable information.

Limitations

There were several methodological limitations. While this study intended to include a total population sample of all programs performing congenital cardiac surgery in the United States, 1 surgical program was not included in the Congenital Cardiology Today directory for 2021 - 2022, and data for 1 program were lost during the archival process. While hospital catchment areas vary in size, from portions of a city to multiple states, this study compared congenital cardiac surgical programs to state-level sociodemographic data and may have missed local or regional factors. In addition, STS (Society of Thoracic Surgeons) Congenital Cardiac Public Reporting Data from 2015 - 2018 was used instead of 2019 - 2023 data. More recent data encompasses surgical volumes and outcomes during the height of the COVID-19 pandemic, which varied substantially from surgical program operations both before and after the pandemic, which would have skewed the data [38,39].

All web searches were conducted in English without the use of incognito mode, or clearance of caches and cookies, potentially influencing search results and leading to either missed or enhanced identification of neurodevelopmental information due to the heavy personalization of search engine algorithms based on browsing history. While many congenital cardiac surgical programs have a social media presence, this study did not evaluate their social media. This was an intentional choice, as more caregivers of children with CHD report using websites than social media (72% - 92% vs 20%, respectively) to learn about their child’s health and development [11,12]. Finally, the choice of inductive content analysis facilitated analysis of what was present on program websites, but not an analysis of potentially useful features that were absent, such as links to or descriptions of how to access local, community-based early intervention programs.

Next Steps

This analysis of information about neurodevelopment on the websites of congenital cardiac surgical programs invites future inquiry into both the topic at hand and the broader application of our findings to other pediatric medical subspecialties. First, what are parents’ and other caregivers’ impressions of available information, and how does the way in which the information is presented (guide on the side vs sage on the stage models) impact follow-up adherence, caregiver stress, and children’s outcomes? Second, how does health literacy mediate disparities in health and neurodevelopmental outcomes in children with CHD? Third, what is the quality of other online sources of information (nonprofit and governmental websites, social media sites, and parent support groups) about the neurodevelopmental outcomes of children with CHD? Finally, do these findings generalize to other areas of pediatric medical subspecialty care, and can we leverage our presentation of online information to improve children’s outcomes across multiple domains?

Conclusions

CHD is a complex, lifelong condition that creates ongoing informational needs for impacted patients and their parents and other caregivers. Neurodevelopmental impairments are the number one morbidity of CHD. Public-facing information about cardiac neurodevelopment on the websites of congenital cardiac surgical programs is sparse, with high-volume surgical programs being the most likely to have any information at all. For websites that do include this information, linguistic factors and poor search engine optimization create additional barriers for parents and other caregivers to access this information. Websites reflect two models of adult learning: the guide on the side, which emphasizes caregivers as key stakeholders and partners in their children’s development, and the sage on the stage, which emphasizes the value of the services and expertise offered by the sponsoring institution. Future studies should evaluate which, if either, model is preferred by caregivers or more strongly influences caregiver behaviors and patient outcomes. This would allow for the development of content that promotes caregivers’ pursuit of optimal neurodevelopmental supports for their children and may have application to other areas of pediatric medical subspecialty care as well.

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Authors' Contributions

JBA conceptualized and designed the study, coordinated and supervised data collection, performed qualitative content analysis, drafted the initial manuscript, and critically reviewed and revised this paper. GC and DC collected data, carried out the initial analyses, performed qualitative content analysis, and critically reviewed and revised this paper. XZ carried out statistical analyses and critically reviewed and revised this paper. KRO conceptualized and designed this study, performed qualitative content analysis, and critically reviewed and revised this paper for important intellectual content. PF conceptualized this study and critically reviewed and revised this paper for important intellectual content.
KRO and PF are co-senior authors.

Conflicts of Interest

None declared.

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Abbreviations

CHD: congenital heart disease
JAMA : Journal of the American Medical Association
SMOG : Simplified Measure of Gobbledygook
STS: Society of Thoracic Surgeons

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Translation and Validation of the Japanese Version of the University of Washington Caregiver Benefit Scale and the Perception of Benefit-Finding by Caregivers of Children With Spina Bifida and Related Factors: Mixed Methods Research and Comparative Analysis

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Abstract

Background: Spina bifida (SB) is a congenital condition that requires long-term multidisciplinary medical collaboration for treatment. Previous research has primarily focused on the negative impacts experienced by caregivers of children with SB. However, with the development of positive psychology, the concept of benefit-finding (BF) has been explored in the context of caregivers of children with various chronic illnesses. Nonetheless, in Japan, BF among caregivers of children with SB remains unexplored, and no appropriate measurement tool has been developed for this population.

Objective: This study aimed to translate and validate the Japanese version of the University of Washington Caregiver Benefit Scale (UW-CBS) based on caregivers of children with SB and to examine the characteristics of BF in these caregivers. A comparative analysis with caregivers of able-bodied children was also conducted to elucidate the parenting stress and social support experienced by families rearing children with SB.

Methods: This 2-part study was carried out from January 2024 to December 2024. In Study 1, the UW-CBS was translated, then face validity was examined through a pretest (n=6) using cognitive interviews. In the main survey, construct validity, known-groups validity, and retest reliability were evaluated (n=60). In Study 2, the characteristics of BF of caregivers of children with SB were analyzed using data from the main survey. Parents of able-bodied children (n=66) completed the same questionnaire. Parenting stress, BF, and social support scores were then compared between caregivers of children with SB and the parents of able-bodied children.

Results: In Study 1, the reliability and validity of the UW-CBS were examined. Internal consistency was high (Cronbach α=0.92), while test-retest reliability had an intraclass correlation coefficient of 0.62 (*P*=.051). In Study 2, caregivers who had a partner (*P*=.009) and those who were rearing both a child with SB and a sibling reported higher levels of BF (*P*=.02). Compared with families rearing able-bodied children, no significant differences emerged in BF or parenting stress, but the level of social support was significantly higher in families of children with SB (*P*=.005).

Conclusions: This study demonstrated the reliability and validity of the Japanese version of the UW-CBS in families rearing children with SB. For caregivers of children with SB, assistance from other family members or shared childcare responsibilities may facilitate positive adjustment. Moreover, the higher level of social support received by caregivers of children with SB may mitigate their parenting stress and foster their perception of benefits.

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KEYWORDS

spina bifida; benefit finding; caregivers; parenting stress; social support

Introduction

Spina bifida (SB) is a congenital disorder caused by incomplete closure of the neural tube that is generally accompanied by a variety of disorders, such as hydrocephalus, cognitive difficulties, bladder and bowel incontinence, and ambulatory dysfunction [1]. The management of SB requires not only multidisciplinary collaboration but also individualized care from caregivers because its clinical manifestations vary widely, with

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severity primarily determined by the level of spinal cord lesions. Caregivers of children with SB often face a range of challenges, having to balance the demands of long-term medical care, such as urinary and fecal incontinence [2], while also focusing on their child's education and future [3].

Previous studies have primarily focused on the negative impacts of rearing children with SB, such as parenting stress [4,5]. A meta-analysis showed that families of children with SB and other chronic illnesses face the highest parental stress levels, highlighting the need for interventions aimed at improving marital relationships, enhancing social support, and equipping parents with strategies to manage parenting stress [6]. Compared with families with typically developing children, families of children with SB report higher levels of parenting stress related to managing children's behavior, reflecting the challenges they face in addressing complex caregiving demands [7]. Further research has shown differences in stress sources between parents of children with SB: Fathers experience greater stress when dealing with children's maladaptive behaviors and insufficient social support, whereas mothers' stress is more closely related to the medical characteristics and dysfunction of the children [8]. Age also emerges as a significant factor affecting maternal parenting stress because older mothers report higher stress levels [9,10]. Among the medical factors, Kanaheswari et al [11] identified clean intermittent catheterization as the only significant contributor to maternal parenting stress in families of children with SB. Moreover, ongoing issues such as limited mobility and bladder and bowel dysfunction in school-aged children also contribute to persistent stress among parents of children with SB [12].

In the process of coping with parenting stress among caregivers of children with SB, social support may play a buffering role. Studies have shown that higher satisfaction with social support is closely associated with greater positive emotional adjustment in mothers [13]. Greater support from the family is also strongly linked to better physical health in mothers [14]. Furthermore, greater levels of social support are strongly related to fewer behavioral problems in children [8,15,16]. Notably, Feldman et al [16] demonstrated that social support plays a crucial moderating role between parenting stress and child adaptation. The aforementioned studies demonstrate that social support plays a critical role in multiple aspects of rearing children with SB. Meanwhile, further research underscores that, in pediatric rehabilitation settings, the importance of social support for families of children with SB cannot be overlooked [17]. In addition to mitigating negative emotions, social support contributes to the positive adjustment of caregivers. A study focused on caregivers of children with developmental disorders suggested that social support facilitates cognitive adaptation, thereby promoting positive emotional changes in caregivers [18].

Although caregiving challenges are substantial in families of children with SB, the demands associated with caregiving roles may create opportunities for personal growth and positive adaptation. Benefit-finding (BF) refers to the recognition of positive life changes that emerge from the process of coping with difficult life events [19]. Research on BF often focuses on the patients themselves [20-22], but caregivers of patients also experience BF. An increasing number of studies have reported positive changes, such as BF in caregivers of children with chronic illnesses [23-25]. In a qualitative study involving nuclear family members of children with chronic food hypersensitivity, a hierarchical BF process model was constructed. The findings suggested that parental modeling and reinforcement facilitated the sharing of positive experiences among family members [25]. This process highlights how BF emerges within families including children with chronic illness as a dynamic mechanism, where shared positive experiences not only strengthen individuals but also contribute to the overall harmony of the family unit.

In the context of SB, a study focused on young adults with SB found that the most prominent aspects of BF they experienced were related to personal strengths, interpersonal relationships, and life philosophy [26]. In addition, Kritikos et al [27] developed a BF scale specifically for individuals with SB based on a sample of 20 adolescents and young adults with SB. Although caregivers of children with SB are likely to experience more challenges, their special caregiving roles may also foster opportunities for positive psychological adaptation. However, research on BF by parents of children with SB remains limited, and the experiences of these families in different cultural contexts, such as Japan, have yet to be fully explored. Whereas the study by Kojo and Fukumaru [28] found that parents of children with SB tend to report high levels of depression, there remains a notable gap in understanding other characteristics, such as BF, parenting stress, and social support, of families of children with SB in the Japanese context.

In Japan, the existing caregivers' BF scale was tailored specifically to caregivers of children with developmental disabilities [29], leaving a gap in measurement tools that adequately capture the BF experiences of caregivers of children with SB. The University of Washington Caregiver Benefit Scale (UW-CBS) developed by Amtmann et al [30] was designed to measure BF by caregivers regardless of whether their children have a medical condition. The flexible design of the UW-CBS makes it suitable for assessing BF in a variety of caregiving contexts.

Overall, this study sought to measure BF to explore the positive changes experienced by caregivers of children with SB. However, because no suitable scale exists in the Japanese context, the first objective of this research was to translate the UW-CBS into Japanese and evaluate its reliability and validity within the Japanese context. As little research in the Japanese context has focused on parenting stress, BF, and social support among caregivers of children with SB, the second goal of this study was to examine the current status of parenting stress, social support, and BF of caregivers of children with SB and clarify the unique characteristics of families of children with SB by including parents of able-bodied children as a comparison group.

Methods

This research consisted of 2 parts and was carried out from January 2024 to December 2024.

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Study 1

Aim

Study 1 aimed to translate the UW-CBS [30] into Japanese and evaluate its reliability and validity using an anonymous cross-sectional questionnaire survey of caregivers of children with SB. To ensure the cultural equivalence and face validity of the UW-CBS, a small-scale pretest incorporating cognitive interviews was conducted, after which, the UW-CBS was revised for application in the main survey. Based on the Consensus-Based Standards for the Selection of Health Measurement Instruments (COSMIN) risk of bias checklist [31], an adequate sample size for cognitive interviews is 4 to 6 participants, and more than 30 participants is considered adequate for a quantitative main study.

Preparation

The International Society for Pharmacoeconomics and Outcomes Research [32] Good Practice for the Translation and Cultural Adaptation Process was adopted as the methodological framework. With the consent of the original author, the target population was defined as caregivers of children with SB. The research team consisted of 2 native Japanese speakers fluent in English with extensive experience in nursing research, together with a bilingual researcher involved in the study.

Forward Translation and Reconciliation

With the consent of the original author, 2 native Japanese speakers (TK and AY) independently translated the UW-CBS scale into Japanese. Discrepancies were discussed within the research team, and consensus was reached on the overall translation, with particular attention paid to the Japanese expressions of “feel closer” and “accepting person” and the use of sentence connectors to ensure natural and conceptual clarity. This reconciliation process resulted in Version 1, which was subsequently back-translated into English by the third bilingual researcher (XC). The back translation demonstrated conceptual equivalence with the original version.

Pretest and Cognitive Debriefing

Adult caregivers of children with SB were recruited using snowball sampling. After recruitment, questionnaires were mailed to the participating caregivers in advance, and subsequently, cognitive interviews were conducted with 6 caregivers via a videoconferencing application (Zoom Video Communications) or telephone. During this process, the time required to complete Version 1 of the UW-CBS was recorded. Using a verbal probing approach, caregivers were asked to comment on response ease, item clarity, discomfort in answering, relevance, and alignment with their experiences [33].

To explore caregivers’ BF experiences further, an open-ended question was included in the questionnaire, followed by approximately 30-minute interviews based on the caregivers’ responses. All interviews were audio-recorded and transcribed verbatim.

During the cognitive interviews, the caregivers indicated that the referent of “other person” was ambiguous. To address this issue, clarification was sought from the original author to ensure that the intended meaning was preserved in the translated version. Based on the feedback obtained, the research team discussed and refined Version 1 of the UW-CBS, resulting in Version 2.

Responses to the open-ended questions were qualitatively coded and categorized by one researcher (XC), with subsequent review and agreement within the research team.

Back Translation, Review, and Proofreading

Following an additional review by the research team to ensure wording and grammatical accuracy, back translation was performed by Editage, an independent professional translation service. Subsequently, the back translation was submitted to the original author for verification and formal approval.

Main Survey and Retest

Using Version 2 of the UW-CBS, the main survey was subsequently conducted (n=60). Caregivers of children with SB aged younger than 16 years were recruited through two methods. Caregivers undergoing treatment for depression or managing other children’s intensive care conditions were excluded. The caregivers’ responses were collected through both paper-based and online (Research Electronic Data Capture [REDcap] platform) methods. Among the caregivers of children with SB recruited through snowball sampling, 8 agreed to participate in the retest. The retest was conducted 2 weeks to 3 weeks after completion of the initial questionnaire and yielded 7 valid responses.

Questionnaire: Pretest

UW-CBS

The UW-CBS [30] is a publicly available, psychometrically sound instrument designed to measure the positive impacts of caregiving on adults. The UW-CBS is an item response theory–based tool composed of 13 items that evaluate the perceived benefits of caregiving, such as appreciation of life, discovering new strengths, and personal growth. Responses are rated from 1 (“Not at all”) to 5 (“Very much”), and scores are converted into an item response theory–based T-score to reflect BF levels. The UW-CBS has demonstrated good validity and reliability, with high test-retest reliability (intraclass correlation coefficient [ICC] >0.92) and strong internal consistency (Cronbach α=0.89). Moreover, to facilitate its use in diverse populations, the UW-CBS has been translated into Spanish, German, French, and Italian [34], demonstrating its potential as an internationally applicable tool for measuring the positive aspects of caregiving.

Open-Ended Responses

To investigate whether caregivers of children with SB experience unique aspects of BF, the following open-ended question was included: “While rearing a child with spina bifida, have you noticed any other aspects of your life where you have experienced positive changes?”

Parenting Stress Index-Short Form

The Japanese version of the Parenting Stress Index-Short Form (PSI-SF) [35], originally developed by Abidin as the Parenting Stress Index (PSI) [36], was used to assess parenting stress. The

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PSI-SF consists of 19 items rated on a 5-point scale and measuring 2 subdomains: parent-related (10 items) and child characteristic-related (9 items) stress scores. Responses range from 1 (“Not at all”) to 5 (“Exactly so”), with higher scores indicating higher levels of parenting stress. The PSI-SF has also been specifically adapted for use with Japanese parents to ensure cultural relevance.

Japanese Short Form of the Multidimensional Scale of Perceived Social Support

The Japanese short form of the Multidimensional Scale of Perceived Social Support (JMSPSS) [37] is derived from the original scale developed by Zimet et al [38], which uses a 7-point Likert-type scale ranging from 1 (“Not at all”) to 7 (“Very much”), with higher scores indicating greater perceived social support. The JMSPSS has a 3-factor structure: family support, significant other support, and friend support. The overall Cronbach α coefficient for reliability is 0.91, indicating good internal consistency.

Tachikawa Resilience Scale

The Tachikawa Resilience Scale (TRS) [39] is a 10-item self-reported measure designed to assess the resilience of Japanese individuals. In this study, the TRS was used to assess the construct validity of the UW-CBS. The TRS uses a 7-point Likert-type scale, ranging from 1 (“Not at all applicable”) to 7 (“Very applicable”), with higher scores indicating greater resilience. The Cronbach α coefficient of the TRS is 0.90, indicating good internal consistency.

Demographic Characteristics

Child-related items included age, sex, bladder condition (International Consultation on Incontinence Questionnaire-Urinary Incontinence Short Form, urinary incontinence, clean intermittent catheterization use and independence), bowel condition (bowel management and method, bowel movement independence, fecal incontinence, bowel management caregiver), mobility status, and shunt utilization of the child with SB; total number of children; and presence of significant illnesses in other children.

Caregiver-related items included age, relationship to the child, educational background, marital status, current mental illness, and self-reported life satisfaction.

Data Analysis

The qualitative data from the pretest were transcribed verbatim, and interview data on BF experiences were analyzed using qualitative descriptive induction [40], which involves coding and categorization.

For the main survey, quantitative data were analyzed using SPSS for Windows (version 29; IBM Corp), with a significance level of $P<.05$. Descriptive statistics were used to summarize the demographic characteristics and the results from the administered scales. In this study, differential item functioning (DIF) was examined across gender and age using ordinal logistic regression, with McFadden $R^2<0.02$ as the criterion [31]. Reliability was evaluated by calculating the Cronbach α coefficient for internal consistency and using the 2-way random effects (2,1) ICC for test-retest reliability. Construct validity was examined by analyzing the correlation between the UW-CBS and TRS. Given the conceptual relatedness between BF and resilience and prior evidence reported in the original study ($r=0.28$) [30], we hypothesized that the UW-CBS would be weakly positively correlated with the TRS. Known-groups validity was also evaluated. Caregivers of children with more severe medical conditions were hypothesized to have higher BF based on prior evidence that posttraumatic growth is higher in more severe and life-threatening medical contexts [41]. Similarly, caregivers with a spouse were hypothesized to have higher BF based on evidence linking marital adjustment and spousal support with greater resilience [42] and psychological health [43] among caregivers of children with chronic developmental conditions.

Study 2

Aim

Study 2 sought to gain a deeper understanding of caregivers rearing children with SB in the main survey by including a control group consisting of the parents of able-bodied children. In the comparison, caregivers of children with SB constituted the SB group, and parents of able-bodied children constituted the able-bodied group. An anonymous cross-sectional survey was conducted to assess BF, parenting stress, and social support, with a subsequent analysis to compare differences between the two caregiver groups.

Comparison Between the SB Group and Able-Bodied Group

The members of the SB group were the participants in the main survey of Study 1 (n=60). Parents of able-bodied children (n=67) were recruited using the following 2 approaches: (1) a family-supporting specified nonprofit corporation (NPO) and (2) a participant recruitment company. The exclusion criteria included caregivers who were receiving treatment for depression or caring for their own children with conditions requiring intensive care. Parents recruited from the NPO responded to the questionnaire through REDcap.

Questionnaire

The same questionnaire used for the main survey of Study 1 was used. Regarding the UW-CBS, the Cronbach α coefficient in the able-bodied group was 0.96.

Data Analysis

We used 1-way ANOVA, independent samples *t* tests, Mann-Whitney *U* tests, and χ^2 tests to measure the characteristics of caregivers of children with SB and the differences between the SB and able-bodied groups. Cohen *d* (≥0.8 for a large effect) indicated the effect size.

Ethical Considerations

This study was approved by the Osaka University Hospital Ethics Committee (approval number: 23426‐4). Prior to participation, all participants received an information sheet explaining the purpose and procedures of the study, and informed consent was obtained through the consent confirmation section of the questionnaire. Participation was voluntary, and participants could withdraw from the study at any time without

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penalty. The questionnaire survey was conducted anonymously, and no personally identifiable information was collected. Data were managed using identification numbers and stored securely in locked cabinets and password-protected computers accessible only to the research team. Participants received a ¥500 (US $3.17) gift card as appreciation for their participation.

Results

Study 1

Pretest

Participants

In the pretest, 9 caregivers of children with SB were recruited; however, 1 was lost to follow-up, and 2 were unable to participate in the interview, resulting in a final sample of 6 caregivers. The 6 caregivers took approximately 2 minutes to complete the UW-CBS.

Validity Assessment

During the face validity cognitive interview, although a few concerns were raised about items 1, 2, 3, 5, and 12, the majority of caregivers indicated that these items were clear and easy to understand. For example, regarding the item "Are you a better advocate for your child/children because of caregiving?," the caregivers mentioned that they felt confident in doing well when their child was younger. However, now that their child has his/her own opinions, they were uncertain about whether they fully and accurately convey their child's intentions. For item 10, which used the Japanese translation of the term "accepting person," most caregivers found the translation understandable but remarked that its phrasing felt slightly awkward. Thus, item 10, "accepting person," was revised to more natural Japanese phrasing without altering its meaning. Overall, the caregivers indicated that most items were clearly expressed and successfully conveyed the intended meaning.

BF Experiences

Interviews with open-ended questions were conducted to explore the BF experiences that emerged among caregivers in the process of rearing their children with SB. The results identified several key aspects of BF: psychological and emotional growth, improvement of knowledge and skills, expansion of social support networks, changes in perspective, and planning for the future.

Psychological and Emotional Growth

For instance, caregivers initially used blogs as a way to gather information about SB and connect with other caregivers in similar situations. Over time, their focus shifted from seeking support to providing it:

> *By starting the blog, I felt that I was able to connect with other children who have the same illness, and that it might also be helpful for children who will be born in the future.* [Caregiver C]

Improvement of Knowledge and Skills

Caregivers not only actively sought information about SB itself but also developed an understanding of how to use assistive devices commonly needed by children with SB, such as wheelchairs and lower-limb orthoses. In addition, caregivers' curiosity expanded beyond SB, leading them to explore information about children with other chronic conditions:

> *Information about leg braces—such as the different types, their names, how to use them, and why they are worn…* [Caregiver E]

Expansion of Social Support Networks

Caregivers expanded their social support networks by connecting with other parents of children with SB or chronic illnesses through activities such as their children's participation in sports or blogging. These interactions provided some level of support and practical insights, which helped them navigate the challenges of caregiving more effectively:

> *We talk about things like different types of wheelchairs. Even when there isn't a specific problem to consult about, we stay connected on a regular basis.* [Caregiver C]

Changes in Perspective

Rearing a child with SB gradually led caregivers to adopt new perspectives in certain areas. For example, caregivers began to see things from the perspective of disabilities; they stated that they focus on celebrating small daily achievements rather than comparing their child with others, emphasizing a mindset of progress and acceptance:

> *It made me realize that there are so many different conditions out there, and I began to pay more attention to that.* [Caregiver A]

Planning for the Future

Due to the unique needs of children with SB, caregivers found it necessary to make more detailed plans for the future, particularly regarding schooling and other key aspects of their child's development:

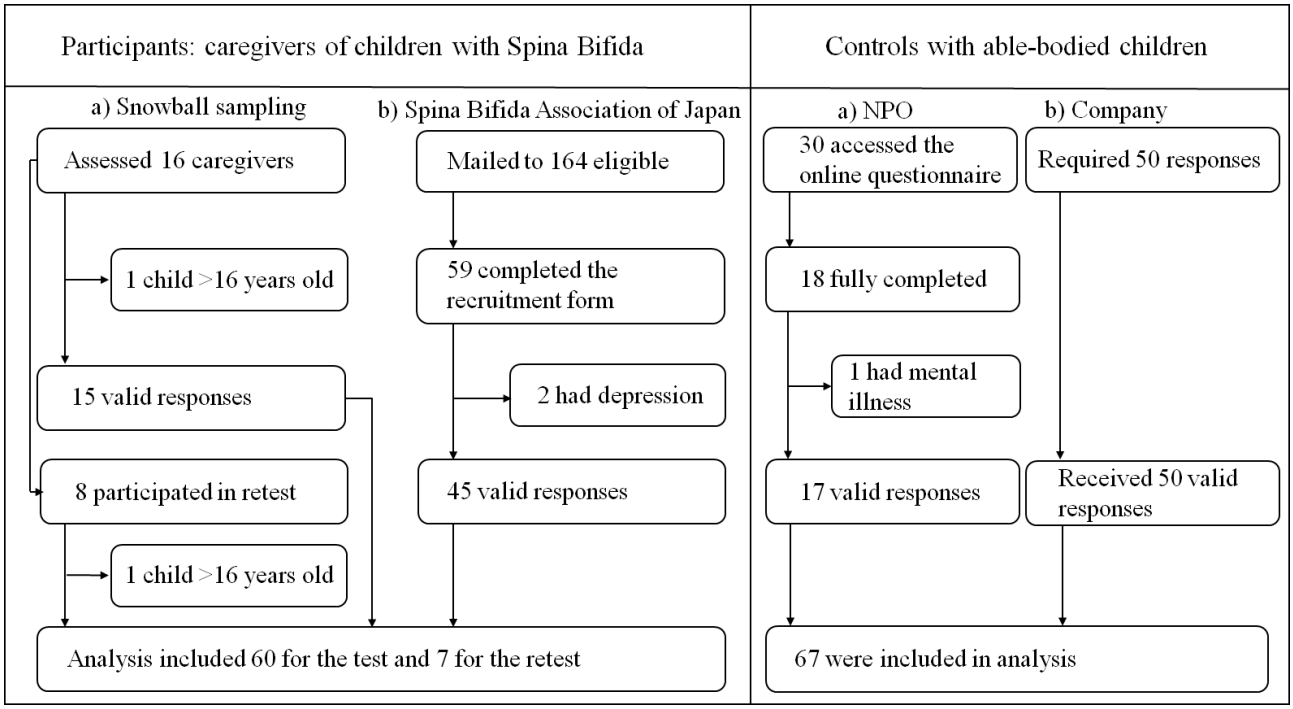
> *We had submitted a request, and arrangements were made so that an elevator would be properly installed in time for the child's school enrollment.* [Caregiver A]

Main Survey

Through snowball sampling, 16 caregivers of children with SB were recruited, 8 of whom participated in the retest of the UW-CBS, as shown in Figure 1. Two responses (1 main survey and 1 retest) were excluded because the child was older than 16 years.

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Figure 1. Recruitment processes in this study. NPO: specified nonprofit corporation.



The study introduction was sent by mail to 164 members of the Spina Bifida Association of Japan. Among these, 45 caregivers completed the questionnaire online (2 reported depression), while 2 responded via mail. The respondents' demographic characteristics are summarized in Table 1. DIF was assessed across gender and age using ordinal logistic regression analysis, and all McFadden R^2 values were <0.012.

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Table . Demographic characteristics of caregivers (n=60) and demographic and clinical characteristics of children with spina bifida.

Characteristic	Results, n	UW-CBS[a] score, mean
Caregivers' age (years)	44.18[b]	N/A[c]
Relationship to child		
Mother	48	43.04
Father	12	43.83
Caregivers' marital status		
Married	53	44.43
Divorced	6	34
Never married	1	33
Caregivers' educational level		
High school or less	12	39.42
Vocational school or junior college	18	43.28
College or more	30	44.67
Caregivers' life satisfaction		
Satisfied	13	46.77
Somewhat satisfied	35	43.31
Somewhat dissatisfied	9	38.56
Dissatisfied	3	40.33
Childs' age (years)	10.72[b]	N/A
Childs' sex		
Male	28	43.71
Female	32	42.75
Total number of children		
1	15	37.80
≥2	45	45
Ventriculoperitoneal shunt		
Yes	43	44.79
No	17	39.18
Clean intermittent catheterization (independence)		
Yes (independence)	38	42.45
No	15	45.73
Social urinary continence (≥4-hour dry period)		
Yes	27	43.56
No	33	42.91
Bowel management		
Yes	54	43.93
Person responsible for bowel management		
Child	14	42.57
Family and/or helper	40	44.40
No one	6	36.67
Mobility		
Community ambulator	36	43.19

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Characteristic	Results, n	UW-CBS[a] score, mean
Nonfunctional ambulator	3	49.33
Nonambulator	21	42.33

[a]UW-CBS: University of Washington Caregiver Benefit Scale.

[b]Mean.

[c]N/A: not applicable.

Distribution

The analysis resulted in no ceiling nor floor effects across the 13 items (Table 2).

Table . Ceiling and floor effects of the overall University of Washington Caregiver Benefit Scale (UW-CBS) scores and for each of the 13 items as well as item-total correlations reported by caregivers of children with spina bifida (n=60).

Item content	UW-CBS score		Ceiling effect	Floor effect	Item-total correlation, *r*
	Mean (SD)	Median (range)			
Appreciate importance	3.60 (0.96)	4.00 (4.00)	4.56	2.64	0.59
Finding new strengths	3.42 (1.01)	3.00 (4.00)	4.43	2.41	0.43
Better advocate for children	3.10 (0.88)	3.00 (4.00)	3.98	2.22	0.50
Better person	2.92 (1.09)	3.00 (4.00)	4.01	1.83	0.67
Put life in perspective	3.22 (1.03)	3.00 (4.00)	4.25	2.19	0.66
More patient	3.60 (1.18)	4.00 (4.00)	4.78	2.42	0.67
Stronger person	3.68 (1.23)	4.00 (4.00)	4.91	2.45	0.72
Gained confidence	2.83 (1.22)	3.00 (4.00)	4.05	1.61	0.73
Add meaning to life	3.73 (1.13)	4.00 (4.00)	4.86	2.60	0.76
More accepting person	3.32 (1.16)	3.00 (4.00)	4.48	2.16	0.75
More caring	3.67 (1.12)	4.00 (4.00)	4.79	2.56	0.79
Closer to other adults	3.25 (0.93)	3.00 (4.00)	4.18	2.32	0.68
Closer to partner	2.88 (1.43)	3.00 (5.00)	4.31	1.45	0.58
Total scores on the UW-CBS	43.20 (10.31)	44.00 (45.00)	53.51	32.90	N/A[a]

[a]Not applicable.

Reliability

The Cronbach α coefficient for the UW-CBS was 0.92. A total of 7 participants completed the retest, and the ICC yielded a result of 0.62 (*P*=.051).

Validity

The correlation between the TRS and UW-CBS was *r*=0.30 (*P*=.02), aligning with the hypothesis. Known-groups validity was examined by comparing UW-CBS total scores across groups defined by children's medical severity and caregivers' marital status. In both comparisons, the groups hypothesized to have greater BF showed higher UW-CBS total scores (Table 3).

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Table . Independent samples *t* test and Mann-Whitney *U* test for known-groups validity.

Characteristic	Sample size, n	UW-CBS[a] score, mean	Statistical test result	*P* value
Ventriculoperitoneal shunt			230[b]	.03
Yes	43	44.79		
No	17	39.18		
Caregivers' relationship status			2.68 (58)[c]	.009
With a partner	53	44.43		
Without a partner	7	33.86		

[a]UW-CBS: University of Washington Caregiver Benefit Scale.

[b]Mann-Whitney *U* test.

[c]*t* test (*df*).

Study 2

Characteristics of BF in Families of Children With SB

The UW-CBS scores for each characteristic are presented in Table 1. Two results with significant differences were identified: Single mothers reported lower UW-CBS scores (t_{58}=2.68, *P*=.009; *d*=0.95), and caregivers rearing only children with SB reported lower UW-CBS scores (t_{58}=2.40, *P*=.02; *d*=0.75). The results are shown in Table 4.

Table . Characteristics of caregivers (n=60) of children with spina bifida with regard to University of Washington Caregiver Benefit Scale (UW-CBS) scores.

Characteristic	Sample size, n	UW-CBS score, mean (SD)	*t* value (*df*)	*P* value	Cohen *d*
Total number of children			2.40 (58)	.02	0.75
1	15	37.80 (9.18)			
≥2	45	45.00 (10.12)			
Caregivers' relationship status			2.68 (58)	.009	0.95
With a partner	53	44.43 (9.45)			
Without a partner	7	33.86 (12.48)			

Correlations Between BF, Parenting Stress, and Social Support Among Families of Children With SB

The JMSPSS had a significant positive correlation with the UW-CBS (*r*=0.30, *P*=.02) and a significant negative correlation with the PSI-SF (*r*=–0.47, *P*<.001). Although the correlation between the UW-CBS and the PSI-SF was not statistically significant, a negative association was observed (*r*=–0.22, *P*=.90).

Comparison Between the SB and Able-Bodied Groups

Comparison of Demographic Characteristics

For the able-bodied group, a total of 18 participants completed the questionnaire through recruitment by the NPO. One answer was excluded because the respondent reported a mental illness but declined to disclose the specific diagnosis. In addition, 50 parents of able-bodied children were recruited through the company. To ensure comparability, the characteristics of the SB and able-bodied groups were compared, but no significant differences were found.

Comparison of Scales

The results of the comparison of each scale between the groups are shown in Table 5. The analysis comparing the 2 groups revealed no significant difference in UW-CBS nor PSI-SF scores, but the SB group had higher JMSPSS scores (*U*=1428.50, *P*=.005).

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Table . Results regarding the distribution of and the Mann-Whitney *U* or independent samples *t* tests of the University of Washington Caregiver Benefit Scale (UW-CBS), Parenting Stress Index-Short Form (PSI-SF), and Japanese short form of the Multidimensional Scale of Perceived Social Support (JMSPSS) scores between the spina bifida (SB; n=60) and able-bodied (n=67) groups.

Scale	SB group		Able-bodied group		Mean difference	
	Mean	Median	Mean	Median	Statistical test result	*P* value
UW-CBS	43.20	44.00	41.25	42.00	1885.50[a]	.55
PSI-SF total scores	43.68	42.50	43.94	45.00	0.12 (125)[b]	.90
Child characteristic-related stress scores[c]	21.58	22.00	20.46	21.00	1726.50[a]	.17
Parent-related stress scores[c]	22.10	22.00	23.48	23.00	1.11 (125)[b]	.27
JMSPSS	65.23	66.00	57.82	60.00	1428.50[a]	.005

[a]Mann-Whitney *U* test.

[b]Independent *t* test (*df*).

[c]Subscale of the PSI-SF.

Discussion

Study 1

The aim of Study 1 was to translate the UW-CBS into Japanese and validate its reliability and validity through a pretest and main survey. Because the UW-CBS was not developed in an Asian context, cognitive interviews were conducted as a critical step to address potential cultural differences in the process of scale adaptation. Overall, nearly all caregivers were able to understand the meaning of all items and found most of them to be clearly expressed. However, caregivers also experienced some hesitation and confusion while responding to certain items. Similar feedback was also provided when the UW-CBS was translated into European languages [34], suggesting that, although the scale is broadly applicable, some conceptual nuances require careful adaptation.

Regarding reliability, internal consistency was high (Cronbach α=0.92), but test-retest reliability yielded an ICC of 0.62 (*P*=.051), which did not reach the level of statistical significance. This marginal result likely reflects a lack of statistical power due to the small sample size (n=7) rather than the inherent instability of the scale. However, given that the original version demonstrated robust stability and our qualitative findings confirmed the items' conceptual clarity, these results provide a preliminary indication of the scale's reliability.

In adapting the UW-CBS to Europe, the mean score (44.50) was lower than that in the United States (47.90) [30]. In Japan, this study yielded an even lower mean score (43.20). In addition to the issues caregivers encountered while responding, this phenomenon may also be attributed to the cultural differences between Asian and Western contexts. Compared with those in the United States, Japanese adults report higher levels of pessimism and are less positive [44]. In addition, adults in the United States perceive self-esteem as both desirable and consequential, whereas Japanese people view self-esteem as desirable but not consequential [45]. Japanese respondents tend to use rating scales more moderately [46], which may also lead to lower observed mean scores. These differences in cultural perspectives may partially explain why the UW-CBS scores observed in this study were lower in the Japanese context, as a more pessimistic outlook and less emphasis on self-esteem may reduce the likelihood of identifying benefits in caregiving situations. In addition, interviews with caregivers about their BF experiences while rearing children with SB revealed several recurring themes, including psychological and emotional growth, improved knowledge and skills, expanded social support networks, changes in perspective, and planning for the future. The results of the semistructured interviews on BF indicated that experiences related to BF exist within caregivers of children with SB, and the themes appear to align with the content of most items on the UW-CBS, suggesting a potential connection between the scale's construction and the lived experiences of the target population.

In the main survey, no ceiling nor floor effects were observed for the 13 items on the UW-CBS, and the total score followed a normal distribution. The absence of meaningful DIF across gender and age, indicated by McFadden R^2 values <0.012, suggests that the UW-CBS demonstrates measurement stability. In addition, the overall Cronbach α coefficient for the Japanese-translated UW-CBS was 0.92. Whereas the original study reported that this correlation was lower than anticipated, the result obtained in this study was similar to the original result. A retest with 7 caregivers was conducted, and the test-retest reliability was 0.62, lower than that in the original study (0.92). Although the result in this study was not significant, likely because of the small sample size, the ICC of 0.62 still suggests that the UW-CBS demonstrates a certain degree of reliability. Construct validity was examined by exploring the correlation between the resilience scale and the UW-CBS. In this study, the correlation was *r*=0.30 (*P*=.02), which is comparable to the original study's correlation of *r*=0.28 (*P*<.01). The known-groups validity comparisons identified differences in BF between caregivers of children with SB who differed in

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medical condition, as indicated by ventriculoperitoneal shunt use, as well as between caregivers with and without a partner, in the expected directions. These findings suggest that the UW-CBS is capable of capturing meaningful variation in BF across caregiver subgroups.

Study 2

The aim of Study 2 was to explore the characteristics of caregivers of children with SB. Because little research has explored BF among caregivers of children with SB, we first examined the characteristics of their scores on the UW-CBS. We found that parents rearing only children with SB scored lower on the UW-CBS than did those who were also rearing other children without serious conditions. This result suggests that a greater number of children may offer caregivers increased emotional support or family resources, which may foster more positive emotional experiences. Previous research concerning parents of children with autism spectrum disorder has indicated that parents and siblings themselves believe that they mature more quickly as a result of taking on a caregiver role [47]. Furthermore, in a study of resilience among families of children with autism, interviewers also noted that siblings tend to look after the child with autism, thereby bringing family members closer together [48]. These findings may also be applicable to families rearing children with SB, where the presence of additional children may contribute to the development of a stronger support network among family members, thereby influencing caregivers' perceptions of BF.

In this study, caregivers with partners had higher UW-CBS scores. This result aligns with previous research emphasizing the importance of marriage, as marital satisfaction contributes to improved psychological adjustment [6] and positive child adjustment outcomes [49]. Another study highlighted that a partner's companionship is an indispensable source for mothers of children with SB, which cannot be easily substituted by other forms of social support [50]. By contrast, single mothers of children with SB reported significantly higher parenting stress [7,11], suggesting that the absence of a partner may exacerbate parenting challenges. Further research should place greater emphasis on providing support for single-parent families of children with SB.

The comparison between caregivers of children with SB and parents of able-bodied children resulted in a significant difference in social support scores, but no significant differences were observed in parenting stress nor BF. The significant difference in social support may stem from the extensive medical needs of children with SB, which often require ongoing help from health care professionals and social workers. In addition, caring for a child with SB can lead caregivers to connect with others in similar situations, further expanding their support networks. These assumptions are partially supported by the pretest findings, in which the category *Expansion of social support networks* emerged. Caregivers mentioned having access to help from specialists in areas like rehabilitation and welfare during difficult times, as well as forming friendships with other caregivers of children with SB.

In prior studies, caregivers of children with SB reporting higher levels of social support also tended to report lower parenting stress [8,16] and distress [13]. Despite the fact that parents of children with SB have generally reported higher levels of parenting stress in most studies [6-12], greater social support may account for the finding in this study that caregivers of children with SB experience levels of parenting stress comparable to those of parents rearing able-bodied children.

Although the original UW-CBS paper reported higher BF scores in community samples compared with those in medical condition samples [30], in this study, no significant difference in UW-CBS scores was found between caregivers of children with SB and the control group. This result may be attributed to the relatively high levels of social support received by the caregivers of children with SB in this study. A study focusing on caregivers of children with developmental disabilities explored a BF-related model, identifying a positive relationship between social support and BF while suggesting that social support nourishes framework reconstruction and potentially facilitates the BF process [18]. This finding raises the possibility that caregivers of children with SB, as fellow caregivers of children with chronic conditions, might experience a greater degree of BF in the context of a well-developed social support network.

Limitations

This study has some limitations. First, the recruitment of caregivers was inherently challenging because of the medical complexity and care demands associated with SB, and recruitment was further constrained by the COVID-19 pandemic. As a result, the sample sizes for the main survey and retest were relatively small, which limited the statistical power. In particular, test-retest reliability did not achieve statistical significance, suggesting that the results regarding the scale's stability should be interpreted as preliminary. Second, the validation of the scale was restricted to caregivers of children with SB as the target group. In future research, the application of the UW-CBS is anticipated to be examined in larger sample sizes and among a broader range of caregivers of children with special needs to evaluate the stability and measurement properties of the UW-CBS. Second, because this study had a cross-sectional design and measured BF at a specific point in time, longitudinal research should be considered to gain a deeper understanding of the positive psychological adaptation process of parents of children with SB within the Japanese context. Third, the recruitment strategy, which relied on associations and snowball sampling, may have led to an overrepresentation of caregivers with higher levels of social support. This may reduce the representativeness of the study sample. Future studies should adopt broader and more systematic recruitment strategies to enhance representativeness and reduce potential selection bias.

Conclusions

This study, based on the context of Japanese caregivers of children with SB, translated and validated the UW-CBS, demonstrating its usability. In addition, BF was observed in families of children with SB, with more pronounced levels in families simultaneously rearing typically developing children and in households with a spouse or partner. Families of children with SB also reported receiving greater levels of social support than parents of able-bodied children.

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Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request.

Conflicts of Interest

None declared.

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Abbreviations

BF: benefit-finding
COSMIN: Consensus-Based Standards for the Selection of Health Measurement Instruments
DIF: differential item functioning
ICC: intraclass correlation coefficient
JMSPSS: Japanese short form of the Multidimensional Scale of Perceived Social Support
NPO: specified nonprofit corporation
PSI-SF: Parenting Stress Index-Short Form
REDcap: Research Electronic Data Capture
SB: spina bifida
TRS: Tachikawa Resilience Scale
UW-CBS: University of Washington Caregiver Benefit Scale

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Increasing Use of a Postpartum and Newborn Chatbot among Birthing Individuals and Caregivers: Development and Implementation Study

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Abstract

Background: The 42 days following childbirth are a high-risk period for birthing individuals and newborns. We created 2 rule-based chatbots, 1 for birthing individuals and 1 for newborn caregivers, to deliver information on postpartum and newborn warning signs, follow-up care, and other relevant resources during this high-risk period.

Objective: This study aims to examine strategies for implementing the chatbot following discharge from a large hospital center, initial chatbot reach, and subsequent reach after chatbot refinement based on end-user feedback.

Methods: Reach was defined as the number of users opening the chatbot out of those who received it. Birthing individuals' demographic (age, ethnicity, race, language, and insurance type) and clinical characteristics (delivery method and prenatal care location) and newborns' time in the hospital were obtained from the medical record. Descriptive statistics, chi-square tests, and multiple logistic regression models were used to analyze the association between demographic and clinical characteristics and chatbot reach.

Results: Both chatbots were developed and revised based on clinician, community, and patient feedback. Overall, 65.9% (4933/7489) of newborn caregivers discharged between October 2, 2022, and January 15, 2025, opened the newborn chatbot, and 63.6% (4140/6505) of birthing individuals discharged between November 21, 2022, and January 15, 2025, opened the postpartum chatbot. Older age (odds ratio [OR] 1.02, 95% CI 1.01-1.03), Black race (OR 0.73, 95% CI 0.61- 0.88; reference: White), languages other than English or Spanish (OR 1.90, 95% CI 1.21-2.98; reference: English), receipt of prenatal care external to the hospital system (federally qualified health center: OR 0.52, 95% CI 0.45-0.60; Kaiser: OR 0.34, 95% CI 0.29-0.39; reference: within the hospital system), and public insurance (OR 0.72, 95% CI 0.64-0.82; reference: private insurance) were significant predictors of postpartum chatbot reach. Older age (OR 1.02, 95% CI 1.01-1.03), Black race (OR 0.61, 95% CI 0.50-0.74; reference: White), receipt of prenatal care external to the hospital system (federally qualified health center: OR 0.50, 95% CI 0.44-0.57; Kaiser: OR 0.30, 95% CI 0.26-0.35; reference: within the hospital system), public insurance (OR 0.63, 95% CI 0.55-0.71) and self-pay (OR 0.56, 95% CI 0.38-0.83; reference: private insurance), and newborn time in the hospital of 2 - 4 days (OR 1.21, 95% CI 1.09-1.35; reference: less than 2 d) were significant predictors of newborn chatbot reach. Including a Spanish-language version in the newborn chatbot improved reach among Spanish-preferring caregivers (from 58% to 66.2%), but additional chatbot content revision and the addition of chatbot information to discharge paperwork did not change chatbot reach.

Conclusions: While there were differences in chatbot reach by patient demographics, the chatbot showed delivery of time-sensitive information and support to >60% of individuals. This intervention demonstrated that chatbots can be used to supplement patient care and help bridge the gaps in connecting patients to care and support after hospital discharge. Future work should address additional ways to improve chatbot reach and explore the impact on targeted health outcomes.

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KEYWORDS

postpartum period; newborn care; health information; chatbot; implementation

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Introduction

The 42-day period after childbirth is widely viewed as high-risk both for the birthing individual and for the newborn [1-3]. Access to timely information about potential warning signs for when to seek emergency care, along with proper follow-up care and support, has the potential to improve maternal and infant health outcomes after discharge from the hospital. Top causes of death for birthing individuals in the 42-day period after delivery are mental health conditions, cardiovascular conditions, and infections [4], while top causes of mortality among infants are birth defects, preterm birth and low birth weight, and sudden infant death syndrome [5]. Previous work has cited the importance of monitoring women post-delivery, with an estimated 15% of severe maternal morbidity cases occurring after discharge [6]. Furthermore, a prior randomized control trial found that enhanced caregiver education via SMS text messaging, timed to the infant's age and most common reasons for emergency department visits, reduced emergency department visits in infants' first year of life [7]. In recent years, SMS text messaging services such as Text4Baby (National Healthy Mothers, Healthy Babies Coalition and Voxiva) [8,9] and apps such as BabyScripts (1EQ, Inc) [10,11] have been developed to provide information to patients during the prenatal and postpartum periods on maternal and infant health.

Chatbots are another mobile health (mHealth) strategy used to deliver timely information. Maternal chatbots are an acceptable and feasible strategy for postpartum and caregiving information and support [12,13]. For example, Rosie is a chatbot that leverages artificial intelligence (AI) to deliver personalized assistance related to pregnancy, labor, postpartum care, and newborn care [13,14]. Another chatbot, Dr. Joy, is an obstetric and mental health-related question-and-answer knowledge-based chatbot that also leverages AI for prenatal and postpartum care [15]. While these chatbots are effective in disseminating relevant health information among select patients, they have been deployed in small trials, as opposed to part of standard of care.

We developed and piloted 2 rule-based chatbots (one for birthing individuals and one for newborn caregivers) to provide timely health information and resources, including connection to care. This study aims to describe the process of developing and piloting an mHealth program aimed at improving education on postpartum and newborn warning signs and appropriate connection to care and resources after hospital discharge. We also aim to describe the chatbot reach (number of patients who opened the chatbot out of those who received it) among patients discharged from a large mid-Atlantic hospital that serves a socioeconomically and racially diverse population overall. We assessed reach after initial launch and after refining the chatbot in response to patient feedback. We hypothesized that with each chatbot refinement, there would be an improvement in reach. Finally, we explored how individuals' demographic and clinical factors were associated with reach for each chatbot.

Methods

Overview

This study was prepared in accordance with the iCHECK-DH (Guidelines and Checklist for the Reporting on Digital Health Implementations) [16].

Chatbot Development, Initial Implementation Strategies, and Setting

The postpartum and newborn chatbots were developed as part of a larger initiative, Safe Babies Safe Moms (SBSM), which was aimed at reducing infant and maternal disparities in the District of Columbia (DC) [17]. These chatbots were designed with key goals of helping patients connect with care teams (eg, information about recommended pediatric and postpartum appointments, list of pediatricians in the area), educating them on warning signs, and providing additional postpartum and newborn information and resources (eg, breastfeeding and wound healing after C-section) [18]. The chatbots operated on a rule-based system with fixed logic for interaction (ie, patients could not ask open-ended questions). Content was developed by a multidisciplinary team of experts in obstetrics, pediatrics, social work, psychiatry, mHealth, and health equity, designed to meet the needs of diverse patients.

We created 2 separate chatbots to account for instances where a birthing individual and newborn did not go home together (eg, adoption, surrogacy, neonatal intensive care unit, or postpartum complication) and provide appropriate information at the appropriate time. Thus, within a nonprofit health care system, caregivers of newborn patients discharged at a large, mid-Atlantic hospital between August 29, 2022, and January 15, 2025, received the newborn chatbot, and birthing individuals discharged between November 21, 2022, and January 15, 2025, received the postpartum chatbot within 24 hours of hospital discharge as standard of care. Individuals discharged after January 15, 2025, did not receive the chatbots due to the funding period ending.

The postpartum chatbot messages were sent in the morning, delivering messages weekly for the first 42 days post-discharge (Figure 1 and Multimedia Appendix 1). The newborn messages started 24 hours after discharge, asked about whether a newborn visit was scheduled, offered support and resources when the caregiver answered no, and followed up with weekly informational outreach messages. A total of 7 messages with unique content were sent for the postpartum chatbot, and 5 messages were sent for the newborn chatbot. Each unique set of chatbot content is referred to as an experience. The topics included in each chatbot experience are listed in Table 1. In short, topics included appointment reminders, warning signs, nutrition recommendations, and developmental milestones for newborns and postpartum care. Both postpartum and newborn messages were sent as standard of care to all individuals who delivered at the hospital, except for one community clinic that opted to only implement the newborn chatbot because they already had a postpartum follow-up process and did not want to confuse patients. There was some content tailoring in the

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postpartum chatbot; for instance, birthing individuals who had a C-section received information about wound care.

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Table . Newborn and postpartum chatbot reach for caregivers and birthing individuals, and topics covered by each chatbot experience.

Experiences and topics covered in the chatbot[a]	General reach by experience, n/N (%)
Newborn chatbot experience[b]	
Experience 1 (day 1 post discharge)	
Original: pediatric appointment reminder; resources to address common challenges for scheduling an appointment (only offered to patients without an appointment); parental leave	1757/4438 (39.6)
Revised: pediatric appointment reminder; resources to address common challenges for scheduling an appointment (offered to all patients); parental leave	1285/2935 (43.8)
Experience 2 (day 7)	
Original: pediatric warning signs; newborn sleep recommendations	930/4384 (21.2)
Revised: pediatric warning signs; newborn sleep recommendations (added recommendations for premature newborns)	652/2989 (21.8)
Experience 3 (day 14)	
Original: newborn nutrition recommendations; resources for breastfeeding and formula; food assistance program	973/4320 (22.5)
Revised: newborn nutrition recommendations; resources for breastfeeding and formula; colic education; newborn bowel movement education; food assistance program	691/3053 (22.6)
Experience 4 (day 28)	
Original: newborn developmental milestones	1104/4192 (26.3)
Revised: pediatric 1-month visit; tips for communicating with providers; newborn developmental milestones; recommended activities with newborns	886/3181 (27.9)
Experience 5 (day 38)	
Original: recommended pediatric visits and vaccines	1608/4104 (39.2)
Revised: 2-month checkup and recommended vaccines; support groups; resources for diapers and baby essentials	1126/3269 (34.4)
Postpartum chatbot experience[c]	
Experience 1 (day 1 post discharge)	
Original: postbirth warning signs; baby blues	1336/3895 (34.3)
Revised: postbirth warning signs; baby blues and recommendations	907/2610 (34.8)
Experience 2 (day 3)	
Original: postbirth warning signs; postpartum check-up; recovering after a C-section; resources to address common challenges for scheduling a postpartum check-up	1317/3874 (34)
Revised: postbirth warning signs; postpartum recovery; recovering and management after a C-section or vaginal birth; breastfeeding tips and resources; pain management; paid family leave	846/2631 (32.2)
Experience 3 (day 7)	
Original: nutrition	903/3846 (23.5)
Revised: nutrition and resources; stress management tips, postpartum check-up and resources to address common challenges for scheduling or attending a postpartum check-up	544/2659 (20.5)
Experience 4 (day 14)	
Original: postpartum depression; sleep recommendations	691/3794 (18.2)
Revised: postpartum depression; sleep recommendations and tips	390/2711 (14.4)
Experience 5 (day 21)	
Original: family planning and sex after birth	1002/3728 (26.9)

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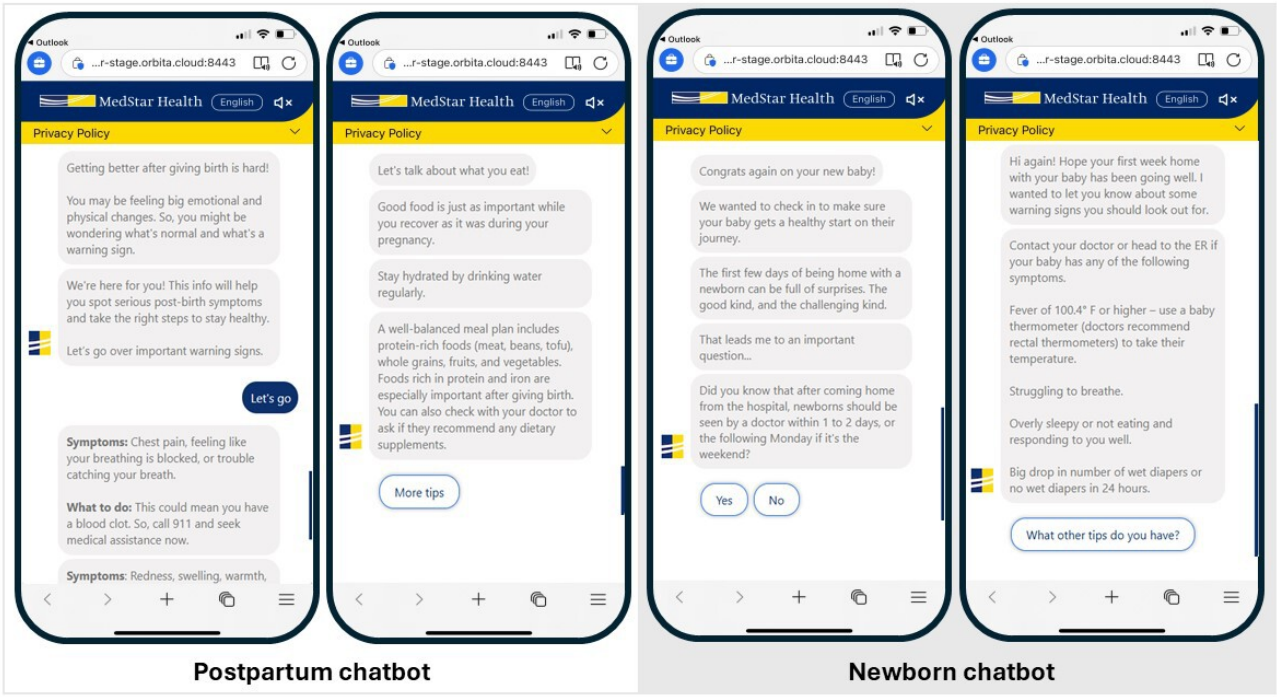
Experiences and topics covered in the chatbot[a]	General reach by experience, n/N (%)
Revised: family planning and sex after birth	706/2777 (25.4)
Experience 6 (day 28)	
Original: pelvic floor - Kegel exercises	656/3660 (17.9)
Revised: physical activity; Pelvic floor - Kegel exercises	511/2845 (18)
Experience 7 (day 42)	
Original: social support; postpartum depression	413/3560 (11.6)
Revised: social support and resources; resources for postpartum depression; health care after birth	250/2945 (8.5)

[a]The topics covered in each experience were revised, and the new content for all experiences was launched on February 21, 2024, for both chatbots. Thus, the total number of patients who received the new content will differ by experience.

[b]Caregivers of newborns discharged from the hospital between October 2, 2022, and January 15, 2025, received the newborn chatbot. A total of 116 caregivers who received the newborn chatbot were excluded due to missing data by experience.

[c]Only birthing individuals discharged from the hospital between November 21, 2022, and January 15, 2025 received the postpartum chatbot.

Figure 1. Chatbot screenshots of the postpartum and newborn chatbots.



Electronic Health Record Data Extraction and Integration

The chatbot system relied on structured electronic health record (EHR) data to identify discharge dates for birthing individuals and newborns. A native EHR data extraction program using Cerner Command Language was designed to retrieve relevant patient information including contact information, preferred language, and prenatal care provider. The data extraction was fully automated and ran daily. These data were securely transmitted to the chatbot vendor system via the enterprise Interface Engine using secured File Transfer Protocol to ensure end-to-end transport layer security, consistent with industry-standard security practices. Upon receiving the contact list, the chatbot vendor delivered the chatbot content through SMS text messaging and email. The vendor generated daily analytics files that included user reach metrics (eg, overall chatbot use) that were securely transferred back to the health care system.

Study Design and Participants

This is a pragmatic implementation study where we described the strategies used to develop the postpartum and newborn chatbots and performed a cross-sectional analysis to evaluate the postpartum and newborn reach. Because patients received the chatbots as standard of care, we included all the birthing individuals and caregivers of newborn patients discharged from a large, mid-Atlantic hospital in the data analyses. Newborn chatbot reach was evaluated for newborn patients discharged from October 2, 2022, to January 15, 2025, who received the newborn chatbot. We were unable to report chatbot delivery and reach during the first month of chatbot launch due to inconsistent documentation by the vendor; these issues were resolved during team meetings. For postpartum reach, all

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birthing individuals discharged from November 21, 2022, to January 15, 2025, and who received the postpartum chatbot were included in the analysis.

Measures

Implementation Strategies and Chatbot Reach

The chatbots were designed to fill a gap in follow-up after patient discharge, particularly among those patients who did not seek care within the health care system before or after birth. Implementation strategies specific to increasing reach and engagement for the chatbot focused on developing stakeholder relationships, reexamining implementation, and engaging consumers. The primary outcome of this analysis is chatbot reach and is defined as the number of people who opened the chatbot link out of those who received outreach messaging. Chatbot reach data were obtained from the chatbot vendor, and the research team linked the data back to the patient's medical record.

Demographic and Clinical Data Collection

Birthing individuals' and newborns' demographic and clinical characteristics were obtained from the EHR. These independent variables were categorized as follows: birthing individual age (<20, 20‐29, 30‐39, 40+ years), ethnicity (Hispanic or non-Hispanic), race (Black or African American, White, other, or unknown), preferred language (English, Spanish, other [eg, Amharic, Arabic, French, etc], or unknown), and insurance type (private or commercial, public, other, self-pay, or unknown). Regarding medical history, we included delivery method (vaginal birth or C-section) for the birthing individuals, newborns' weight at birth (very low birthweight: <1500g, low birthweight: 1500g to <2500g, or normal birthweight: ≥2500g), gestational age (<37 wk or ≥37 wk), time in the hospital between birth and discharge (<2 d, 2‐4 d, or >4 d), and prenatal care location (care within the MedStar Health system where they delivered, Kaiser [where both care and insurance are provided within the same system], other external clinics (largely federally qualified health centers [FQHCs] or unknown sources of care). Birthweight and gestational age data were only available for newborns discharged from October 2, 2022, to September 30, 2024, as they were obtained from the EHR for a prior SBSM project [17].

Data Analysis

We used descriptive statistics to describe reach and chi-square tests to evaluate demographic and clinical factors related to the postpartum and newborn chatbot reach. We also assessed changes in reach after modifying chatbot outreach and content. We used backward selection of the independent variables (birthing individual age, ethnicity, race, preferred language, insurance type, and prenatal care location) to finalize the multivariate logistic regression models. For the postpartum chatbot reach, we also included birthing individual delivery method (vaginal vs cesarian), and for the newborn chatbot, we included time in the hospital. In addition, we tested the impact of adding birthweight and gestational age as independent variables to the newborn chatbot logistic regression limiting the population to the date range October 2, 2022, to September 30, 2024, (as these 2 variables were only available between these dates).

Ethical Considerations

The study protocol was approved by the Institutional Review Board (IRB) from MedStar Health Research Institute (IRB #5741). This project was completed in accordance with the ethical standards of the MedStar Health Research Institute IRB and the Helsinki Declaration of 1975 and the 2000 revision. We did not ask for consent or compensate patients in this study as the chatbots were automatically sent to patients as standard of care. Our IRB granted a Health Insurance Portability and Accountability Act waiver to link chatbot engagement to the patients' demographic and clinical data (eg, age, race, preferred language, type of insurance, and prenatal care location). Identifiers were needed to link patients to their relevant EHR information. All patients' identifiers were deleted from all files after data analysis was completed.

Results

Implementation Strategies

Developing Stakeholder Relationships

Before developing the chatbot, we met with the clinical leaders in labor and delivery, including physicians, nurses, and administrators. We also consulted with our community partners on key content and outreach strategies, as two-thirds of those delivering at the target hospital seek prenatal and postpartum care outside of the hospital's health care system. We then identified a lead in each of the clinical areas involved (pediatrics, labor and delivery, and behavioral health) to help with the development of the chatbot content.

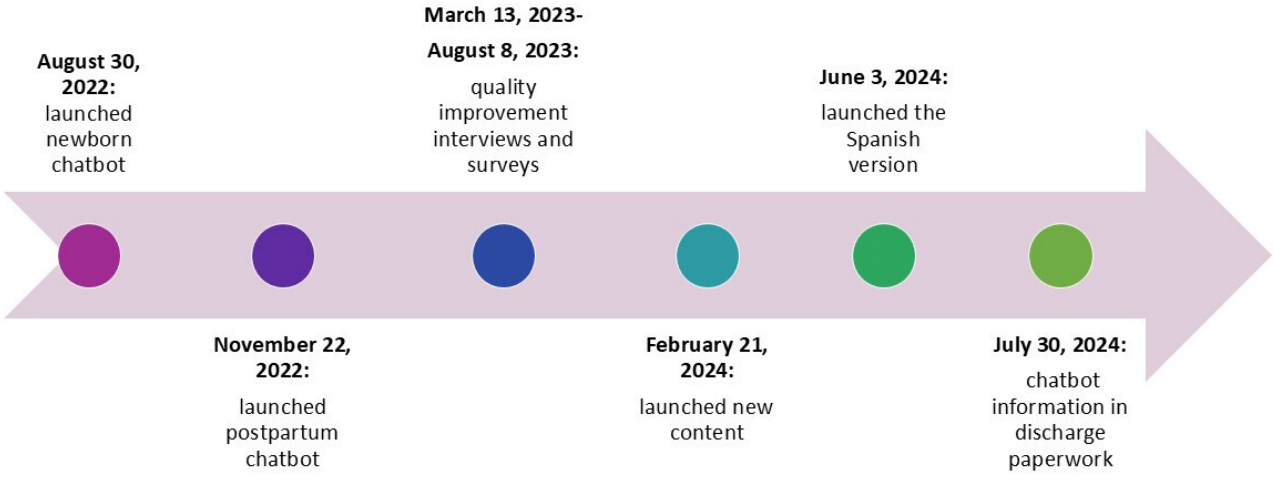
We iteratively developed the chatbot content, incorporating feedback from birthing individuals and caregivers (n=9) recruited from two pediatric clinics, who reviewed the content and participated in an individual semistructured interview. We notified providers and health care system leaders once the program was ready to launch and invited feedback on integration with existing workflows. Throughout this project, clinical leads were invited to participate in scientific abstracts to increase a sense of buy-in and were given opportunities to reflect on progress. Additionally, we presented ongoing successes and challenges to the parent project's strategic advisory board, which includes clinical and community maternal and infant health equity experts, to solicit feedback. In response to provider feedback about the busy pace and competing priorities of the labor and delivery unit, we automated outreach to eliminate any need to ask providers to enroll patients. Despite the automation, building stakeholder relationships was vital to ensure that clinical teams were comfortable with their patients receiving the outreach, optimize the outreach content, and increase the likelihood that they would support introducing it into discharge paperwork.

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Iterative Processes, Including Purposefully Re-Examining the Implementation and Reaching Consumers

The timeline for chatbot launch and iterative refinement is shown in Figure 2. The research team met with the chatbot vendor weekly to review data. With input from the research team, the vendor created a dashboard to monitor reach and certain engagement metrics (eg, user response to the question about scheduling their first newborn pediatric appointment). After assessing baseline rates of reach and preliminary engagement, between March and August of 2023, we collected qualitative and quantitative feedback from diverse users (46% identified as Black, 25% as Hispanic, and 54% had public insurance) to solicit input on increasing reach and use of chatbot content [18].

Figure 2. Postpartum and newborn chatbot implementation and refinement timeline.



Based on initial reach data and patient feedback (reported elsewhere [18]), we created the following changes: (1) we modified the outreach messages to include more information about each week's content, (2) we added relevant topics and resources within each chatbot experience (revised topic content listed in Table 1), (3) we translated the chatbot content into Spanish, (4) we added information about the chatbot to the discharge paperwork so that patients who reviewed the paperwork might have a frame of reference for the outreach.

The outreach messages were changed from a generic script to specify the topics covered in the corresponding experience. Overall, language was revised to improve readability and clarity (eg, "postpartum" was replaced with "after giving birth"). The chatbot content was changed in various ways (Table 1). First, we added additional tailored information for recovery after a C-section or vaginal birth, and options to read more about breastfeeding, with sensitivity to patient experiences around whether they chose to or were able to breastfeed. Second, additional resources such as Maternal Mental Health Hotline, Postpartum Support International, Breastfeeding Center of Greater Washington, and Safe Sleep Program from DC Department of Health were added. Third, we included a voice-over feature to facilitate reviewing the chatbot information using audio, as well as an option for patients to download the content as a PDF so that they could refer back to the information and share it with their partners or family members. We reviewed the revised content with 5 patients at an obstetrics clinic and 5 caregivers at a pediatric clinic to solicit in-person feedback via brief interviews. The interviewer took structured notes on patients' and caregivers' recommendations to share with the study team. Recommendations included: slowing down the speed that chatbot messages added text, shortening the messages, bolding the most important information, and adding a summary of the information included in the shared links. The speed at which new messages appeared in the chatbot was slowed to 2500 milliseconds, and we divided the information into more segments where patients could choose response options. This allowed us to shorten the messages and increase the potential for interaction within the chatbot. The updated outreach messages and chatbot content were launched on February 21, 2024.

A Spanish version of each chatbot was implemented on June 3, 2024, after professional translation, given that Spanish is the second most common primary language among our patient population. We also revised the outreach message to include a Spanish explanation for changing the chatbot language to Spanish as preferred language in the EHR may not capture all appropriate patients. Finally, on July 30, 2024, we added screenshots about the chatbot outreach and content in the discharge paperwork for both birthing individuals and newborns to inform patients about the chatbot and address concerns that the chatbot outreach messages were potentially a scam.

Chatbot Reach Overall

A total of 6505 individuals out of 6684 birthing individuals (97.3%) discharged from the hospital successfully received the postpartum chatbot outreach message; those who did not receive it either had a landline phone number or did not have a working phone number or email in the EHR. Overall, 7489 out of 7525 caregivers (99.5%) successfully received the chatbot outreach message for each newborn. Less than 1% of recipients opted out of the chatbots. Approximately 63.3% of patients had a valid email (postpartum: 4107/6505 and newborn: 4757/7489), and 99.9% (postpartum: 6505/6505 and newborn: 7488/7489) had a valid phone number. A total of 6107 birthing individuals/caregivers received the postpartum and newborn chatbot messages, 398 birthing individuals only received the postpartum chatbot, 1076 unique caregivers only received the

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newborn chatbot, and 298 caregivers received additional newborn chatbot messages for each newborn (due to multiparous, or births at different times; eg, 8 individuals had 3 newborns each during the project period).

Approximately two-thirds of recipients opened messages from either chatbot (Table 2). Newborn chatbot reach by experience ranged from 41.3% (3042/7373, experience 1) to 21.5% (1582/7373, experience 2), and the postpartum chatbot reach ranged from 34.5% (2243/6505, experience 1) to 10.2% (663/6505, experience 7; Table 1). Birthing individuals and caregivers who had a valid phone and email had a significantly higher chatbot reach (postpartum chatbot: 2980/4107, 72.6% and newborn chatbot: 3561/4756, 74.9%) than patients with only a valid phone number (postpartum chatbot: 1160/2398, 48.4% and newborn chatbot: 1372/2732, 50.2%). Only one caregiver had a valid email only and was not reached. For both chatbots, approximately 57% of users opened the messages by SMS text messaging only (postpartum: 2388/4140 and newborn: 2831/4933), 14% by email only (postpartum: 601/4140 and newborn: 678/4933), and 28% by both SMS text messaging and email (postpartum: 1151/4140 and newborn: 1424/4933).

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Table . Patients' demographic and clinical characteristics by postpartum and newborn chatbot reach.

Patients' demographic	Postpartum chatbot[a]				Newborn chatbot[b]			
	Total received	Total reach	Reach[c], %	*P* value[d]	Total received	Total reach	Reach[c], %	*P* value[d]
Total	6505	4140	63.6		7489	4933	65.9	
Age (years)				<.001				<.001
<20	285	153	53.7		332	189	56.9	
20 - 29	2310	1349	58.4		2746	1669	60.8	
30 - 39	3466	2337	67.4		3945	2720	69.0	
40+	444	301	67.8		466	355	76.2	
Race				<.001				<.001
Black	2926	1749	59.8		3527	2217	62.9	
White	940	713	75.9		1001	823	82.2	
Other	1294	860	66.5		1468	953	64.9	
Unknown	1345	818	60.8		1493	940	63.0	
Ethnicity				.01				<.001
Hispanic	470	318	67.7		517	355	68.7	
Non-Hispanic	3937	2539	64.5		4589	3108	67.7	
Other	101	67	66.3		113	69	61.1	
Unknown	1997	1216	60.9		2270	1401	61.7	
Language				.003				<.001
English	5633	3589	63.7		6498	4321	66.5	
Spanish	699	436	62.4		793	480	60.5	
Other	113	86	76.1		123	93	75.6	
Unknown	60	29	48.3		75	39	52.0	
Insurance				<.001				<.001
Private	2670	1866	69.9		2955	2197	74.4	
Public	2941	1749	59.5		3498	2103	60.1	
Self-pay	106	67	63.2		120	72	60.0	
Other	79	59	74.7		68	52	76.5	
Unknown	709	399	56.3		848	509	60.0	
Delivery method				.13				N/A[e]
Vaginal	3987	2509	62.9		N/A	N/A	N/A	
Cesarean	2518	1631	64.8		N/A	N/A	N/A	
Baby weight[fg]				N/A				.07
Very low birthweight (<1500 g)	N/A	N/A	N/A		64	47	73.4	
Low birthweight (1500 to <2500 g)	N/A	N/A	N/A		633	396	62.6	
Normal birthweight (≥2500 g)	N/A	N/A	N/A		5863	3890	66.4	
Gestational age[fg]				N/A				.003
<37 weeks	N/A	N/A	N/A		738	452	61.3	

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Patients' demographic	Postpartum chatbot[a]				Newborn chatbot[b]			
	Total received	Total reach	Reach[c], %	*P* value[d]	Total received	Total reach	Reach[c], %	*P* value[d]
≥37 weeks	N/A	N/A	N/A		5822	3881	66.7	
Time in hospital after birth [g]				N/A				<.001
<2 days	N/A	N/A	N/A		3070	1972	64.2	
2 - 4 days	N/A	N/A	N/A		3304	2257	68.3	
>4 days	N/A	N/A	N/A		1115	704	63.1	
Prenatal care location				<.001				<.001
Within the hospital integrated health system	2895	2148	74.2		3042	2380	78.2	
Kaiser clinics[h]	1234	630	51.1		1342	721	53.7	
Other external clinics (eg, FQHCs)[i]	1864	1072	57.5		2609	1546	59.3	
Unknown clinics	512	290	56.6		496	286	57.7	

[a]Among birthing individuals discharged from the hospital between November 21, 2022, and January 15, 2025, who received the postpartum chatbot.

[b]Among caregivers of newborns discharged from the hospital between October 2, 2022, and January 15, 2025, who received the newborn chatbot.

[c]Reach is defined as the number of people who opened the chatbot link out of those who received outreach messaging.

[d]Chi-square statistics.

[e]N/A: not applicable.

[f]Data are only available through September 30, 2024.

[g]Data specific to newborn patients obtained from the electronic health record.

[h]Kaiser clinics are external clinics where both care and insurance are provided within the same system.

[i]FQHC: federally qualified health center.

Significant differences in reach were identified by age, ethnicity, race, preferred language, and insurance type across both chatbots (Table 2; all significant *P* values <.001). Birthing individuals who opened messages were more likely to be 30 years and older (2638/3910, 67.5%) compared to 29 years and younger (1502/2595, 57.9%), Hispanic (318/470, 67.7%) compared to non-Hispanic (2539/3937, 64.5%); White (713/940, 75.9%) compared to Black (1749/2926, 59.8%), had private insurance (1866/2670, 69.9%) compared to public insurance (1749/2941, 59.5%), and had prenatal care within the hospital's integrated health system (2148/2895, 74.2%) compared to external prenatal clinics (Kaiser patients 630/1234, 51.1%), other largely FQHC clinics (1072/1864, 57.5%), unknown prenatal care location (290/512, 56.6%). No significant differences in reach were found by the delivery method (ie, vaginal vs C-section).

Similarly, newborn chatbot caregiver reach was higher among birthing individuals who were 30 years and older (3075/4411, 69.7%) compared to 29 years and younger (1858/3078, 60.4%), White (823/1001, 82.2%) compared to Black (2217/3527, 62.9%), and had private insurance (2197/2955, 74.4%) compared to public insurance (2103/3498, 60.1%). Newborn chatbot reach was also higher when the newborn had a gestational age of 37 weeks or more (3881/5822, 66.7%) compared to a gestational age of less than 37 weeks (452/738, 61.3%), stayed in the hospital 2 - 4 days (2257/3304, 68.3%) compared to less than 2 days (1972/3070, 64.2%) and more than 4 days (704/1115, 63.1%), and had prenatal care within the hospital integrated health system (2380/3042, 78.2%) compared to external prenatal clinics Kaiser (721/1342, 53.7%), other largely FQHC clinics (1546/2609, 59.3%), and unknown prenatal care location (286/496, 57.7%). No significant differences were found for birth weight.

Postpartum Chatbot Analyses

In the final postpartum multivariate logistic regression model, we included age, race, preferred language, type of insurance, and prenatal location (Table 3). The odds of opening the postpartum chatbot were significantly lower for individuals identified in the EHR as Black (odds ratio [OR] 0.73, 95% CI 0.61- 0.88) compared to White individuals. Patients with a preferred language of "other" (OR 1.90, 95% CI 1.21-2.98) had greater odds of postpartum chatbot reach compared to English-preferring patients. Patients with public insurance (OR 0.72, 95% CI 0.64-0.82) and unknown insurance (OR 0.57, 95% CI 0.47-0.69) had lower odds of postpartum chatbot reach compared to individuals with private insurance. Patients who received prenatal care at clinics external to the hospital, including Kaiser clinics (OR 0.34, 95% CI 0.29-0.39), other

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clinics (OR 0.52, 95% CI 0.45-0.60), or unknown clinics (OR 0.45, 95% CI 0.37-0.55), had lower odds of postpartum chatbot reach compared to patients who received prenatal care within the hospital integrated health system. Age was also a significant predictor, with each one-year increase in age associated with a 2% higher likelihood of chatbot reach (OR 1.02, 95% CI 1.01-1.03).

Table . Multivariate logistic regression for postpartum chatbot reach among birthing individuals discharged from the hospital between November 21, 2022, and January 15, 2025. Reach is defined as the number of people who opened the chatbot link out of those who received outreach messaging.

Characteristics	OR[a] (95% CI)	*P* value
Age (continuous)	1.02 (1.01-1.03)	<.001
Race		
White (reference)	N/A[b]	N/A
Black	0.73 (0.61-0.88)	<.001
Other	1.10 (0.88-1.37)	.40
Unknown	0.92 (0.75-1.13)	.40
Language		
English (reference)	N/A	N/A
Spanish	1.04 (0.86-1.27)	.66
Other	1.90 (1.21-2.98)	.005
Unknown	0.69 (0.41-1.16)	.16
Insurance		
Private (reference)	N/A	N/A
Public	0.72 (0.64-0.82)	<.001
Self-pay	0.75 (0.49-1.14)	.18
Other	1.07 (0.63-1.82)	.80
Unknown	0.57 (0.47-0.69)	<.001
Prenatal location		
Within the hospital system where delivery occurred (reference)	N/A	N/A
Kaiser clinics[c]	0.34 (0.29-0.39)	<.001
Other external clinics (eg, FQHCs)[d]	0.52 (0.45-0.60)	<.001
Unknown clinics	0.45 (0.37-0.55)	<.001

[a]OR: odds ratio.

[b]N/A: not applicable.

[c]Kaiser clinics are external clinics where both care and insurance are provided within the same system.

[d]FQHC: federally qualified health center.

Newborn Chatbot Analyses

For the final newborn multivariate logistic regression model, we included the birthing individual's age, race, insurance type, prenatal care location, and their newborn's time in the hospital (Table 4). Age was a significant predictor, with each one-year increase in age associated with a 2% higher likelihood of chatbot reach (OR 1.02, 95% CI 1.01-1.03). Birthing individuals who were listed in the EHR as Black (OR 0.61, 95% CI 0.50-0.74), other race (OR 0.73, 95% CI 0.59-0.91), and unknown race (OR 0.74, 95% CI 0.60-0.91) had lower odds of newborn chatbot reach than when the newborn's birthing individual was White. Patients with public insurance (OR 0.63, 95% CI 0.55-0.71), self-pay (OR 0.56, 95% CI 0.38-0.83), and unknown insurance (OR 0.58, 95% CI 0.48-0.69) had lower odds of reach than patients with private insurance. Patients who received prenatal care at clinics external to the hospital, including Kaiser clinics (OR 0.30, 95% CI 0.26-0.35), other clinics (OR 0.50, 95% CI 0.44-0.57), unknown clinics (OR 0.40, 95% CI 0.32-0.48), had lower odds of postpartum chatbot reach compared to patients who received prenatal care within the hospital health system. Finally, caregivers of newborns who stayed in the hospital for 2 - 4 days after birth (OR 1.21, 95% CI 1.09-1.35) had greater odds for chatbot reach compared to newborns who stayed in the hospital less than 2 days, but no significant differences were found for the newborns who stayed more than 4 days (OR 0.99, 95% CI 0.86-1.15).

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Table . Multivariate logistic regression for newborn chatbot reach among caregivers of newborns discharged from the hospital between October 2, 2022, and January 15, 2025. Reach is defined as the number of people who opened the chatbot link out of those who received outreach messaging.

Characteristics	OR[a] (95% CI)	*P* values
Age (continuous)	1.02 (1.01-1.03)	<.001
Race		
White (reference)	N/A[b]	N/A
Black	0.61 (0.50-0.74)	<.001
Other	0.73 (0.59-0.91)	.004
Unknown	0.74 (0.60-0.91)	.005
Insurance		
Private (reference)	N/A	N/A
Public	0.63 (0.55-0.71)	<.001
Self-pay	0.56 (0.38-0.83)	.004
Other	0.85 (0.48-1.53)	.60
Unknown	0.58 (0.48-0.69)	<.001
Time in hospital		
<2 days (reference)	N/A	N/A
2 - 4 days	1.21 (1.09-1.35)	.001
>4 days	0.99 (0.86-1.15)	.92
Prenatal location		
Within the hospital integrated health system (reference)	N/A	N/A
Kaiser clinics[c]	0.30 (0.26-0.35)	<.001
Other external clinics (eg, FQHCs)[d]	0.50 (0.44-0.57)	<.001
Unknown clinics	0.40 (0.32-0.48)	<.001

[a]OR: odds ratio.

[b]N/A: not applicable.

[c]Kaiser clinics are external clinics where both care and insurance are provided within the same system.

[d]FQHC: federally qualified health center.

We conducted additional analyses limited to those where we had information on birthweight and gestational age (newborns discharged between October 2, 2022, and September 30, 2024). Birthing individual age, race, insurance, newborn time in the hospital, and prenatal care location remained in the model when including and excluding newborn birthweight and gestational age; ethnicity and preferred language were eliminated for both final models to fit the best model. Caregivers of newborns with very low birthweight (OR 2.44, 95% CI 1.32-4.50) had greater odds of opening the chatbot compared to newborns with normal birthweight, although no significant differences were found for the newborns with low birthweight (OR 1.11, 95% CI 0.88-1.39). In relation to gestational age, for newborns born at <37 weeks (OR 0.77, 95% CI 0.61-0.97), the caregivers were less likely to open the chatbot than caregivers with newborns born at term (37+ weeks). The ORs for other variables in the model were similar to those in the model with the full cohort that did not include birthweight and gestational age (Multimedia Appendix 2).

Chatbots Reach Changes Over Time

No significant changes in reach were found after launching the updated version of the newborn and postpartum outreach and chatbot content, nor after including the chatbot information in patients' discharge paperwork (Table 5); thus, we focused on results in the combined analyses for the full time period. We found significant improvements in reach for Spanish-speaking patients after deploying the Spanish version of the newborn chatbot (OR 1.42, 95% CI 1.03-1.96), but no significant differences in reach were found for the postpartum chatbot (OR 1.09, 95% CI 0.78-1.53). For a graphic description of the evolution of postpartum and newborn chatbots' reach over time (Multimedia Appendices 3 and 4).

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Table . Change in chatbot reach before and after changes in outreach, content, and awareness efforts.

Implementation strategies	Postpartum chatbot				Newborn chatbot			
	Total received	Total reach[a]	Reach, %	OR[b] (95% CI)	Total received	Total reach[a]	Reach, %	OR (95% CI)
Outreach and content revisions[c]								
Original content (reference)	3554	2278	64.1	N/A[d]	4212	2775	65.9	N/A
New content	2610	1639	62.8	0.95 (0.85-1.05)	2935	1914	65.2	0.97 (0.88-1.07)
Content in Spanish[e]								
Pre-Spanish language (reference)	448	277	61.8	N/A	519	301	58	N/A
Spanish language	213	136	63.9	1.09 (0.78-1.53)	237	157	66.2	1.42 (1.03-1.96)
Discharge paperwork[f]								
Prior (reference)	5150	3274	63.6	N/A	5967	3950	66.2	N/A
Included in discharge paperwork	1355	866	63.9	1.02 (0.90-1.15)	1522	983	64.6	0.93 (0.83-1.05)

[a]Reach is defined as the number of people who opened the chatbot link out of those who received outreach messaging.

[b]OR: odds ratio.

[c]Individuals discharged before January 9, 2024, for the postpartum chatbot and January 13, 2024, for the newborn chatbot were included in the analysis as the original content group, and individuals discharged between February 20, 2024, and January 15, 2025, for both chatbots were included in the new content group.

[d]N/A: not applicable.

[e]Only Spanish-speaking individuals identified in the medical record were included in the analysis. Individuals discharged before April 21, 2024, for the postpartum chatbot and April 25, 2024, for the newborn chatbot were included in the analysis as the pre-Spanish language group, and patients discharged from June 2, 2024, through January 15, 2025, were included in the Spanish-language group.

[f]Individuals discharged before July 29, 2024, were included in the analysis as before discharge paperwork, and individuals discharged from July 29, 2024, through January 15, 2025, were included in the discharge paperwork group.

Lessons Learned

This project highlighted the importance of involving stakeholders, including clinical staff, providers, patients, and community before and during the chatbot implementation to ensure acceptability, usefulness, and reach of the chatbot. The clinical teams were supportive of the rollout throughout the project. However, there were significant challenges in data collection and reporting from the third-party vendor, which may be better addressed in future work by working through specific needs, data accuracy, and various use cases for data before deploying the chatbot. Also, relying on a third-party vendor with ongoing expenses for hosting the chatbot limited the sustainability of this project after the project funding ended. Other health care systems or groups may consider options that are integrated into existing licenses so that ongoing fees are not prohibitive. Finally, given the design of the project and the vendor's limited capability to track individual level engagement with the program over time, we were unable to assess the impact of the chatbot on health outcomes.

Discussion

Principal Findings

This study describes strategies to develop a postpartum and newborn chatbot that was offered as standard of care for birthing individuals and caregivers of newborns discharged at a large hospital that serves a socioeconomically and racially diverse population. The chatbots' reach was close to two-thirds of the eligible birthing individuals and caregivers. Differences in reach were identified by age, race, prenatal care location, and insurance status for both chatbots, while newborn weight at birth, gestational age, and newborn time in the hospital were also significant predictors of the newborn chatbot reach. While disparities were present, this study demonstrated that chatbots have the potential to reach a significant proportion of this at-risk

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population and elucidates opportunities to conduct additional targeted supports.

Previous commercial and research programs have shown satisfaction among those who choose to receive messages about maternal and infant care. In other large-scale programs such as Text4Baby, a national SMS text messaging strategy in the US, about 150,000 individuals have chosen to enroll annually to receive SMS text messaging about prenatal, postpartum, and infant health recommendations, with users reporting high satisfaction [8]. Other interventions have also shown that patients and caregivers report high satisfaction when receiving SMS text messaging with health recommendations about postpartum depression [19] and infant care [7]. Health chatbots are also positively viewed [20,21], and parents tend to appreciate the informational and emotional support provided by chatbots [21]. In addition to high acceptability, mHealth strategies are also effective in improving health behaviors. For example, mHealth strategies have been shown to be effective in infant emergency room visit reduction [7], blood pressure monitoring [22], prenatal and postpartum weight management [23], and smoking cessation [24], among others [25].

In this project, about 65% of the individuals opened the chatbots, suggesting interest in reviewing information about postpartum and newborn care. In a randomized control trial, patients who received Rosie, an AI chatbot for new mothers, found that 87% (13/15) of the users reported using the chatbot at least weekly [13]. Another study of a postpartum AI chatbot found that of the 290 enrolled patients in the study, 99% of the patients responded to the platform at least once, and 52% asked a question to the chatbot [26]. However, to our knowledge, there are no comparable standard of care for newborn and postpartum mHealth educational outreach strategies that have evaluated reach in real-world settings, underscoring the need for this work. Prior real-world behavioral interventions on various health topics have documented SMS text messaging reach ranging from 14% to 60% [27-29]; our findings thus surpassed expectations. For example, a study among smokers and at-risk drinkers found that a total of 14% of the patients clicked on the embedded link to the apps in the SMS text messaging [27]. Another project using EHR data to identify smokers found that 15% responded to the smoking cessation SMS text messaging program after a single recruitment text [28]. Another project for patients aged 65 years and older found that 60% of the patients responded to the COVID-19 vaccine SMS text messaging outreach strategy [29].

We found notable differences in chatbot reach by age, race, insurance type, and prenatal care location for both chatbots. Lower chatbot reach among younger patients, Black patients, patients with public insurance, and those who received prenatal care at clinics external to the hospital health care system may be attributed to differences in desire for information, disparities in health/technological literacy, concerns about data plans, or trust in the health care system or chatbots [29,30]. We were also unable to deliver the chatbot to patients without a valid email or cell phone number in the EHR. To improve equity, it is crucial to develop interventions that address these issues, whether through additional in-clinic outreach to inform patients and caregivers about the chatbot, ensuring a valid email and phone number is documented in the EHR before discharge, or improving patient access to health information via different channels (eg, phone calls, SMS text messaging, and community outreach). Costs to the health care system and potential models for covering such low-cost services should also be explored. Future research could also consider intentional partnership with community groups focused on Black birthing individuals and underserved populations to avoid disparities in chatbot implementation.

While significant changes to the chatbot content and strategies were made to improve the chatbot's reach, these strategies did not result in significant improvements. Similar findings were found in a prior study where no significant improvements in acceptability were found after intervention refinement based on participants' feedback [30]. Our study suggests that further research is needed to understand the drivers of chatbot reach post-hospital discharge, such as user experience and how outreach and content can be optimized to capture and retain user interest over time. Additional strategies, such as identifying the best outreach time of day, further tailoring the outreach messages/content, and potentially including AI for personalization [13] may play a role in how users access and engage with similar chatbots. Community-based approaches may also be useful for addressing concerns about chatbots and identifying ways to increase the attractiveness of chatbots to patients who experience disparities. In addition, these changes could potentially impact other areas of user experience that we did not measure, like usability, satisfaction, and engagement. Ongoing audit and feedback may also prevent gaps in study metrics and provide timely information on how patients are using these types of mHealth interventions.

Limitations and Strengths

In this study, patients did not have the opportunity to request that the chatbots be sent to their preferred contact information, which could have impacted reach. Furthermore, because our chatbot followed a rule-based system with fixed logic for user interaction, it did not allow patients to ask questions or review the information in their preferred order. While efforts were made to match the content to when patients might need this information, for some patients, the information presented in the chatbots might not have been relevant. Future integration of conversation AI is recommended to provide personalized responses; however, it needs to be done with caution to guarantee that patients are receiving accurate information.

Two-thirds of the birthing individuals and most newborns seek postpartum or newborn care, respectively, outside the system. Thus, we could not evaluate the impact on patient health outcomes. Even within our system, there was limited ability to link engagement with specific outcomes due to the variability in the ways that individuals could engage with the chatbot and view tailored information. Future longitudinal studies within an integrated health care system, through partnership across facilities or designed in a manner where relevant outcome data can be linked to specific aspects of chatbot engagement, are also needed to assess the impact of chatbot reach and engagement on maternal and infant health outcomes, such as postpartum depression, follow-up care, and visits to the

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emergency room. Further research is also needed to understand patterns of reach related to gestational age, birthweight, or duration of hospital stay.

Despite these limitations, this study has many strengths. Delivering this program at scale provides unique information on who might engage with this type of digital outreach. This chatbot was intended to reach all patients and especially those who might not have a regular care provider to help them establish appropriate care. Finally, to our knowledge, our study presents the first example about chatbot reach to birthing individuals and newborn caregivers as standard of care within an urban hospital.

Conclusions

Our intervention demonstrated that chatbots can deliver important health information to many individuals efficiently, offering timely guidance on postpartum recovery, infant care, and follow-up appointments. These tools may serve as a supplement to patient care, helping bridge gaps in communication and support between health care providers and patients, especially for those who do not seek regular care. Understanding how constant interaction with digital health tools influences clinical outcomes, including a focus on racially and socioeconomically diverse populations, will help refine usability and effectiveness of these technologies.

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Data Availability

The datasets generated or analyzed during this study are not publicly available because the data analyzed in this study could be used to identify patients. However, deidentified data obtained for this study will be made available (as allowable according to institutional review board standards) by emailing the corresponding author.

Authors' Contributions

JNRR wrote the first draft with input from HA. JNRR, MS, SM, and HA engaged in data collection, data curation, and analysis. JNRR and HA were responsible for study methodology, project administration, and supervision of the study team. KEA contributed to the development of the chatbot, and ADT contributed to the project conceptualization. All authors reviewed and edited the final article. There was no generative AI used in article writing.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Postpartum and newborn chatbot outreach message schedules.
[DOCX File, 94 KB - pediatrics_v9i1e81844_app1.docx]

Multimedia Appendix 2
Multivariate logistic regression for newborn chatbot reach including birthweight and gestational age variables for patients discharged from October 2, 2022, to September 30, 2024.
[DOCX File, 17 KB - pediatrics_v9i1e81844_app2.docx]

Multimedia Appendix 3
Postpartum chatbot reach by week of initial outreach.
[DOCX File, 69 KB - pediatrics_v9i1e81844_app3.docx]

Multimedia Appendix 4
Caregivers' newborn chatbot reach by week of initial outreach.
[DOCX File, 74 KB - pediatrics_v9i1e81844_app4.docx]

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Abbreviations

EHR: electronic medical record
FQHC: federally qualified health center
iCHECK-DH: Guidelines and Checklist for the Reporting on Digital Health Implementations
IRB: Institutional Review Board
mHealth: mobile health

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Supporting Parents of Young Children With Type 1 Diabetes Through Telehealth: Randomized Controlled Trial of the Reducing Emotional Distress for Childhood Hypoglycemia in Parents Intervention

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Abstract

Background: Parents of young children with type 1 diabetes (T1D) are vulnerable to experiencing fear of hypoglycemia (FH), an emotional condition that includes persistent and intense worry about hypoglycemia and/or use of unhealthful behaviors to avoid hypoglycemia. Despite greater uptake of continuous glucose monitors (CGMs) and automated insulin delivery systems, FH remains prevalent and under-addressed in parents of young children. As such, we developed Reducing Emotional Distress for Childhood Hypoglycemia in Parents (REDCHiP), a video-based telehealth intervention designed to reduce FH in parents by providing T1D education and teaching parents how to apply evidence-based strategies from cognitive behavioral therapy and behavioral parent training in their child's daily T1D care.

Objective: This study aimed to compare the REDCHiP intervention to a novel attention control condition (ATTN) to better isolate treatment effects for REDCHiP based on parents' FH and diabetes distress.

Methods: This was a multisite randomized controlled trial. We enrolled 197 families and randomized 183 to either REDCHiP or ATTN. Both REDCHiP and ATTN parents completed 10 video-based telehealth sessions. Our primary outcome was changes in parental FH; secondary outcomes included changes in parental diabetes distress and children's glycated hemoglobin A_{1c} (HbA_{1c}). We used a series of mixed-effects models and logistic regression to evaluate treatment effects.

Results: Parents in REDCHiP and ATTN attended >95% of sessions with high treatment fidelity. FH and diabetes distress decreased significantly over time in both REDCHiP and ATTN. Treatment-slope effects slightly favored REDCHiP but were not statistically significant for FH (P=.09) or distress (P=.06). However, parents receiving REDCHiP were significantly less likely to report clinically elevated diabetes distress over time compared to ATTN (P=.02). Child HbA_{1c} showed a small, nonsignificant reduction over time (P=.06). Parents with elevated depressive symptoms consistently reported higher FH and distress across all time points.

Conclusions: REDCHiP demonstrated high feasibility, acceptability, and potential clinical relevance in reducing diabetes distress among parents of young children with T1D. While overall treatment effects were modest, use of an attention control condition represents a meaningful advancement in trial rigor for pediatric behavioral interventions. Future adaptations of REDCHiP may enhance its impact, particularly for parents experiencing comorbid depressive symptoms.

Trial Registration: ClinicalTrials.gov NCT3914547; https://clinicaltrials.gov/study/NCT3914547

International Registered Report Identifier (IRRID): RR2-10.2196/17877

(JMIR Pediatr Parent 2026;9:e86616) doi:10.2196/86616

KEYWORDS

pediatric diabetes; type 1 diabetes; hypoglycemia fear; parenting; caregivers; digital health; psychosocial outcomes

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Introduction

Young children (<8 years old) living with type 1 diabetes (T1D) are particularly vulnerable to hypoglycemia due to heightened insulin sensitivity [1,2], unpredictable eating and exercise patterns [3], and challenges in recognizing and self-reporting symptoms of hypoglycemia [4]. Consequently, severe hypoglycemia occurs at nearly twice the rate in young children compared to older children and adolescents [5]. Parents, who bear primary responsibility for managing their young child's T1D regimen, are vulnerable to experiencing fear of hypoglycemia (FH) [4,6]. FH is a multisymptom emotional condition characterized by persistent and intense worry about the occurrence of hypoglycemia and/or reliance on unhealthful behaviors to avoid hypoglycemia (eg, treating normal glucose levels and underdosing insulin) [4]. FH affects up to 60% of parents of young children with T1D [4,7] and relates to lower quality of life [8,9], higher parenting stress [10], higher diabetes-related distress, and burnout, perhaps related to parents' experiencing a constant state of vigilance for hypoglycemic events [11].

Despite the high prevalence and negative impact of FH, there are few evidence-based interventions specifically designed to address this emotional challenge in parents of young children with T1D. To fill this gap, our team developed Reducing Emotional Distress for Childhood Hypoglycemia in Parents (REDCHiP) [12,13], a video-based telehealth intervention that merges principles of cognitive behavioral therapy and behavioral parent training with T1D education to help parents reduce their feelings of FH and their reliance on unhealthful hypoglycemia avoidance behaviors.

REDCHiP conceptualizes parents' FH as a specific phobia, which is readily treatable with cognitive-behavioral therapy [14,15]. Specifically, parents learn to identify unhelpful thoughts, feelings, and behaviors related to managing their child's T1D. Parents build a personal fear hierarchy of specific anxiety-provoking T1D-related situations and identify current maladaptive coping strategies that they desire to change. Parents then learn cognitive and behavioral strategies to help manage their fear while challenging themselves to gradually navigate fearful T1D-related situations or events differently (eg, response prevention). Finally, through imaginary and in vivo exposures, parents practice using the strategies they have learned to reduce feelings of FH [12].

Both individual and group treatment delivery appear effective when targeting anxiety [16] and providing behavioral parent training [17]. In the context of T1D education, group-based delivery is common [18]. REDCHiP combines individual and group treatment delivery so that parents can both receive personalized care during individual sessions and benefit from social support and the shared lived experiences of other parents of young children with T1D in the group sessions. In recent years, widespread uptake of video-based telehealth has transformed the delivery of pediatric behavioral interventions [19]. These platforms offer unique advantages for busy families, including less travel burden [20], flexible scheduling [21,22], and the ability for families to receive care in the home environment [21]. By designing REDCHiP for delivery via telehealth, we aimed to enhance its accessibility among parents of young children with T1D across diverse geographic locations.

To develop REDCHiP, we followed the Obesity-Related Behavioral Intervention Trials (ORBIT) model for behavioral treatment development [23]. This systematic approach to treatment development has multiple phases, each comprised of different preliminary studies designed to yield the incremental data necessary to increase the likelihood that the final treatment can influence a clinically meaningful target. In an earlier ORBIT Phase 2a study, we completed a waitlist-controlled pilot trial of REDCHiP [12] that included 36 families. We had high retention (86%), high session attendance (94%), and high parental satisfaction [24]. Moreover, our between-group comparisons demonstrated a significant reduction in FH for REDCHiP parents compared to waitlist parents, and once all parents had received REDCHiP, we found significant reductions in parents' FH and diabetes distress from pre- to posttreatment [12].

Thus, as a next step, we conducted an ORBIT Phase 2b study to better determine the source of our REDCHiP treatment effects [23]. Specifically, in a multisite randomized clinical trial (RCT), we compared our REDCHiP intervention to an attention control condition (ATTN). Our primary hypothesis was that parents randomized to REDCHiP would report greater reductions in FH compared to parents randomized to ATTN. However, we also explored changes in parents' diabetes distress as a secondary outcome, given its association with parents' FH and our pilot data, and we explored any reductions in young children's glycated hemoglobin A_{1c} (HbA_{1c}) following parental participation in REDCHiP or ATTN. If parents were purposefully engaging in behaviors to avoid the occurrence of hypoglycemia due to FH, we expected that HbA_{1c} could decrease among young children whose parents received REDCHiP versus ATTN. Here, we report the outcomes of our ORBIT Phase 2b trial of the REDCHiP intervention.

Methods

Study Design

This multisite RCT enrolled parents of young children with T1D from all regions of the United States through one of 3 recruitment sites located in the Southeast, Midwest, or Mountain regions of the United States. Our primary outcome was change in parental FH. Our secondary outcomes were change in parental diabetes distress and children's HbA_{1c}. We measured outcomes pretreatment, immediately post treatment, and 3-month post treatment, with the last assessment point intended to explore any maintenance effects.

Procedures

We recruited participants from 2019 to 2023; however, to comply with COVID-19 restrictions, we halted recruitment from March to July 2020. Additionally, due to slow recruitment, in August 2022, we expanded our efforts and launched a media campaign through the Type 1 Diabetes Exchange to advertise for the trial nationally. Our inclusion criteria were parents (including legal guardians) of young children with T1D, aged

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2 - 6.99 years old, ≥6 months post diagnosis, and using intensive insulin therapy. We excluded parents if their child had a comorbid chronic condition (eg, renal disease), their child was allergic to the adhesive or skin preparation used for continuous glucose monitors (CGMs), their child was on conventional insulin therapy, or parents did not identify as English speaking. We did not restrict families based on the child's HbA_{1c}, though we required young children to be at least 6 months post diagnosis to allow for their HbA_{1c} to begin to stabilize following insulin initiation. We targeted parents who self-identified as primarily responsible for their child's daily T1D management to complete the treatment sessions and study questionnaires. However, parents who identified as a secondary caregiver for daily T1D management were also welcome to attend the treatment sessions, and multiple caregivers from the same family were able to participate together if preferred, though only one caregiver was included in our analyses.

We used both in-clinic and remote recruitment procedures. We screened all families who expressed an interest in participating in the trial for eligibility. After obtaining parent-informed consent, we randomized families 1:1 to either our treatment (REDCHiP) or ATTN. Families then completed visit 1, which included REDCap (Research Electronic Data Capture) [25] questionnaires and a measurement of child HbA_{1c} via a validated home kit, which was analyzed in a central lab. Families completed visit 2 at the end of the treatment phase and visit 3 approximately 3 months later. Visits 2 and 3 repeated the same study procedures as visit 1.

We compensated families for completing the study visits (US $35 per study visit). Parents received this incentive via a reloadable debit card (Clincard). We also gifted children a toy, valued at up to US $15, at each study visit as a thank you for completing the home HbA_{1c} kit.

Study Conditions

REDCHiP

Parents randomized to REDCHiP participated in 10 video-based telehealth sessions completed over a 12-week period [13]. There was a combination of individual and group sessions. Initially, parents attended 3 individual sessions and 7 group sessions. However, due to COVID-19 and scheduling challenges, we modified the format to 7 individual and 3 group sessions without changing content. Individual and group sessions typically lasted between 30 and 60 minutes each.

REDCHiP leaders included licensed psychologists, supervised psychology trainees, and a certified diabetes educator. They completed structured training in REDCHiP content and delivery, shadowed experienced leaders, and co-led sessions before leading sessions independently. They also received ongoing supervision from one of the designers of REDCHiP during intervention delivery to promote fidelity to the manual and consistent application of cognitive-behavioral strategies. For individual sessions, parents worked one-on-one with a REDCHiP leader, while group sessions brought together up to 5 parents and 1 - 2 trained REDCHiP leaders. We digitally recorded sessions and reviewed about one-third to code for treatment fidelity.

ATTN

Parents randomized to ATTN completed 10 video-based telehealth sessions over 12 weeks, matching REDCHiP in dose and format [13]. Initially, ATTN included 3 individual and 7 group telehealth sessions, but we later modified the schedule to 7 individual and 3 group sessions to remain consistent with REDCHiP. Individual and group sessions lasted 30 - 60 minutes.

ATTN leaders included supervised psychology trainees and clinical trials assistants. They completed structured training in ATTN content and delivery, shadowed experienced leaders, and co-led sessions before leading independently. During the sessions, parents learned content relevant to all parents of young children, such as important developmental milestones, child health and safety, school readiness, early childhood literacy, and positive parenting strategies. Leaders redirected any T1D-related questions to the child's T1D care team. We digitally recorded sessions and reviewed about one-third to code for treatment fidelity.

Measures

Families randomized to REDCHiP or ATTN completed the same online questionnaires, and young children completed a validated home HbA_{1c} kit. We previously published a description of our trial battery [13]. For this report, we focus on describing our sample characteristics and examining treatment effects based on changes in parent FH and diabetes distress and child HbA_{1c}.

Family and Children's T1D History

In visit 1, parents completed a study-specific questionnaire to describe themselves (age, sex, relationship to the child, race and ethnicity, marital status, and highest grade completed) and their child (age, sex, race and ethnicity, date of T1D diagnosis, T1D treatment regimen, and history of severe hypoglycemia).

Hypoglycemia Fear

At all study visits, parents completed the 22-item Hypoglycemia Fear Survey-Parents of Young Children (HFS-PYC) [6], which measures FH based on worries and the frequency of hypoglycemic avoidance behaviors. Parents respond to items using a 5-point Likert scale (1=Never to 5=Very Often), with higher scores indicating greater fear. In line with published scoring recommendations, we removed 4 items with poor performance for young children on intensive insulin therapy, resulting in a modified initial total score (range=22 - 110). To enhance interpretation, we rescored the HFS-PYC to fit a 0 - 100 scale by calculating the item mean score and multiplying by 20.

Diabetes Distress

At all study visits, parents completed the 18-item Problem Areas in Diabetes-Parent Revised (PAID-PR) [26], which is a validated measure of parent-reported diabetes distress. Parents respond to items using a 5-point Likert scale (0=Not a problem-4=Serious problem). The PAID-PR scoring uses a 0 - 100 scale with higher scores indicating greater distress. Additionally, a total score ≥56 may indicate the presence of significantly elevated diabetes distress [27].

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Depressive Symptoms

At all study visits, parents completed the 20-item Center for Epidemiological Studies Depression Scale-Revised (CESD-R) [28,29], which is a measure of depressive symptoms over the past 2 weeks. Parents respond to items using a 5-point Likert scale (0=Not at all-4=Nearly every day). Based on normative data, a total score ≥16 suggests elevated depressive symptoms [29]. We dichotomized parent depressive symptoms, categorizing CESD-R scores ≥16 as "elevated depressive symptoms" and scores <16 as "non-elevated symptoms." We included the presence of elevated depressive symptoms as a covariate in all models because of its known association to FH and distress in the extant literature [30,31].

Child HbA_{1c}

At all study visits, children completed a validated home HbA_{1c} kit [32] to obtain a proxy measure of children's average glycemia using a finger-prick blood sample. We analyzed the samples in a single laboratory using automated high-performance liquid chromatography with measurement methods reliable to Diabetes Control and Complications Trial standards (reference range 4.0% - 6.0%; Tosoh 2.2; Tosoh Corporation) [33].

Sample Size and Power

We conservatively based our original power analysis on the assumption of completing 40 groups (20 REDCHiP and 20 ATTN) with an average size of 3.6 parents (40×3.6=144, or a final sample of n=144 parents). Based on this sample size, a standardized effect size of 0.4 SDs, and an intraclass correlation of 0.10, we projected an estimated power of 85%. We originally estimated an attrition rate of 20%, thereby setting our target sample size at 180 families. However, during the trial years affected by COVID-19, we experienced a higher rate of attrition. Thus, to account for this higher attrition rate, we over-recruited for the trial; our final sample comprised 197 families.

Statistical Analyses

To compare families randomized to REDCHiP or ATTN based on sociodemographic characteristics collected at visit 1, we used independent 2-tailed *t* tests, chi-square tests, or 2-sample Wilcoxon rank-sum tests for nonnormally distributed variables. Because preliminary analyses indicated correlations between parent depressive symptoms and both FH and distress, we elected to include the presence of elevated parental depressive symptoms as a covariate in all our models to better isolate treatment effects. To examine reductions in parents' FH (primary outcome), we ran a mixed effects model with participant as a random effect and fixed effects for randomization (REDCHiP or ATTN), visit (slope of the respective outcome over the study timeline), and the interaction of randomization by study timeline. For diabetes distress (secondary outcome), we repeated the mixed effects model when analyzing distress as a continuous variable. We conducted a logistic regression to analyze distress dichotomously (elevated vs not elevated) as a sensitivity analysis to examine whether parents were less likely to report clinically elevated distress over time based on an established threshold, using the same random effect structure and covariate. In exploratory analyses, we examined reductions in child HbA_{1c} by repeating the mixed effects model. We conducted all analyses in StataNow/SE 18.5 (StataCorp LLC). Because our hypotheses were directional and prespecified, we applied one-sided *P* values to test for changes in the expected direction. We did not adjust for multiplicity because we designed the trial as an ORBIT Phase 2b study exploring treatment effects rather than providing definitive efficacy estimates [23]. Consistent with CONSORT (Consolidated Standards of Reporting Trials; Checklist 1) reporting guidelines [34], we report estimates of effect sizes for observed treatment-slope trends based on the methods described by Feingold [35] to aid interpretation of the magnitude of change; they should not be interpreted as evidence of statistical significance.

Ethical Considerations

We operated this multisite RCT under a single institutional review board (IRB) agreement, with Children's Mercy Hospital-Kansas City as the IRB of record. We used IRB-approved procedures to obtain electronic documentation of parent informed consent before enrolling parents into the trial. All children were younger than 7 years; therefore, we did not require separate child assent. We registered the trial on ClinicalTrials.gov (NCT3914547) before proceeding with any trial activities. We collected and managed study data using secure, password-protected systems and deidentified all data prior to analysis. Participation involved minimal risk, and parents could skip questionnaire items or withdraw from the study at any time without penalty. We compensated participants for their time.

Results

Sample Characteristics

We enrolled 197 families of young children with T1D and randomized 183 families (n=93 to REDCHiP and n=90 to ATTN). At visit 1, we collected parent and child demographics. Young children had a mean age of 4.4 (SD 1.2) years, a mean HbA_{1c} of 7.54% (SD 1.15), and a mean time since diagnosis of 1.67 (SD 1.15) years. Children were 55% (100/183) male. Parents had a mean age of 36.3 (SD 5.9) years and 93% (170/183) self-identified as the child's mother. Table 1 displays sample characteristics and comparisons by group. The CONSORT table details our recruitment and retention across the seven-and-a-half-month trial (Figure 1). Of the total enrolled, 77% (152/197) of families completed all study visits.

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Table . Sample characteristics.

Demographics	Overall (n=183)	REDCHiP[a] (n=93)	ATTN[b] (n=90)
Child characteristics			
Age (years), visit 1, mean (SD)	4.4 (1.2)	4.5 (1.2)	4.3 (1.2)
Sex (male), n (%)	100 (55)	51 (55)	49 (54)
Parent characteristics			
Visit 1, n	177	90	87
Age (years), mean (SD)	36.3 (5.9)	36.7 (5.3)	35.9 (6.6)
Sex (female), n (%)	170 (93)	84 (90)	86 (96)
Marital status (partnered), n (%)	169 (92)	90 (97)	79 (88)
Highest parental education (college graduate and above), n (%)	113 (62)	61 (66)	52 (58)
Family race and ethnicity			
Non-Hispanic White, n (%)	147 (80)	80 (86)	67 (74)
Non-Hispanic Black, n (%)	5 (3)	1 (1)	4 (4)
Hispanic or Latinx, n (%)	18 (10)	3 (3)	15 (17)
Asian, n (%)	2 (1)	2 (2)	0 (0)
Native American, n (%)	1 (<1)	0 (0)	1 (1)
More than one race, n (%)	10 (5)	7 (8)	3 (3)
Clinical characteristics			
HbA_{1c}[c] (visit 1), n	178	88	—[d]
HbA_{1c} (%), mean (SD)	7.54 (1.15)	7.42 (1.02)	7.65 (1.26)
Since diagnosis (at visit 1), n	182	—	89
Time since diagnosis (years), at visit 1, mean (SD)	1.67 (1.15)	1.55 (1.00)	1.78 (1.28)
CGM[e] use, n (%)	151 (83)	78 (84)	73 (81)
AID[f] use, n (%)	93 (51)	45 (48)	48 (53)

[a]REDCHiP: Reducing Emotional Distress for Childhood Hypoglycemia in Parents.

[b]ATTN: attention control condition.

[c]HbA_{1c}: hemoglobin A_{1c}.

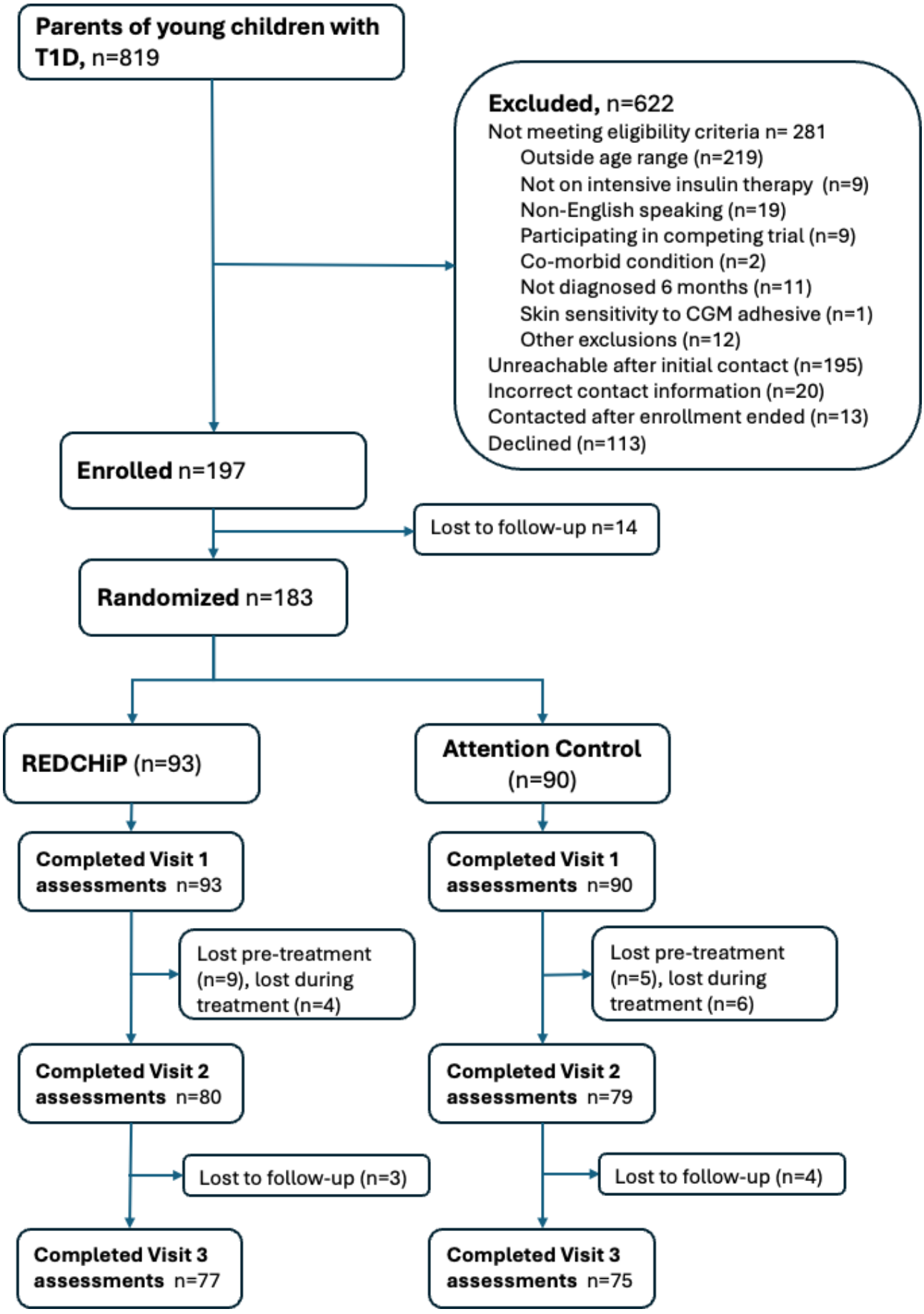
[d]Not applicable.

[e]CGM: continuous glucose monitor.

[f]AID: automated insulin delivery.

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Figure 1. CONSORT (Consolidated Standards of Reporting Trials) diagram. REDCHiP: Reducing Emotional Distress for Childhood Hypoglycemia in Parents.



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Intervention Characteristics

Overall, parents randomized to REDCHiP attended 95.2% of sessions, and parents randomized to ATTN attended 95.9% of sessions. While there was no difference in the mean length of group sessions for the REDCHiP and ATTN arms (*P*=.22), there was a difference in the mean length of individual sessions for the REDCHiP and ATTN arms (*P*=.003). Specifically, individual sessions in the REDCHiP arm were on average 7 minutes longer in duration than individual sessions in the ATTN arm (mean 39.6, SD 4.2 vs mean 32.7, SD .7 minutes for REDCHiP and ATTN, respectively). We coded treatment fidelity for 170 out of 517 (33%) of ATTN sessions and 199 out of 532 (37%) of REDCHiP sessions using structured, session-specific checklists. Overall, both arms achieved a high treatment fidelity rate (85/100, 85% for ATTN and 89/100, 89% for REDCHiP).

Survey Outcomes

Table 2 describes outcomes for parent FH, diabetes distress, and the percentage of parents with clinically elevated depressive symptoms for the entire sample and within each treatment arm. Across both arms, parent FH, diabetes distress, and the percentage of parents with clinically elevated depressive symptoms decreased from visits 1 to 3. However, at all study visits, parents with clinically elevated depressive symptoms reported higher FH and distress than parents without clinically elevated depressive symptoms (*P*=.001; Table 3).

Table . Survey outcomes at each time point by group.

Overall	REDCHiP[a]			ATTN[b]		
	Visit 1	Visit 2	Visit 3	Visit 1	Visit 2	Visit 3
Hypoglycemia fear, mean (SD)	55.44 (13.42)	49.43 (10.95)	46.89 (9.46)	57.43 (14.38)	53.30 (13.24)	51.75 (12.02)
Diabetes distress, mean (SD)	43.00 (19.70)	29.57 (16.67)	28.01 (15.29)	46.14 (20.90)	39.05 (22.05)	34.70 (20.16)
Clinically elevated depressive symptoms, n (%)	40 (43)	22 (28)	18 (23)	37 (41)	23 (29)	15 (20)

[a]REDCHiP: Reducing Emotional Distress for Childhood Hypoglycemia in Parents.

[b]ATTN: attention control condition.

Table . Hypoglycemia fear and diabetes distress over time by presence of elevated depressive symptoms.

*insertMeasure	Parents with elevated depressive symptoms	Parents without elevated depressive symptoms	*P* value
Visit 1, mean (SD)			
Hypoglycemia fear	61.74 (13.92)	52.56 (12.59)	.001
Diabetes distress	57.18 (17.21)	35.36 (17.26)	.001
Visit 2, mean (SD)			
Hypoglycemia fear	57.49 (11.90)	48.93 (11.57)	.001
Diabetes distress	47.31 (20.20)	29.13 (17.55)	.001
Visit 3, mean (SD)			
Hypoglycemia fear	55.48 (11.36)	47.57 (10.36)	.001
Diabetes distress	49.16 (16.23)	26.35 (15.32)	.001

Mixed Effects Models

In a series of mixed effects models, we examined treatment effects for parents' FH and diabetes distress, with randomization (REDCHiP or ATTN), visit (slope of the respective outcome over study timeline), interaction of randomization by study timeline, and presence of elevated depressive symptoms as covariates. In our first model, results revealed that parents' FH decreased over time for both treatment arms (coefficient=−2.57; 95% CI −3.81 to −1.33; *P*=.001), with a treatment-slope effect that slightly favored the REDCHiP group, though it was not significant (coefficient=−1.16; 95% CI −2.88 to 0.57; *P*=.09). Similarly, in our second model, results revealed a decrease in parents' diabetes distress over time for both treatment arms (coefficient=−3.93; 95% CI −5.63 to −2.23; *P*=.001), with a nonsignificant treatment slope effect (coefficient=−1.87; 95% CI −4.23 to 0.50; *P*=.06) that slightly favored the REDCHiP group. Although the interaction terms were not statistically significant, we calculated effect sizes to describe the magnitude of observed trends in accordance with CONSORT recommendations [34]. For parents' FH, the effect size for REDCHiP was Feingold d=0.18, and for diabetes distress, the effect size for REDCHiP was Feingold d=0.21.

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Logistic Regression

We also examined treatment effects for parents dichotomized as having either clinically elevated or not elevated diabetes distress, with randomization (REDCHiP or ATTN), visit (slope of the respective outcome over the study timeline), interaction of randomization by study timeline, and presence of elevated depressive symptoms as covariates. There was no time effect (coefficient=−0.25; 95% CI −0.61 to −0.11; *P*=.08). However, we observed a significant treatment-slope effect (coefficient=−0.70; 95% CI −1.35 to −0.05; *P*=.02), suggesting that, over time, REDCHiP parents were less likely to endorse clinically elevated diabetes distress.

Glycemic Outcomes

In mixed effects models, we explored treatment effects for children's HbA_{1c}, with randomization (REDCHiP or ATTN), visit (slope of the respective outcome over study timeline), interaction of randomization by study timeline, and presence of elevated depressive symptoms as covariates. Results revealed a small but nonsignificant reduction in child HbA_{1c} over time for both treatment arms (coefficient=−0.05; 95% CI −0.12 to 0.03; *P*=.11), with a nonsignificant treatment-slope effect for children of parents in the REDCHiP group (coefficient=0.04; 95% CI −0.06 to 0.15; *P*=.21).

Discussion

Overview

Our aim was to examine the source of treatment effects for REDCHiP, a telehealth-delivered intervention to reduce FH in parents of young children with T1D, by conducting an RCT. We recruited a large sample of parents from across the United States and randomized them to receive either REDCHiP or an attention control treatment (ATTN). We hypothesized parents receiving REDCHiP would report greater reductions in FH and diabetes distress compared to parents who were randomized to ATTN. We also explored whether children experienced an HbA_{1c} reduction based on parents' exposure to REDCHiP or ATTN.

Primary Results

Contrary to our primary hypothesis, our results suggest that all participating parents experienced significant reductions in FH with treatment-slope effects that slightly favored REDCHiP parents and were nonsignificant (*P*=.09). When we examined parents' diabetes distress as a secondary outcome, our model with diabetes distress as a continuous variable showed a similar time and treatment slope effect (*P*=.06). However, the model analyzing diabetes distress as a dichotomous variable identified a significant treatment-slope effect for REDCHiP. Specifically, we found that parents receiving REDCHiP were less likely to report clinically elevated diabetes distress over time than parents receiving ATTN (*P*=.02). Our results also suggest a small and nonsignificant decrease in children's HbA_{1c} over time, regardless of intervention group.

Although both REDCHiP and ATTN were associated with reductions in FH and diabetes distress, the reasons for improvement in the ATTN group remain unclear. ATTN sessions did not include content on emotional regulation or stress management, and there is limited evidence that general support groups reduce anxiety or depressive symptoms in adults [36]. One possibility is that nonspecific factors, such as social connection during sessions (especially surrounding the COVID-19 pandemic), contributed to improvements, though this is only speculative and would require further dismantling studies to confirm. Importantly, we designed ATTN as a comparator versus its own scalable intervention. Furthermore, it is unknown whether a longer follow-up post treatment would reveal greater divergence between groups. In a context where virtually no interventions exist to address FH in parents of young children with T1D, we believe the observed reductions, even if nonsignificantly different by condition, represent an important step forward in the field.

While there is an emerging trend in testing new behavioral interventions uniquely tailored to parents of young children with T1D, the literature remains small compared to parents of older children with T1D [37]. As such, we believe this trial adds valuable insight into how to support parents of young children with T1D in managing symptoms of FH and diabetes distress. Moreover, because this is the first behavioral intervention trial among parents of young children with T1D to use an attention control arm, we assert that it marks a notable improvement in trial design rigor directed at families of young children with T1D [38,39].

Our trial recorded a very high attendance rate (~95% of sessions attended) for parents randomized to REDCHiP and ATTN. We think the telehealth format of our treatments was likely the main contributor to our high session attendance. Parents could participate from home, thereby eliminating typical barriers to traditional, in-person behavioral health sessions (eg, transportation, childcare, and time off from work) [19,21,22]. However, it is possible another contributor to our high attendance rate may be parents' keen interest in receiving support for the emotional and behavioral challenges of managing T1D in their young child. Indeed, our telehealth format allowed us to recruit nationally, potentially reaching families who may not have access to behavioral health care through their local diabetes center [40]. Thus, it appears REDCHiP's telehealth format helped enhance feasibility and engagement in this trial and may provide preliminary evidence to support its broader dissemination and integration into pediatric diabetes care through existing telehealth infrastructure.

Though we did not find support for our main hypothesis, our trial builds on previous research that suggests that parents of young children with T1D may be particularly vulnerable to FH [3,6]. Parents in this trial reported baseline levels of FH that were comparable to levels reported in published studies [6]. We think this is notable in the context of our sample's high rate of personal CGM (151/183, 83%) and automated insulin delivery (AID; 93/183, 51%) use. Within the larger literature, the results are mixed as to whether CGM and AID use are associated with lower FH in parents of young children [11,41-43]. Thus, our data may further support the notion that some parents require treatment specifically focused on their fear to experience any improvements [36]. We also think it is notable that REDCHiP parents experienced an absolute mean reduction in FH (−8.22)

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that was comparable to our previous REDCHiP pilot trial (−9.02) [12]. This may suggest that REDCHiP is still an effective treatment in helping parents to learn the skills to manage FH, even though the reduction was only slightly and non-significantly greater than among ATTN parents.

Our trial examined reductions in parents' diabetes distress using 2 approaches, as a continuous variable and as a dichotomous variable based on clinically elevated versus nonelevated diabetes distress. We examined distress as a continuous variable to provide a precise estimate of treatment effects and calculate effect sizes. We conducted a sensitivity analysis using the dichotomous measure to assess clinical significance, whether parents moved from elevated to nonelevated distress, a threshold clinics would likely use to guide referral and treatment decisions. Results suggested that REDCHiP had a small effect on parents' diabetes distress when analyzed continuously, with an absolute mean reduction (−12.88) comparable to our pilot trial (−11.11) [12]. This suggests REDCHiP helped parents manage diabetes distress, even if the treatment-specific effect was attenuated by the ATTN group. However, when analyzed dichotomously, exposure to REDCHiP was associated with a lower occurrence of elevated distress over time compared to ATTN, suggesting REDCHiP may help parents achieve clinically meaningful reductions in diabetes distress. This finding may be particularly relevant for clinical practice.

It is important to recognize the impact of a parent report of elevated depressive symptoms on FH and diabetes distress. At every assessment point and regardless of treatment group, parents with elevated depressive symptoms reported significantly higher FH and diabetes distress than parents without depressive symptoms. Unfortunately, we conducted this trial during the COVID-19 pandemic, a time when depressive symptoms were on the rise and parents of children vulnerable to COVID-19 were more likely to report depressive symptoms than adults prepandemic [44]. While not formally recorded, many parents in our trial described limiting social behaviors or not enrolling children in childcare or preschool. Many parents reported challenges in balancing working from home with parenting secondary to the COVID-19 pandemic. Moreover, some parents described additional concerns specific to COVID-19 and its potential added risk in youth with chronic illness. In our earlier REDCHiP pilot, we did not observe a change in parents' depressive symptoms after exposure to the intervention [12]. We believe this may be because REDCHiP focuses specifically on changing parents' unhelpful thoughts and behaviors related to fear. Nevertheless, the data from this trial suggest that parents with elevated depressive symptoms may require a different treatment approach. Therefore, a future direction could be to adapt REDCHiP to incorporate strategies specifically targeting depressive symptoms, such as behavioral activation [45], to better support parents experiencing depressive symptoms and FH.

While our trial demonstrated a small but nonsignificant reduction in child HbA_{1c} related to parent exposure to either REDCHiP or ATTN, this outcome may be expected. In our REDCHiP pilot, we only observed a small change in HbA_{1c} among young children who started the trial with an HbA_{1c} that was above the clinical target [12]. In the current sample, nearly one-third of young children had a baseline HbA_{1c} <7%. This suggests the possibility that we may have encountered a floor effect; there was simply not enough variability in young children's HbA_{1c} to detect a meaningful change. In the future, it may be helpful to use young children's CGM data to explore any glycemic changes related to their parents' exposure to REDCHiP or stratify enrollment by baseline child HbA_{1c} to better detect glycemic effects.

Limitations

Our use of a large national sample may enhance the generalizability of our results, though as a limitation we acknowledge that our sample was majority non-Hispanic White and that future research should explore the efficacy of REDCHiP in a more racially and ethnically diverse sample. Related, we acknowledge a limitation in that our trial primarily recruited mothers versus fathers and other caregivers. Because less is known about FH in fathers and other caregivers of young children with T1D [4], it is important that future research explore these other caregivers' experience with FH and response to treatment. We acknowledge a limitation in that we did not restrict our sample to only include families of children with an above-target HbA_{1c}. We made this decision based on past data showing moderately high levels of FH even among parents of young children with an HbA_{1c} at or below their target [6]. Nonetheless, to see any child glycemic effects related to parents' exposure to REDCHiP, it may be important for future trials to limit enrollment to families of young children with an above-target HbA_{1c}. Because this trial included multiple outcomes and 1-sided *P* values without adjustment for multiplicity, we acknowledge the risk of type 1 error. We made these analytic decisions to prioritize clinical relevance and to explore treatment effects in this Phase 2b trial. Nevertheless, future studies should confirm these findings using more conservative approaches. As important strengths of the trial, we highlight the high rate of CGM and AID use among young children, our use of a central laboratory to analyze children's HbA_{1c}, our acceptable retention rate, our high attendance rate (~95% of sessions), our relatively low rate of data missingness (<10%) [46], and our rigorous trial design that included an attention control condition [38] and an assessment of treatment fidelity.

Conclusions

In summary, even with uptake of CGM and AID in young children with T1D, some parents continue to experience FH and diabetes distress and may require specialized treatment. REDCHiP is a telehealth-delivered intervention to reduce FH in parents of young children with T1D. Though our trial shows treatment-slope effects that only slightly and nonsignificantly favored REDCHiP parents with respect to FH and diabetes distress, we remain optimistic with respect to REDCHiP's potential treatment impact. We found that parents' exposure to REDCHiP was associated with a lower occurrence of elevated diabetes distress over time than ATTN. Also, we observed that parents exposed to REDCHiP reported high treatment satisfaction. REDCHiP aligns with broader trends in pediatric

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digital behavioral health with its remote delivery, personalization, and integration of evidence-based strategies from cognitive behavioral therapy and behavioral parent training into parents' daily T1D care [19]. Moreover, because of its telehealth format, it is possible REDCHiP could be integrated into pediatric diabetes care as a first-line treatment, leaving more intensive in-person treatment for families with more complex needs [40]. Future refinements and adaptations of REDCHiP will aim to increase its treatment effect, especially for parents experiencing comorbid depressive symptoms and young children with elevated HbA_{1c}. We also intend to explore ways to tailor REDCHiP for other caregiver populations, including fathers, grandparents, and teachers. Finally, future adaptations of REDCHiP will explore how to incorporate other digital health delivery methods, such as asynchronous content for self-paced learning and mobile app integration to track and reinforce skill learning to further promote its scalability and implementation.

Acknowledgments

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Data Availability

Data supporting the findings of this trial are not publicly available due to participant privacy and institutional restrictions. Deidentified data may be made available upon reasonable request to the corresponding author, contingent on appropriate data use agreements and ethical approvals.

Authors' Contributions

Conceptualization: SRP
Formal analysis: DDW
Writing – original draft: SRP
Writing – review & editing: SRP, DDW, NK, HO, KD, MC

Conflicts of Interest

SRP reports receiving grants from the National Institutes of Health; honorarium from the American Diabetes Association; and serving on a Clinical Advisory Board for Glooko, Inc. MC is Chief Medical Officer of Glooko, Inc, and has received research support from Dexcom and Abbott Diabetes Care. HO is a consultant at Sanofi. All other authors declare no conflict of interest.

Checklist 1
CONSORT checklist for eHealth trials.
[PDF File, 2778 KB - pediatrics_v9i1e86616_app1.pdf]

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Abbreviations:

AID: automated insulin delivery
ATTN: attention control condition
CESD-R: Center for Epidemiologic Studies Depression Scale-Revised
CGM: continuous glucose monitor
CONSORT: Consolidated Standards of Reporting Trials
FH: fear of hypoglycemia
HbA_{1c}: hemoglobin A_{1c}
HFS-PYC: Hypoglycemia Fear Survey-Parents of Young Children
IRB: institutional review board
ORBIT: Obesity-Related Behavioral Intervention Trials
PAID-PR: Problem Areas in Diabetes-Parent Revised
RCT: randomized clinical trial

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REDCap: Research Electronic Data Capture
REDCHiP: Reducing Emotional Distress for Childhood Hypoglycemia in Parents
T1D: type 1 diabetes

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Caring for a Child With Cerebral Palsy: Cross-Sectional Study

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Abstract

Background: Caregivers of children with cerebral palsy (CP) encounter unique challenges that are not common in typical families. The distress of these families starts in the diagnosis period, which is marked by a "wait and see" approach, and continues because of the lack of a clear prognosis.

Objective: This study aimed to identify the level of perceived ease of care faced by families of children with CP in Kuwait and its effect on their satisfaction with daily activities.

Methods: This cross-sectional study recruited caregivers of children with CP aged 5 to 16 years. The Ease of Caregiving for Children (ECC) scale, the self-care domain of the Child Engagement in Daily Life Measure (CEDLM), and the Satisfaction with Daily Occupations (SDO) questionnaire were used.

Results: Fifty-three caregivers participated (mean age 39.77, SD 7.56 years; children's mean age 8.04, SD 2.57 years; Gross Motor Function Classification System: level I, n=18; level II, n=10; level III, n=13; level IV, n=5; and level V, n=7). ECC score was significantly correlated with SDO score (P=.03) and the participation score in the self-care scale of the CEDLM (P=.001).

Conclusions: Challenges of caring for a child with CP are positively correlated with caregivers' satisfaction with daily activities and the child's self-care abilities. Regular check-ins with caregivers and the establishment of support groups for caregivers would help with providing help sooner. Qualitative assessment is needed to explore these challenges in this region.

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KEYWORDS

cerebral palsy; caregivers; self-care; satisfaction

Introduction

Cerebral palsy (CP) is a group of permanent, nonprogressive disorders that affect the infant and fetal brain, hindering the development of movement and posture [1,2]. Children with CP may experience impairments such as sensory disturbances, cognitive disabilities, communication limitations, behavioral disorders, epilepsy, and secondary musculoskeletal problems [2,3]. Other comorbidities reported in children with CP include pain, bladder control problems, blindness, sleep disorders, and hip displacement [3,4].

Caregivers of children with CP encounter unique challenges that are not commonly seen among caregivers in typical families. The distress of these families starts with the diagnosis period, which is marked by a "wait and see" approach, and continues because of the lack of a clear prognosis [4,5]. The exploratory journey that is required to discover the type of comorbidities children with CP exhibit is another demanding task for caregivers [6]. Later on, caregivers of children with CP are confronted by the constant challenges displayed by their child and the ever-present need to engage in problem-solving [2,4,6]. Families of children with CP also express concern about the transition to adolescence and, later, adulthood for these children and the level of independence they can achieve [7]. This roller coaster takes a toll on caregivers of children with CP as individuals and on the family unit as a whole [8-10]. In a recent systematic review exploring the lived experience of caregivers, the burden of caring for a child with CP was positively correlated with feelings of depression [8]. Other factors that were associated with increased caregiver burden in this group were self-efficacy and anxiety among caregivers [11,12]. Interestingly, despite the degree of depression and anxiety leading to burden, feelings of resilience have also been explored and were found to be moderately negatively correlated with caregiver burden [10].

Literature exploring burden has primarily highlighted the impact of caregiver-related factors on caregiver burden but has rarely included child-related factors (eg, child functional level or cognitive level) [8]. It is therefore imperative to include the child's behavior, family function, and caregiving demand when exploring caregiver burden, given that they have been noted to be key predictors for caregivers' well-being [13,14].

Despite the abundance of current literature that has greatly contributed to our understanding of the dynamics of the burden experienced by caregivers of children with CP, most of these studies have been conducted in high-income countries (ie,

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Canada, South Korea, and Spain). Although Kuwait is a high-income country, the information available in the literature on caregivers' burden in Kuwait is scarce. Cultural differences in the region call for the need to explore these variables. Examining these variables (ie, caregiver burden) would allow for better tailoring of interventions to meet the needs of families with children with CP. Kuwait, similar to its surrounding region in the Arabian Peninsula (ie, Kingdom of Saudi Arabia and United Arab Emirates), has a cultural structure that is very different from that of the Western world. The family-centered culture and the availability of hired, live-in domestic caretakers [15] present a distinctive combination of advantages and disadvantages, which merits further exploration.

This study aimed to identify (1) the level of perceived ease of care faced by families of children with CP aged 5 to 16 years in Kuwait, (2) the child factors (demographics and level of independence) that influence this perceived level of burden, and (3) the relationship between the perceived level of burden and Satisfaction With Daily Occupations (SDO) score among caregivers of children with CP in Kuwait. The age range was chosen based on the cutoff used for children with CP in pediatric rehabilitation departments in Kuwait.

Methods

Ethical Considerations

This project was approved by the ethics committee at the Ministry of Health in Kuwait (2021/1865). The study adhered to the Declaration of Helsinki. Electronically signed informed consent forms were obtained from all participants.

Design

This cross-sectional study used a web-based questionnaire to assess the level of perceived ease of care faced by families of children with CP aged 5 to 16 years. Inclusion criteria were (1) being a caregiver of at least one child aged 5 to 16 years with a documented diagnosis of CP, (2) residing in and receiving care in Kuwait (ie, working or studying), and (3) being able to communicate effectively (ie, read and write) in either Arabic or English. A purposive nonprobability sampling method was used to recruit participants. Study flyers were distributed in waiting rooms of rehabilitation clinics throughout Kuwait to inform parents of children with CP about the study. Interested parents contacted the research team. After screening for the inclusion and exclusion criteria, parents were sent an electronic form to complete.

Procedure

Health care professionals in rehabilitation clinics around Kuwait working with developmental disorders were contacted by the research team and asked to inform their clients about the study using the study flyer. Participants who agreed to take part in the study were screened for the inclusion and exclusion criteria, then sent a link to the web-based form. Participants were asked to complete an electronic form about the demographics of the caregivers and the child with CP for whom they were providing care. Caregiver-related variables included age, gender, educational level, marital status, working hours, and the number of other caregivers. Child-related variables included age, gender, topographic type, Gross Motor Function Classification System (GMFCS) level, hand function (ie, independent, partially dependent, or totally dependent), height and weight, and schooling situation. Next, participants scored their experience using (1) the Ease of Caregiving for Children (ECC) measure, (2) participation in the self-care domain of the Child Engagement in Daily Life Measure (CEDLM), and (3) the SDO measure. The language in which each of the tools was presented was based on the participant's preferences.

Instruments

ECC is a self-reported tool developed to examine the physical demands of caring for a child with CP [16]. Caregivers were asked to rate their perceived level of physical demands associated with caring for children using 12 items relating to mobility, positioning, and self-care. The level of demand was rated using a 5-point Likert scale (1="very difficult" to 5="no help is needed"). Higher scores (maximum 60) indicate greater ease of care perceived by the caregiver (ie, less burden of caregiving) [17]. Both English and Arabic versions were reliable (intraclass correlation coefficient [ICC] >0.69) and valid [17,18]. Cultural adaptation was established in Arabic [17].

The self-care domain of the CEDLM is an 18-item caregiver-reported measure that assesses the caregivers' perceptions of the child's level of independence with their self-care activities (eg, toileting, dressing, feeding, drinking, and grooming) [17]. The level of independence is rated using a 5-point Likert scale (1="does not do the activity" to 5="does the activity independently most of the time"). A high level of independence with self-care activities is indicated by a higher score (maximum 90) [17]. Both English and Arabic versions of the scale were reliable (ICC=0.96) and valid [17,19]. Cultural adaptation was established in Arabic [17].

The SDO is a self-reported tool that was used to assess caregivers' satisfaction with daily activities. This tool explores different daily activities where a higher score indicates a higher level of participation and satisfaction across the constructs of work (4 items), leisure (3 items), home management (4 items), and self-care (3 items) [20,21]. This 14-item tool examines level of performance (range 0 - 14) and the level of satisfaction (range 14 - 70) [20,21]. Reliability (ICC=0.93) and validity of both Arabic and English versions of the scale were established [20,21]. Cultural adaptation was established in Arabic [20].

Data Analysis

The data were analyzed using SPSS Statistics for Windows (version 27.0; IBM Corp). The statistical significance level was set at α=.05 and normality of all variables was explored using the Shapiro-Wilk test. Normally distributed variables were assessed using parametric tests, whereas variables that did not follow a normal distribution were assessed using nonparametric tests. Descriptive variables were expressed as mean and SD for continuous variables and as count (n) and percentage (%) for categorical variables. BMI was calculated and presented according to the classification presented by Hurvitz et al [22].

For both the ECC and self-care domain of the CEDLM, the scaled scores (using the conversion tables) [16] were calculated. The chi-square test was used to assess whether the prevalence

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of the CP burden, the independence of the child, and the satisfaction of the caregiver differed across categories of sociodemographic factors. Because cutoff scores were not established for these questionnaires, a 50% cutoff was used for all the tools (scaled score of ECC ≤40=substantial burden; scaled score of CEDLM ≥50.2=independent child; score of SDO ≥56=satisfied with daily occupation). These suggested cutoffs were used to establish categorization for each tool and enhance interpretation of the tools. The established criteria enabled comparison between scales. Regarding the self-care domain of the CEDLM and ECC items, the independent 1-tailed *t* test, and Mann-Whitney *U* test were used to assess the difference in means across the questionnaire items. The relationship between the total score of each of the tools (ie, ECC, the self-care domain of the CEDLM, and SDO) was evaluated using Pearson correlation coefficients.

Results

A total of 53 caregivers (n=40, 75.5% female) participated in this study with a mean age of 39.77 (SD 7.56) years (Table 1). The mean age of the children with CP was 8.04 (SD 2.75) years (GMFCS: 1: level I, n=18; level II, n=10; level III, n=13; level IV, n=5; and level V, n=7).; Table 2). All participants chose to use the Arabic forms of the assessment tools.

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Table . Characteristics of the study sample—caregiver data[a].

	Total sample (n=53)	Ease of Caregiving for Children			Child Engagement in Daily Life Measure			Satisfaction With Daily Occupations		
		Significant burden (n=17)	No significant burden (n=36)	*P* value[b]	Independent (n=25)	Dependent (n=28)	*P* value[b]	Yes (n=12)	No (n=41)	*P* value[b]
Sex, n (%)				.60			.41			.13
Male	13 (24.5)	4 (23.5)	9 (25)		7 (28)	6 (21.4)		1 (8.3)	12 (29.3)	
Female	40 (75.5)	13 (76.5)	27 (75)		18 (72)	22 (78.6)		11 (91.7)	29 (70.7)	
Age (years), mean (SD)	39.77 (7.56)	41.24 (7.90)	39.08 (7.32)	.34	37.76 (6.36)	41.57 (8.08)	.046	36.50 (9.10)	40.73 (6.80)	.09
Marital status, n (%)				.62			.26			.22
Married	49 (92.5)	16 (94.1)	33 (91.7)		22 (88)	27 (96.4)		10 (83.3)	39 (95.1)	
Divorced or widowed	4 (7.5)	1 (5.9)	3 (8.3)		3 (12)	1 (3.6)		2 (16.7)	2 (4.9)	
Relationship, n (%)				.46			.57			.13
Mother	38 (71.7)	12 (70.6)	26 (72.2)		18 (72)	20 (71.4)		10 (83.3)	28 (68.3)	
Father	13 (24.5)	4 (23.5)	9 (25)		7 (28)	6 (21.4)		1 (8.3)	12 (29.3)	
Other[c]	2 (3.8)	1 (5.9)	1 (2.8)		0 (0)	2 (7.2)		1 (8.3)	1 (2.4)	
Education level, n (%)				.37			.44			.09
High school or less	11 (20.8)	2 (11.8)	9 (25)		3 (12)	8 (28.6)		1 (8.3)	10 (24.4)	
Diploma	15 (28.3)	6 (35.3)	9 (25)		7 (28)	8 (28.6)		1 (8.3)	14 (34.1)	
Bachelor's degree	24 (45.3)	9 (52.9)	15 (41.7)		13 (52)	11 (39.3)		9 (75)	15 (36.6)	
Postgraduate degree	3 (5.7)	0 (0)	3 (8.3)		2 (8)	1 (3.6)		1 (8.3)	2 (4.9)	
Occupation status, n (%)				.39			.91			.60
Employed	31 (58.5)	9 (52.9)	22 (61.1)		15 (60)	16 (57.1)		6 (50)	25 (61)	
Unemployed	12 (22.6)	3 (17.6)	9 (25)		5 (20)	7 (25)		4 (33.3)	8 (19.5)	
Retired	10 (18.9)	5 (29.4)	5 (13.9)		5 (20)	5 (17.9)		2 (16.7)	8 (19.5)	
Working hours per week, n (%)				.21			.61			.27
<20	8 (15.1)	1 (11.1)	7 (31.8)		3 (20)	5 (31.3)		3 (50)	5 (20)	
20 - 40	20 (37.7)	6 (66.7)	14 (63.6)		11 (73.3)	9 (56.3)		3 (50)	17 (68)	
>40	3 (5.7)	2 (22.2)	1 (4.5)		1 (6.7)	2 (12.5)		0 (0)	3 (12)	
Economic security, n (%)				.09			.16			.04
Good	23 (43.4)	4 (23.5)	19 (52.8)		13 (52)	10 (35.7)		9 (75)	14 (34.1)	
Mediocre	26 (49.1)	12 (70.6)	14 (38.9)		9 (36)	17 (60.7)		3 (25)	23 (56.1)	
Poor	4 (7.5)	1 (5.9)	3 (8.3)		3 (12)	1 (3.6)		0 (0)	4 (9.8)	
Living space, n (%)				.46			.11			.04
House	26 (49.1)	9 (52.9)	17 (47.2)		15 (60)	11 (39.3)		9 (75)	17 (41.5)	
Apartment	27 (50.9)	18 (47.1)	19 (52.8)		10 (40)	17 (60.7)		3 (25)	24 (58.5)	

[a]Missing values: n=20.

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[b]*P* values calculated using the chi-square test.

[c]Aunt and grandmother.

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Table . Characteristics of the study sample—children with cerebral palsy (CP)[a].

	Total sample (n=53)	Ease of Caregiving for Children			Child Engagement in Daily Life Measure			Satisfaction With Daily Occupations		
		Significant burden (n=17)	No significant burden (n=36)	*P* value[b]	Independent (n=25)	Dependent (n=28)	*P* value[b]	Yes (n=12)	No (n=41)	*P* value[b]
Sex, n (%)				.23			.22			.52
Male	11 (20.7)	2 (11.8)	9 (25)		7 (28)	4 (14.3)		2 (16.7)	9 (22)	
Female	42 (79.2)	15 (88.2)	27 (75)		18 (72)	24 (85.7)		10 (83.3)	32 (78)	
Age (years), mean (SD)	8.04 (2.75)	8.71 (3.62)	7.72 (2.22)	.23	7.52 (2.18)	8.50 (3.14)	.20	8.25 (2.52)	7.98 (2.84)	.77
BMI, (kg/m^2)				.92			.45			.91
Underweight (<5th percentile)	13 (24.5)	5 (31.3)	8 (25)		4 (17.4)	9 (36)		2 (20)	11 (28.9)	
Normal (5th-85th percentile)	11 (20.8)	3 (18.8)	8 (25)		7 (30.4)	4 (16)		2 (20)	9 (23.7)	
Risk of overweight (85th-95th percentile)	4 (7.6)	1 (6.3)	3 (9.4)		2 (8.7)	2 (8)		1 (10)	3 (7.9)	
Overweight (>95th percentile)	20 (37.7)	7 (43.8)	13 (40.6)		10 (43.5)	10 (40)		5 (50)	15 (39.5)	
Diagnosis or topographic type, n (%)				.10			.06			.68
Spastic diplegic CP	7 (13.2)	2 (11.8)	5 (13.9)		2 (8)	5 (17.9)		2 (16.7)	5 (12.2)	
Spastic quadriplegic CP	5 (9.4)	4 (23.5)	1 (2.8)		0 (0)	5 (17.9)		0 (0)	5 (12.2)	
Spastic hemiplegic CP	6 (11.3)	3 (17.6)	3 (8.3)		2 (8)	4 (14.3)		1 (8.3)	5 (12.2)	
Ataxic CP	1 (1.9)	0 (0)	1 (2.8)		1 (4)	0 (0)		0 (0)	1 (2.4)	
Dyskinetic CP	34 (64.2)	8 (47.1)	26 (72.2)		20 (80)	14 (50)		9 (75)	25 (61)	
Gross Motor Function Classification System level, n (%)				.12			.49			.88
Level I	18 (34)	6 (35.3)	12 (33.3)		7 (28)	11 (39.3)		4 (33.3)	14 (34.1)	
Level II	10 (18.9)	2 (11.8)	8 (22.2)		4 (16)	6 (21.4)		2 (16.7)	8 (19.5)	
Level III	13 (24.5)	3 (17.6)	10 (27.8)		9 (36)	4 (14.3)		3 (25)	10 (24.4)	
Level IV	5 (9.4)	1 (5.9)	4 (11.1)		2 (8)	3 (10.7)		2 (16.7)	3 (7.3)	
Level V	7 (13.2)	5 (29.4)	2 (5.6)		3 (12)	4 (14.3)		1 (8.3)	6 (14.6)	
Functional level with hands, n (%)				.001			.001			.70
Independent	17 (32.1)	1 (5.9)	16 (44.4)		15 (60)	2 (7.1)		5 (41.7)	12 (29.3)	
Partially dependent	22 (41.5)	6 (35.3)	16 (44.4)		9 (36)	13 (46.4)		4 (33.3)	18 (43.9)	
Totally dependent	14 (26.4)	10 (58.8)	4 (11.1)		1 (4)	13 (46.4)		3 (25)	11 (26.8)	

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	Total sample (n=53)	Ease of Caregiving for Children			Child Engagement in Daily Life Measure			Satisfaction With Daily Occupations		
		Significant burden (n=17)	No significant burden (n=36)	*P* value[b]	Independent (n=25)	Dependent (n=28)	*P* value[b]	Yes (n=12)	No (n=41)	*P* value[b]
Schooling, n (%)				.07			.004			.30
No	19 (35.8)	9 (53)	10 (27.7)		4 (16)	15 (53.6)		3 (25)	16 (39)	
Yes, regular	6 (11.3)	1 (5.8)	5 (13.8)		5 (20)	1 (3.6)		2 (17)	4 (10)	
Yes, private	28 (52.8)	7 (41.2)	21 (58.3)		16 (64)	12 (42.8)		7 (58.3)	21 (51.2)	
Number of people involved in childcare, n (%)				.03			.62			.55
≤3 persons	50 (94.3)	14 (82.4)	36 (100)		24 (96)	26 (92.9)		11 (91.7)	39 (95.1)	
>3 persons	3 (5.6)	3 (17.6)	0 (0)		1 (4)	12 (7.1)		1 (8.3)	2 (4.9)	
Total number of siblings, n (%)				.45			.40			.20
≤3 persons	32 (60.4)	11 (64.7)	21 (58.3)		17 (68)	15 (53.6)		9 (75)	23 (56.1)	
>3 persons	21 (39.6)	6 (35.3)	15 (41.7)		8 (32)	13 (46.4)		3 (25)	18 (43.9)	

[a]Missing values: n=20.

[b]*P* values calculated using the chi-square test.

The ECC mean raw score for all caregivers was 38.17 (SD 11.62; 95% CI 34.97 - 41.37) and the mean scaled score was 48.78 (SD 16.18; 95% CI 44.33 - 53.25), which showed that the entire sample had some degree of perceived burden. With further analysis using suggested cutoff scores (scaled score ≤40=substantial burden), 32.1% (17/53) of caregivers scored as having a significant perceived burden (Table 1). Two demographic factors were correlated with higher levels of perceived burden, the child's functional level with hands (*P*=.001) and the number of people involved in childcare (*P*=.03; Table 2). Cross-tabulation of the questions of the self-care domain of the CEDLM with ECC cutoff scores (significant burden vs insignificant burden) showed that all questions were negatively correlated (ie, children of caregivers with perceived significant burden were more dependent; Table 3).

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Table . Child Engagement in Daily Life Measure self-care (SC) domain items.

	Total sample, mean (SD)	Ease of Caregiving for Children			Satisfaction With Daily Occupations		
		Significant burden, mean (SD)	No significant burden, mean (SD)	*P* value	Yes, mean (SD)	No, mean (SD)	*P* value
SC1: feed self finger foods	3.64 (1.67)	2.29 (1.65)	4.28 (1.26)	.001	3.92 (1.68)	3.56 (1.68)	.39
SC2: feed self with a spoon or fork (solid food)	3.02 (1.57)	1.71 (1.16)	3.64 (1.36)	.001	3.67 (1.67)	2.83 (1.51)	.09
SC3: feed self with a spoon or fork (semisolid food)	3.17 (1.61)	1.88 (1.27)	3.78 (1.40)	.001	3.75 (1.71)	3.00 (1.57)	.14
SC4: feed self with a spoon or fork (liquid food)	2.83 (1.64)	1.41 (1.06)	3.50 (1.44)	.001	3.42 (1.56)	2.66 (1.65)	.15
SC5: drink from a closed cup or feeding bottle	3.30 (1.77)	2.18 (1.59)	3.83 (1.61)	.002	3.67 (1.83)	3.20 (1.76)	.35
SC6: drink from an open bottle or cup	3.55 (1.68)	2.18 (1.55)	4.19 (1.33)	.001	3.92 (1.68)	3.44 (1.69)	.24
SC7: dress upper body	2.30 (1.45)	1.41 (0.80)	2.72 (1.37)	.001	2.17 (1.47)	2.34 (1.33)	.63
SC8: undress upper body	2.47 (1.47)	1.47 (0.80)	2.94 (1.49)	.001	2.17 (1.47)	2.56 (1.48)	.40
SC9: dress lower body	2.32 (1.39)	1.29 (0.59)	2.81 (1.41)	.001	2.50 (1.62)	2.27 (1.34)	.72
SC10: undress lower body	2.53 (1.55)	1.35 (0.61)	3.08 (1.56)	.001	2.67 (1.83)	2.49 (1.49)	.84
SC11: wear shoes or socks or put on or take off an orthosis or brace	1.85 (1.03)	1.18 (0.39)	2.17 (1.08)	.001	1.92 (1.00)	1.83 (1.05)	.67
SC12: wash and dry hands	2.81 (1.65)	1.88 (1.45)	3.25 (1.57)	.003	3.17 (1.85)	2.71 (1.60)	.44
SC13: bathe or clean	2.30 (1.38)	1.47 (0.87)	2.69 (1.41)	.002	2.33 (1.67)	2.29 (1.31)	.88
SC14: body dry	2.25 (1.31)	1.35 (0.61)	2.67 (1.35)	.001	2.33 (1.50)	2.22 (1.28)	.87
SC15: combing hair	2.32 (1.44)	1.59 (1.23)	2.67 (1.41)	.004	2.42 (1.62)	2.29 (1.40)	.81
SC16: brush teeth	2.64 (1.62)	1.76 (1.25)	3.06 (1.62)	.006	3.00 (1.86)	2.54 (1.55)	.49
SC17: clean nose with a napkin	3.00 (1.60)	1.94 (1.35)	3.50 (1.48)	.001	3.25 (1.91)	2.93 (1.52)	.46
SC18: use the potty or toilet	2.30 (1.50)	1.35 (0.61)	2.75 (1.59)	.002	2.50 (1.73)	2.24 (1.45)	.68
Total	—[a]	23.21 (21.61)	51.32 (18.67)	—	44.92 (24.64)	41.53 (23.46)	—

[a]Not applicable.

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The mean score for the self-care domain of the CEDLM was 48.60 (SD 23.09; 95% CI 42.24 - 54.97), whereas the scaled score for this tool was 43.60 (SD 23.53; 95% CI 35.81 - 48.79), which indicated that our sample scored near the lower end of the scale (Table 2). When suggested cutoff scores (scaled score ≥50.2=independent child) were used, the self-care domain of the CEDLM was positively correlated with the child's functional level with hands (P=.001) and school enrollment (P=.004). Cross-tabulation with the questions of the ECC and self-care domain of the CEDLM cutoff scores revealed that all the questions but one (ECC 7: "to put on or take off an orthosis or brace"; P=.23) were negatively correlated (ie, the caregivers of independent children had less perceived burden; Table 4).

Table . Ease of Caregiving for Children (ECC) items.

		Child Engagement in Daily Life Measure (self-care domain)			Satisfaction With Daily Occupations		
	Total sample, mean (SD)	Independent, mean (SD)	Dependent, mean (SD)	*P* value	Yes, mean (SD)	No, mean (SD)	*P* value
ECC 1: to move at home and in the community?	2.74 (1.14)	3.24 (1.23)	2.29 (0.85)	.002	3.25 (1.22)	2.59 (1.10)	.08
ECC 2: to position for sleeping?	3.42 (1.21)	3.96 (1.10)	2.93 (1.12)	.002	4.00 (1.28)	3.24 (1.6)	.04
ECC 3: to position for feeding?	3.47 (1.20)	3.96 (1.06)	3.04 (1.17)	.006	3.83 (1.27)	3.37 (1.18)	.18
ECC 4: to position for bathing?	2.83 (1.72)	3.40 (1.12)	2.32 (0.98)	.001	3.33 (1.16)	2.68 (1.15)	.07
ECC 5: to position for playing?	3.21 (1.41)	3.80 (1.29)	2.68 (1.34)	.004	4.08 (1.31)	2.95 (1.36)	.01
ECC 6: to put on or take off clothing?	2.98 (1.16)	3.40 (1.00)	2.61 (1.19)	.01	3.58 (1.08)	2.80 (1.15)	.05
ECC 7: to put on or take off an orthosis or brace?	2.81 (1.09)	3.00 (1.00)	2.64 (1.16)	.23	3.42 (1.17)	2.63 (1.02)	.03
ECC 8: to bathe, clean, and tidy?	2.85 (1.11)	3.20 (1.16)	2.54 (0.99)	.03	3.33 (0.99)	2.71 (1.12)	.07
ECC 9: to use the potty or toilet, or for you to change his or her diapers?	2.87 (1.27)	3.44 (1.16)	2.36 (1.16)	.002	3.83 (1.12)	2.59 (1.18)	.003
ECC 10: to eat?	4.04 (1.16)	4.40 (1.00)	3.71 (1.21)	.03	4.58 (0.90)	3.88 (1.19)	.06
ECC 11: to drink?	4.13 (1.11)	4.64 (0.70)	3.68 (1.22)	.003	4.58 (0.90)	4.00 (1.14)	.10
ECC 12: to get in and out of a car, van, or bus?	2.83 (1.22)	3.36 (1.19)	2.36 (1.06)	.003	3.33 (1.30)	2.68 (1.17)	.12
Total	—[a]	56.46 (17.28)	41.93 (11.64)	—	56.96 (12.88)	46.39 (16.40)	—

[a]Not applicable.

Finally, the mean satisfaction score for SDO was 9.49 (SD 2.87; 95% CI 8.70 - 10.28), indicating that the children participated in most daily occupations, and the mean satisfaction score with their activity level was 45.15 (SD 13.17; 95% CI 41.52 - 48.78), which showed that the participants were somewhat satisfied with their daily occupations. Further analysis with established cutoff scores of the SDO (score ≥56=satisfied with daily occupations) showed that economic security and living space were negatively correlated with their SDO scores (ie, perceived mediocre or poor economic security and living in an apartment were linked with low SDO score; Table 1). Cross-tabulation with the questions of the ECC and SDO cutoff scores showed that some of the questions (questions 2, 5 - 7, and 9) were negatively correlated with the perceived ease of care reported by the caregivers (ie, caregivers who had higher SDO scores had a perception of less caregiving burden; ECC 2: to position for sleeping; P=.04; ECC 5: to position for playing; P=.01; ECC 6: to put on or take off clothing; P=.05; ECC 7: to put on or take off an orthosis or brace; P=.03; ECC 9: to use the potty or toilet, or for you to change his or her diapers; P=.003; Table 4).

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ECC scaled scores were positively correlated with the self-care domain of the CEDLM (r=0.64; P<.001) and the SDO (r=0.29; P=.03; Table 5). On the other hand, the self-care domain of the CEDLM was not correlated with the SDO score.

Table . Correlations among tools.

Comparison	Pearson coefficient (r)	P value
ECC[a] vs self-care domain of CEDLM[b]	0.641	.001[c]
ECC vs SDO[d]	0.298	.03[e]
Self-care domain of CEDLM vs SDO	0.195	.16

[a]ECC: Ease of Caregiving for Children.

[b]CEDLM: Child Engagement in Daily Life Measure.

[c]Correlation is significant at the .01 level.

[d]SDO: Satisfaction With Daily Occupations.

[e]Correlation is significant at the .05 level.

Discussion

Principal Findings

To the best of our knowledge, this is the first study to explore the challenges faced by families of children aged 5 to 16 years with CP in Kuwait, including the perceived level of ease of care, caregivers' satisfaction with daily activities, and the associations of these outcomes with other possible factors. Analyses showed that caregivers of children with CP in Kuwait reported an average level of ease of care and an above-average satisfaction level with their performance of different life activities. The analyses also showed that the higher perceived ease of care was only associated with the child's hand functional level and the number of people involved in childcare. The level of perceived ease of care reported in the current study was similar to that reported by caregivers in different regions of the world (ie, Poland and Turkey) [9,23]. This demonstrated that despite cultural and socioeconomic differences, the burden of caring for a child with CP was comparable [4]. On the other hand, the number of people involved in childcare being a significant factor can provide insights into a unique element of the culture in Kuwait and the surrounding region, where extended family and domestic workers [24] are involved in childcare and can affect the level of burden of care. This is a testament to the "village" families create to care for their children, which shows resilience and the coping measures taken to help care for children with CP.

Additionally, around half of the samples in this study scored at levels I and II of the GMFCS, which represents a higher functional capacity of the child. Nevertheless, the self-care domain of the CEDLM was toward the lower end of the scale as a total score and for individual items in our sample. This could be caused by a lack of focus on building independence (ie, performing self-care activities), which would reduce the number of tasks falling under the caregiver's responsibility. Factors such as children's hand functional level, their self-care abilities, and the number of people involved in childcare were found in previous studies to be variables that decreased the perceived level of caregiver burden for children with CP [9,10,23].

Contrary to expectations, this study did not find any significant difference in caregivers' ease of care level according to the child's BMI or CP subtype, which does not align with findings presented in the literature [9,23]. This finding may be explained by the characteristics of the children with CP, the majority of whom were at GMFCS levels I to III (41/53, 77.4%) while previous research was conducted with children at higher GMFCS levels. Additionally, the dyskinetic type of CP (34/53, 64.2%) was the most common type in our study; therefore, a lack of heterogeneity in the types of CP may have contributed to the findings [9,23].

A distinctive parameter that this study investigated was caregiver satisfaction with their daily life activities, and the literature suggests that the level of burden impacts caregivers' quality of life [8,25]. Our findings demonstrated that caregivers were active participants in most of their children's daily activities and were somewhat satisfied with their daily occupations. The current investigation also found that the higher the perceived ease of care, the more satisfied the caregivers were. This might be explained by an indirect association between the extensive care required when having a child with CP and the perceived burden of care that could hinder caregivers from being active members of the community [10].

A qualitative study conducted among parents of children with CP in Saudi Arabia revealed that caregivers expressed being under stress and experiencing challenges in navigating health and educational services [26]. These parents also emphasized the role of Islamic values expressed through religious practices in helping them cope with stress and perceived burden. The Kuwaiti population shares similar values to the Saudi Arabian population. Although it produced different data from the current study, that work showed trends similar to those exhibited in our study. These findings showed the need for further exploration of the population in the Arabian Peninsula region.

Given the differences identified in the present study compared with the published literature on caregiver burden among this patient population, it could conceivably be suggested that caring for children with CP in Kuwait should not rely on Western evidence alone. In a recent systematic review on the epidemiology of CP in Arabic-speaking countries, no articles referencing this population were found in Kuwait [27]. Given

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the scarcity of research in this region, normative data should be established for this population as it is crucial for different communities to understand their populations to tailor treatments to their communities' specific needs.

As is the case with every scientific endeavor, this study is not without its limitations. The main limitation is the small sample size recruited, which also limited further investigation of some possible related factors, such as lower GMFCS levels or different CP subtypes. The nature of the cross-sectional study design limits the establishment of causal relationships or changes over time. Another limitation is self-report bias, which limits the interpretation of the results. The recruitment of participants from rehabilitation clinics may have introduced selection bias, which could have excluded caregivers of children with a high functional level and children with a very low functional level. Future studies should focus on adapting these classification systems for Arabic-speaking individuals to enable the use of these tools for upcoming research studies on children with CP and their caregivers. Further exploration of the individuals involved in caring for children with CP is warranted in future studies, especially differentiating between hired help and family members.

Conclusions

CP is a lifelong health condition that requires special management and care throughout an individual's life, impacting not only the individual with CP but also their family and primary caregivers. Caregivers might experience high levels of burden due to their assigned responsibilities, which could affect their life satisfaction. The preliminary perceived level of burden among caregivers of children with CP in Kuwait was correlated with caregivers' daily activities satisfaction and the child's self-care abilities. The findings of this study can inform practice in Kuwait and guide research advances in the region to improve care for caregivers of children with CP. Regular check-ins with caregivers and the establishment of caregiver support groups would help provide support sooner. Future studies with larger sample sizes and across multiple lifelong conditions would provide a clearer picture. Mixed methods strategies are encouraged in future studies to identify other contributing factors that may be unique to the region.

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Data Availability

The datasets generated or analyzed during this study are available from the corresponding author (ABA) on reasonable request.

Authors' Contributions

ABA, ZJ, and AS designed the study. ABA and MA collected and analyzed data. ABA and ZJ wrote the manuscript. AS and MA gave technical support and conceptual advice. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

CEDLM: Child Engagement in Daily Life Measure
CP: cerebral palsy
ECC: Ease of Caregiving for Children
GMFCS: Gross Motor Function Classification System
ICC: intraclass correlation coefficient
SDO: Satisfaction With Daily Occupations

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Original Paper

Exploring Perspectives and Barriers in Implementing Home Monitoring for Pediatric Pulmonary Diseases: Mixed Methods Study

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Abstract

Background: Home monitoring has the potential to enable early detection of disease progression in pediatric lung diseases such as asthma and cystic fibrosis (CF). There is minimal evidence regarding the opinions of caregivers and children on home monitoring.

Objective: This study aimed to explore children's and caregivers' perspectives on home monitoring.

Methods: This multicenter, mixed methods study included children aged 6 to 18 years with asthma or CF and their caregivers. Participants were recruited from Juliana Children's Hospital and Erasmus MC Sophia Children's Hospital between September 2023 and June 2025. Participants completed a structured questionnaire assessing experiences, attitudes, and potential barriers and facilitators to home monitoring. Fourteen children and their caregivers took part in in-depth interviews. Conventional content analysis was applied to both open-text and interview data.

Results: A total of 113 caregiver-child dyads (62 [54.9%] asthma and 51 [45.1%] CF) participated in this study. Willingness to use home monitoring was high among both children (asthma: n=47, 83.9%; CF: n=30, 62.5%) and caregivers (asthma: n=54, 87.1%; CF: n=44, 86.3%). Children with asthma and their caregivers showed significantly greater willingness to use the proposed types of home monitoring than children with CF and their caregivers. Caregivers who expressed difficulty with symptom interpretation were significantly more motivated to use home monitoring. Key barriers included time demands, usability, device size, and concerns about maintaining personal contact with health care providers. Facilitators included compact, user-friendly devices, clear instructions, and improved disease understanding.

Conclusions: High willingness to adopt home monitoring was observed among children with asthma and children with CF, but preferences and perceived barriers differ. Tailoring device choice and implementation strategies to patient needs, minimizing burden, and integrating medical oversight are important for successful uptake.

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KEYWORDS

telemedicine; child; asthma; cystic fibrosis; patient perspectives; patient acceptance of health care; caregiver perspectives; digital health

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Introduction

Asthma and cystic fibrosis (CF) are chronic diseases in the pediatric population, characterized by recurrent pulmonary exacerbations that may lead to hospital visits and admissions. These exacerbations are associated with a higher perceived disease burden, a decline in pulmonary function, and higher health care costs [1]. Effective control of asthma and CF is crucial for reducing the clinical burden and adverse outcomes associated with exacerbations. Ideally, it would be possible to predict pulmonary exacerbations to start treatment in a timely manner before symptoms have progressed. Remote health care, digital biomarkers, and home monitoring offer the potential to recognize exacerbations early, minimizing both acute complications and long-term damage while also reducing health care costs [2].

In the pediatric population, assessing disease activity and predicting exacerbations are especially challenging. Young children find it difficult to perceive and express their symptoms, causing difficulty in parental recognition of symptoms [3], which home monitoring may help alleviate [4-9]. Real-time data may be necessary to effectively monitor disease activity using objective measurements. Devices such as smartwatches, spirometers, and other home monitoring devices have been used previously. However, the compliance of patients significantly decreases when the duration and frequency of home monitoring assessments increase [10]. In contrast, evidence suggests that patient empowerment and patients' capacity to understand and interpret their health-related data facilitate sustained engagement with digital health tools [11]. Despite these findings, most studies on home monitoring primarily focus on clinically relevant outcomes, while the patient perspective, particularly the pediatric perspective, is underrepresented [12]. It is essential to understand children's and caregivers' views and motivations regarding home monitoring tools to successfully implement them. Therefore, this exploratory study aims to assess the perspectives of children and caregivers regarding home monitoring and to identify barriers and facilitators to its use and implementation. In addition, preferences for different home monitoring methods and devices are investigated, as well as the circumstances under which home monitoring would be considered acceptable.

Methods

Study Design

This study was conducted at Juliana Children's Hospital (Haga Teaching Hospital, The Hague, the Netherlands) and Erasmus MC Sophia Children's Hospital (Rotterdam, the Netherlands). Data were collected between September 2023 and June 2025.

Ethical Considerations

This study was submitted to the Medical Ethics Committee Leiden Delft Den Haag (Zuid-Holland, the Netherlands), which concluded that the study did not fall under the Dutch Medical Research Involving Human Subjects Act (Wet Medisch-Wetenschappelijk Onderzoek Met Mensen [WMO]). The study protocol was reviewed and approved by the institutional review board of the Haga Teaching Hospital (T23-050). Written informed consent was obtained from caregivers and children aged ≥12 years, while children aged <12 years provided verbal assent.

Recruitment

Participants were recruited from the outpatient clinics and inpatient wards to include children with different disease severities. Participants were informed about the study by their treating pediatrician. If they were interested in participating, the researcher subsequently provided further information about the study. Eligible participants were aged 6 to 18 years with a confirmed diagnosis of asthma (per Global Initiative for Asthma [GINA] guidelines) or CF (confirmed by genetic testing). The only exclusion criterion was insufficient proficiency in Dutch, based on the caregiver's indication that the child was able to understand the questionnaire independently. A formal power calculation was not performed due to the exploratory nature of the study. The target sample of 120 participants (60 with asthma and 60 with CF) was considered sufficient to allow meaningful subgroup comparisons and thematic saturation.

Study Procedures

This study followed a convergent mixed methods design, combining quantitative survey data and qualitative interviews to explore and contextualize participants' perspectives. The study was reported in accordance with the Good Reporting of A Mixed Methods Study (GRAMMS) recommendations (Multimedia Appendix 1) [13]. The mixed methods approach was used to quantify preferences regarding home monitoring while also exploring the underlying reasons, barriers, and facilitators that could not be fully captured through predefined questionnaire responses alone. Participants were asked to complete a structured questionnaire, developed for this study, assessing experiences and attitudes toward home monitoring. At the start of the study, participants were also invited to participate in a semistructured interview to explore these themes in greater depth after completing the questionnaire. Completing the questionnaire took approximately 30 minutes and consisted of 2 sections. One section was to be completed by the caregiver first, and subsequently, a shorter section was completed by the child. Questionnaires were administered using multiple methods to accommodate participant preferences: electronically or on paper. The digital questionnaire could also be completed at home; the paper questionnaire was completed in the hospital. Research staff were available for assistance.

Incomplete caregiver questionnaires were excluded from analysis at the case level. The first item of the pediatric questionnaire asked caregivers whether their child was able to understand and answer the questions independently. This was included to account for differences in age and level of comprehension among the participating children. Participants were not excluded based on this item because caregiver-reported data were available regardless of whether the child was able to complete the questionnaire.

Instruments

The questionnaire (Multimedia Appendix 2) was specifically developed for the purpose of this study and was not based on a

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previously validated instrument. The questionnaire was reviewed and informally pretested by members of the research team, laypersons, children, parents, and medical specialists to assess the quality of the questions, ensuring they did not imply or use unclear terminology that could potentially influence the participants. On the basis of several rounds of feedback, the wording and structure of the questions were refined before study initiation.

Most questions had a 5-point Likert scale outcome or a yes or no outcome. All questions had a text box option to elaborate on the answers provided. The questionnaire consisted of 5 categories. The first category included demographic and clinical characteristics of the participants. The second category assessed whether caregivers had prior exposure to digital monitoring tools. The third category explored caregivers' attitudes toward various monitoring devices, including smartwatches, lung function meters, cough detectors, smart inhalers, air quality monitors, medication reminders, and symptom questionnaires. A smart inhaler is a small electronic device attached to an inhaler that automatically detects and time stamps inhaler use. These monitoring devices were selected based on previous literature [14-18]. The fourth category focused on the conditions under which caregivers would consider using such devices. The final category included open-ended questions about potential barriers and facilitators to the implementation of home monitoring systems.

The semistructured interviews addressed the themes mentioned in the questionnaire and were conducted by 1 researcher. The interviews were audio-recorded and transcribed verbatim by 2 researchers without the use of transcription software. Member checking was not performed. Data saturation was reached after 14 interviews.

Data Analysis

All analyses were performed using RStudio (version 4.4.2; R Foundation for Statistical Computing). Participant characteristics were analyzed descriptively. To summarize participants' overall attitude toward home monitoring, a cumulative device score was calculated. For each proposed monitoring modality, willingness to use the device was scored as +1, unwillingness as –1, and a neutral or "no opinion" response as 0. Neutral and "no opinion" responses were both assigned a value of 0 because neither reflects a definitive driver of, nor a barrier to, device adoption. All modalities were weighted equally to capture broad technological acceptance, rather than being weighted by patient burden or clinical utility, which was beyond the scope of this exploratory measure. A score of –7 means that a participant had a negative attitude toward every type of device, and a score of +7 means that a participant had a positive attitude toward all devices. The children with CF and their caregivers could reach a maximum of 6 points, as most children with CF did not use inhalers. No normalization of the cumulative device score was performed.

Normally distributed variables are reported as mean (SD), and nonnormally distributed variables are reported as median (IQR). Categorical variables were summarized as absolute numbers and percentages. Comparative analyses were performed to assess differences between the asthma and CF groups. Likert scale questions were analyzed using the Mann-Whitney *U* test. Categorical variables were compared between the asthma and CF groups using the chi-square test. Associations between ranked variables were evaluated with the Spearman rank correlation coefficient. A 2-sided $P<.05$ was considered statistically significant. As this was an exploratory study, no correction for multiple testing was applied.

Qualitative open-text responses and interview transcripts were analyzed using conventional content analysis to identify key barriers and facilitators to home monitoring adoption [19]. The data were coded inductively without the use of a predefined coding framework. As new concepts emerged from the data, new descriptive codes were created, and similar codes were grouped into broader categories representing the main barriers and facilitators. For both data sources, 1 researcher performed the initial analysis, and a second researcher subsequently reviewed the data, coding, and resulting interpretation. The final coding framework and categories were then discussed within the research team and refined where appropriate.

Quantitative and qualitative data were analyzed separately and integrated during the interpretation of the findings, in accordance with the convergent mixed methods design. The quantitative questionnaire data were used to identify general patterns in participants' responses regarding home monitoring, while the qualitative data from open-text responses and interviews were used to provide context and explain the reasons underlying these response patterns.

Results

Participant Characteristics

Of the 131 parent-child dyads who provided informed consent, 113 parent-child dyads (Juliana Children's Hospital: n=86, 76.1%; Sophia Children's Hospital: n=27, 23.9%) completed the questionnaire. One parent-child dyad was excluded from the analysis because the caregiver questionnaire was incomplete. Seventeen dyads did not return the questionnaire. These children were all diagnosed with asthma, had a median age of 13.0 (IQR 10-15) years, and had been approached during an outpatient clinic visit. No further clinical information or information on the reasons for noncompletion was available. Of the 113 children with completed questionnaire data, 54.9% (n=62) were diagnosed with asthma, and 45.1% (n=51) were diagnosed with CF. A total of 9 children (n=6 with asthma and n=3 with CF) did not complete the pediatric part of the questionnaire due to an inability to understand the questions. The mean pediatric age was 10.5 (SD 3.2) years in the asthma group and 12.7 (SD 3.6) years in the CF group. A total of 23 (20.4%) caregivers described the disease burden of their child as very or somewhat heavy.

Of the 113 caregivers, 46 (40.7%) reported lung complaints as the most burdensome aspect of their child's disease, while 39 (34.5%) caregivers indicated that daily medication caused the greatest disease burden. Caregivers of children with asthma more frequently attributed the disease burden to lung complaints than did caregivers of children with CF (n=38, 61.3% vs n=8, 15.7%; $\chi^2_1=22.3$; $P<.001$). In contrast, caregivers of children

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with CF more often identified daily medication use as the main contributor to disease burden than caregivers of children with asthma (n=24, 47.1% vs n=14, 22.6%; χ^2_1=6.5; *P*=.01). Additional participant characteristics are presented in Table 1.

Table 1. Participant characteristics (N=113).

Characteristics	Total participants	Participants with asthma (n=62)	Participants with cystic fibrosis (n=51)
Age (years), median (IQR)	11 (8.0-14.0)	10 (8.0-12.8)	13 (10.0-16.0)
Sex: male n (%)	62 (54.8)	40 (64.5)	22 (43.1)
Distance to hospital (km), n (%)			
<5	43 (38.1)	34 (54.8)	9 (17.6)
6-20	42 (37.2)	24 (38.7)	18 (35.2)
>20	28 (24.8)	4 (6.5)	24 (47.1)
Caregiver-reported disease burden, n (%)			
Heavy	23 (20.4)	15 (24.2)	8 (15.7)
Average	36 (31.9)	16 (25.8)	20 (39.2)
Light	54 (47.8)	31 (50)	23 (45.1)
Hospital visits in the previous year			
Outpatient clinic visits, median (IQR)	4.0 (2.0-4.0)	3.0 (2.0-4.0)	4.0 (4.0-4.0)
≥1 emergency department visit, n (%)	18 (15.9)	15 (24.2)	3 (5.9)
≥1 hospital admission, n (%)	12 (10.6)	7 (11.3)	5 (9.8)
Medication, n (%)			
Short-acting β-agonist	51 (45.1)	46 (74.2)	5 (9.8)
Long-acting β-agonist	29 (25.7)	23 (37.1)	6 (11.8)
Inhaled corticosteroid	48 (42.5)	48 (77.4)	0 (0)
Leukotriene receptor antagonist	4 (3.5)	4 (6.5)	0 (0)
Biologic	4 (3.5)	4 (6.5)	0 (0)
Cystic fibrosis transmembrane conductance regulator modulator	48 (42.5)	0 (0)	48 (94.1)
Home monitoring, n (%)			
Currently using	24 (21.2)	13 (21)	11 (21.6)
Used previously	42 (37.2)	18 (29)	24 (47.1)
Device used, n (%)			
Spirometer	22 (19.5)	2 (3.2)	20 (39.2)
Oxygen level measurement	17 (15)	13 (21)	4 (7.8)

Home Monitoring Experience

A total of 42 (37.2%) caregivers reported that their child had used home monitoring previously (n=18, 29% caregivers of children with asthma vs n=24, 47.1% caregivers of children with CF; χ^2_1=3.2; *P*=.08). Among children with CF, the most commonly used device was a handheld spirometer, which was reported for 20 (39.2%) children. Among children with asthma, pulse oximeters were most commonly reported (n=13, 21%). According to caregivers, most children (n=30, 71.4%) primarily used home monitoring devices during symptomatic episodes rather than incorporating them into a routine for regular monitoring. Caregivers stated that reasons for discontinuing home monitoring included unreliable measurements, perceived lack of necessity, and the added uncertainty it caused. One caregiver of a child with CF stated, “it was useful in the past, it is not necessary anymore with the new medication,” indicating the availability of newer CF transmembrane conductance regulator (CFTR)–modulating therapies.

Willingness to Use Home Monitoring

Most caregivers (98/113, 86.7%) expressed willingness to use home monitoring. About 77% (n=87) of caregivers would use home monitoring if it resulted in fewer outpatient visits. Of the 113 caregivers, 99 (87.6%) would use home monitoring if it led to fewer admissions, while 96.5% (n=109) would use it if it led to less lung damage. Summarized responses are displayed in Table 2. There were no associations between the age of the participants, diagnosis, use of home monitoring in the past, or perceived disease severity and the willingness of caregivers to use home monitoring (Multimedia Appendix 3).

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Of all children, 74% (77/104) indicated willingness to use home monitoring in general. Children with asthma were significantly more willing (Likert scale score: median 2.0, IQR 1.0-2.0) than those with CF (Likert scale score: median 2.0, IQR 2.0-3.0; Mann-Whitney *U* test, *P*<.001). Age did not influence children's willingness to use home monitoring (Multimedia Appendix 3).

Table 2. Willingness to use home monitoring.

Willingness to use home monitoring	Participants with asthma, n (%)	Participants with cystic fibrosis, n (%)	*P* value
Caregivers' perspective[a]			
If it was available	54 (87.1)	44 (86.3)	.99
If it resulted in fewer outpatient visits	48 (77.4)	39 (76.5)	.99
If it resulted in a telephonic consultation instead of an outpatient visit	50 (80.6)	36 (70.6)	.30
If it led to fewer hospital admissions	55 (88.7)	44 (86.3)	.92
If it led to a decrease in long-term lung damage	60 (96.8)	49 (96.1)	.99
Children's perspective[b]			
If it was available	47 (83.9)	30 (62.5)	<.001[c]
If it resulted in fewer outpatient visits	45 (80.4)	36 (75)	.36
If it led to fewer hospital admissions	54 (96.4)	46 (95.8)	.99

[a]Caregiver responses were based on 62 participants with asthma and 51 participants with cystic fibrosis. The questions required yes or no responses. Differences were assessed using the chi-square test.

[b]Child responses were based on 56 participants with asthma and 48 participants with cystic fibrosis. The questions used a 5-point Likert scale, and participants were considered willing if they selected "I would like to use" or "I would be fine to use." Differences were assessed using the Mann-Whitney *U* test.

[c]*P*<.05 was considered statistically significant.

Home Monitoring Tools

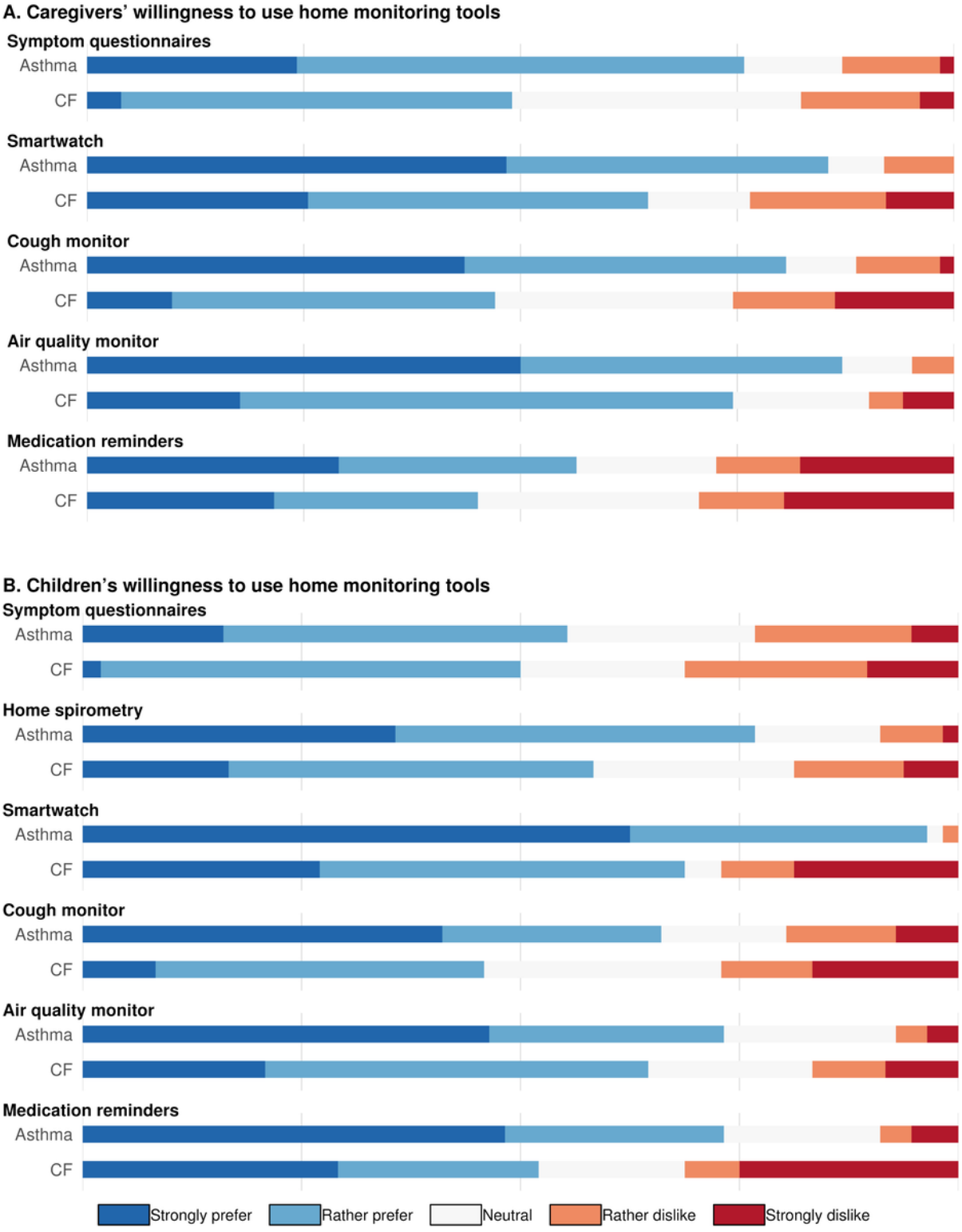
Figures 1A and 1B present caregivers' and children's willingness to use different home monitoring devices, respectively. Overall, caregivers' willingness was highest for air quality meters (91/113, 80.5%), followed by daytime smartwatches (86/113, 76.1%), nighttime smartwatches (83/113, 73.5%), cough monitors (74/113, 65.5%), symptom questionnaires (72/113, 63.7%), and medication reminders (59/113, 52.2%). A total of 61 (98.4%) caregivers of the children with asthma would use an additional meter on the inhaler. Overall, children showed the greatest willingness to use a smartwatch during the daytime (87/104, 83.6%), whereas symptom questionnaires were the least preferred option (55/104, 52.8%). Acceptance of the other monitoring devices included a nighttime smartwatch (76/104, 73.1%), a spirometer (71/104, 68.2%), a cough monitor (68/104, 65.4%), an air quality meter (66/104, 63.5%), and medication reminders (65/104, 62.5%). The additional meter on the inhaler was acceptable for 78.6% (44/56) of children with asthma.

Among both children and caregivers, all devices were significantly more often preferred by participants with asthma, except for symptom questionnaires in the pediatric population and medication reminders in the caregiver population (Multimedia Appendix 4). Previous use of home spirometry in the pediatric population was not associated with willingness to use a spirometer in this questionnaire (Likert scale score median 2.0, IQR 2.0-3.0 vs median 2.0, IQR 1.0-3.0; Mann-Whitney *U* test, *P*=.50).

To summarize caregivers' and children's overall attitudes across the different home monitoring modalities, a cumulative device score was calculated and displayed in Figures 2A (asthma) and 2B (CF). Higher scores represent greater overall willingness to use the proposed home monitoring modalities. A higher subjective disease burden was significantly associated with a higher cumulative device score in both asthma caregivers (Spearman rank correlation coefficient ρ=0.29; *P*=.02) and CF caregivers (Spearman rank correlation coefficient ρ=0.40; *P*=.003).

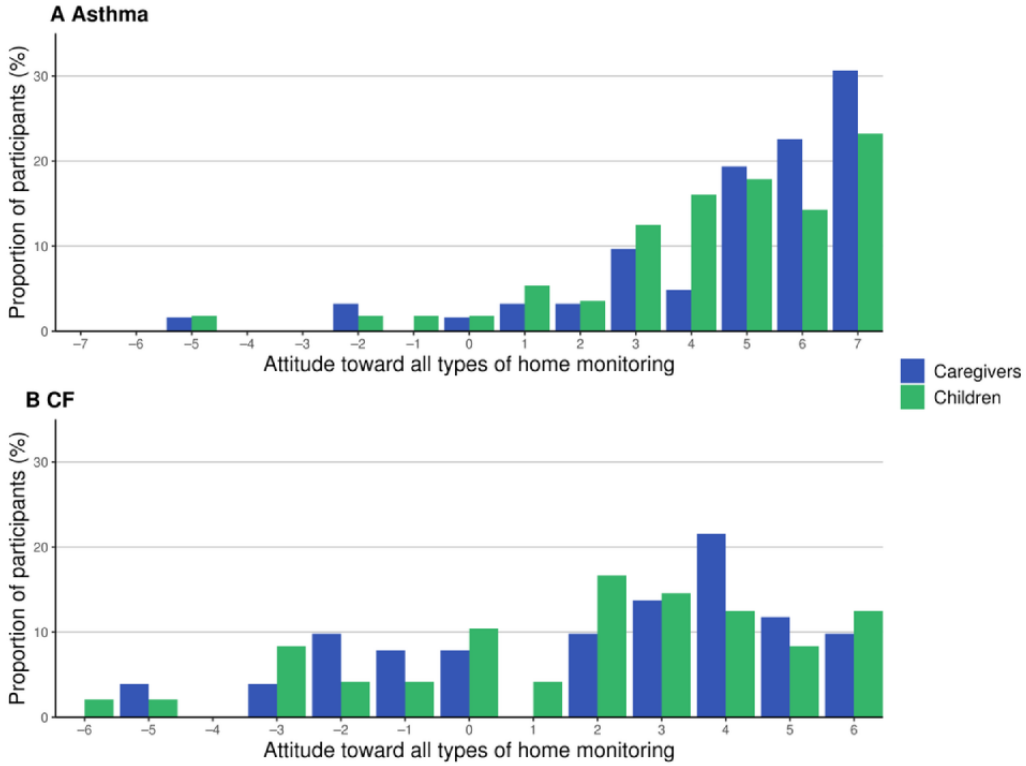
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Figure 1. Willingness to use home monitoring tools. (A) Caregivers' willingness to use different home monitoring tools for children with asthma and cystic fibrosis (CF) and (B) children's willingness to use different home monitoring tools.



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Figure 2. Distribution of the cumulative device willingness score among caregivers and children with (A) asthma and (B) cystic fibrosis (CF). For each applicable home monitoring modality, willingness to use the modality was scored as +1, unwillingness as –1, and a neutral response or no opinion as 0. The maximum possible cumulative score was 7 in the children with asthma and 6 in the children with CF.



Symptom Interpretation

Symptom recognition was generally comparable between the asthma and CF groups (Multimedia Appendix 5). A total of 69 (61.1%) caregivers reported an accurate assessment of disease symptoms. About 42.5% (48/113) of caregivers reported that when they first noticed symptoms, they believed those symptoms had already been present for >1 day. Caregivers who expressed difficulty with symptom interpretation were significantly more motivated to use home monitoring in general (Spearman rank correlation coefficient ρ=–0.19; *P*=.04) and had a higher cumulative device score (Spearman rank correlation coefficient ρ=–0.272; *P*=.004). This correlation was not significant in children who expressed difficulty with symptom interpretation (Spearman rank correlation coefficient ρ=–0.18; *P*=.07). Multimedia Appendix 5 shows the ability of caregivers and children to notice disease-specific complaints.

Data Interpretation

Of the 113 caregivers, 82 (72.6%) would only use home monitoring if insight into the results was provided (n=42, 67.7% caregivers of children with asthma vs n=40, 78.4% caregivers of children with CF; χ^2=1.1; *P*=.30), while 72.6% (n=82) would only use home monitoring if a physician reviewed the results regularly (n=46, 74.2% caregivers of children with asthma vs n=36, 70.6% caregivers of children with CF; χ^2=0.05; *P*=.83). Only 38.1% (n=43) of caregivers would follow algorithmically generated treatment advice before discussing the results with their physicians, although the asthma cohort was significantly more willing to follow algorithmically generated treatment advice without consulting a medical specialist than caregivers in the CF cohort (n=30, 48.4% vs n=13, 25.5%; χ^2_2=6.4; *P*=.04).

Barriers and Facilitators

In total, 14 children (n=8 with asthma and n=6 with CF) and their caregivers also took part in an interview to elaborate on their answers. A total of 88 (77.8%) caregivers answered the open-ended question about expected barriers, and 79 (69.9%) caregivers answered the question about expected facilitators.

Responses were generally similar between the asthma and CF groups. Content analysis of barriers and facilitators identified the following themes: time commitment, ease of use, safety, and motivation, as displayed in Figure 3. The main barrier was the perceived time burden of home monitoring (n=23). Other caregivers highlighted the importance of user-friendly, compact devices that minimally disrupt the child's daily life (n=19). The child's motivation (n=6) was another possible barrier to the use of home monitoring. Adoption of devices would be enhanced by clear instructions before use and education on the interpretation of the results (n=15). Caregivers also expressed concerns about device safety, privacy, and electromagnetic exposure (n=8), emphasizing the importance of trust in the equipment. Finally, worries about reduced patient-physician interaction (n=6) were accentuated by the desire for continued contact with physicians or specialized nurses to interpret results and maintain a human-centered approach to care (n=6). In addition, several caregivers (n=12) indicated that home monitoring could enhance their understanding of their child's illness and help them anticipate clinical deterioration.

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Figure 3. Content analysis of barriers and facilitators of home monitoring. Four main themes—time commitment, safety, ease of use, and motivation—are illustrated with representative participant quotes.



Discussion

Principal Findings

Home monitoring may support early detection of disease activity in pediatric lung disease, but its implementation in clinical practice remains limited [20-23]. This study explored perspectives, barriers, and facilitators related to home monitoring in pediatric pulmonology and showed that 86.7% (98/113) of caregivers and 74% (77/104) of children expressed a general willingness to use home monitoring. Several important factors were identified that should be addressed in future research, development, and implementation of home monitoring.

Caregivers were particularly motivated to use home monitoring if it could reduce long-term lung damage or lead to fewer hospital admissions. In addition, access to data and physician involvement were shown to be important factors for caregivers. Associations with a positive attitude toward multiple home monitoring modalities were found for caregivers of children with a higher disease burden and lower proficiency in symptom recognition, while age did not appear to be a significant factor. These results suggest that researchers should focus on gathering evidence that consistently shows whether home monitoring systems may improve long-term outcomes. However, previous studies on this subject have demonstrated that home monitoring did not achieve better long-term outcomes [24-27]. Additionally, it appears that children and caregivers value having access to their own health data and guidance in interpreting these results, as this may support symptom recognition and enhance their sense of control. This observation is in line with previous literature showing that access to personal health data can improve illness perception [28-31].

The qualitative component of this study provides context for the generally high willingness observed in the quantitative results by identifying important barriers to the implementation of home monitoring in practice. In line with previous literature, time commitment and sustained motivation were key barriers to implementation [32,33], as well as ease of use. Therefore, future research should focus on passive monitoring with "dummy proof" devices and minimize active measurements as much as possible. Caregivers also stressed the need for continued physician involvement in this section of the questionnaire. These barriers may help explain the gap between the apparent willingness to use home monitoring and its limited uptake in current clinical practice [34,35]. Home spirometry is a well-studied example: although widely investigated [36,37], long-term use is hampered by declining measurement quality [38] and reduced motivation over time [10].

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Several notable differences between the asthma and CF groups were found in this study. These differences should be interpreted with caution, as the groups also differed in several participant characteristics, including age, sex, distance from the hospital, and previous experience with home monitoring, which may have contributed to the observed differences. In both children with asthma and their caregivers, home monitoring of pulmonary symptoms seemed to align well with patient needs, while caregivers and children in the CF group showed less interest in monitoring focused specifically on pulmonary symptoms. This may partly reflect the introduction of modern CFTR modulators, which have substantially improved lung function and symptom control in people with CF [39]. This may also be explained by the more variable and episodic nature of symptoms in asthma, which can develop rapidly, whereas exacerbations in CF are often preceded by a more gradual onset of symptoms.

A strength of our study is that, to our knowledge, it is one of the largest cohorts to examine the perspectives of children and caregivers on home monitoring. Including both perspectives provides a broader understanding of preferences and expectations. In addition, participants represented a range of ages and disease severities, improving the representativeness of the sample. Finally, the combination of quantitative and qualitative data provided a deeper understanding of motivations, concerns, and needs relevant to implementation in pediatric pulmonary care. The main limitation of this study is that it relied on self-reported data via a questionnaire that was not previously validated in other studies, which may have induced recall bias or social desirability bias. However, the questionnaire was developed through several feedback loops to improve face validity, clarity, and relevance for the target population. The sample in this study was drawn from 2 large urban hospitals in the Netherlands, which may limit the generalizability of the findings to broader, more diverse, or rural populations. Moreover, 51 parent-child dyads were included in the CF group rather than the planned 60, as the rarity of the disease limited the achievable sample size within the recruitment period. The relatively small sample size, particularly within subgroup analyses, may have limited the ability to detect significant associations. Despite not reaching the predefined target, the collected data were sufficient to provide a comprehensive overview. No correction for multiple testing was applied, as the analyses were exploratory in nature. In addition, as interviews were conducted in a subset of participants, selection bias cannot be excluded for this analysis, and the qualitative findings may not capture the full range of perspectives within the study population. Further research with a more diverse sample and a longitudinal design may lead to a better understanding of the implementation of home monitoring programs for children with asthma and children with CF. Finally, future work with a quantitative or qualitative approach should gather insights from children with other lung diseases.

Conclusions

Interest in home monitoring is high among children with asthma and CF and their caregivers, particularly in families with poorer symptom recognition. To translate this interest into clinical practice, home monitoring strategies should demonstrate clear clinical benefit, minimize patient burden through user-friendly or passive systems, and be integrated into routine care with active physician involvement.

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ChatGPT (version 5.6; OpenAI) was used for language editing purposes, including rephrasing and improving the readability and clarity of the manuscript. No scientific content, interpretation, or conclusions were generated by the tool [40].

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Data Availability

All data presented in this manuscript are available from the corresponding author upon reasonable request.

Authors' Contributions

MHPS and RK collected and analyzed the data. MHPS wrote the manuscript and performed the analysis. AJS, MN, IG, HMJ, and BHANM provided input on the study, recruited participants, and reviewed the manuscript. MDK designed and supervised the study and reviewed the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
GRAMMS (Good Reporting of a Mixed Methods Study) checklist.
[DOCX File , 13 KB - pediatrics_v9i1e101452_app1.docx]

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Multimedia Appendix 2
Questionnaire.
[PDF File (Adobe PDF File), 798 KB - pediatrics_v9i1e101452_app2.pdf]

Multimedia Appendix 3
Statistical analysis and variables influencing willingness to use home monitoring across subgroups.
[DOCX File , 13 KB - pediatrics_v9i1e101452_app3.docx]

Multimedia Appendix 4
Median Likert scale score for different types of home monitoring tools for asthma and cystic fibrosis.
[DOCX File , 15 KB - pediatrics_v9i1e101452_app4.docx]

Multimedia Appendix 5
Ability of caregivers and children to notice disease-specific symptoms.
[DOCX File , 13 KB - pediatrics_v9i1e101452_app5.docx]

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Abbreviations

CF: cystic fibrosis
CFTR: cystic fibrosis transmembrane conductance regulator
GINA: Global Initiative for Asthma
GRAMMS: Good Reporting of a Mixed Methods Study
WMO: Wet Medisch-Wetenschappelijk Onderzoek Met Mensen

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Physical Activity Guidance Resources for Rural Families of Neurodiverse or Developmentally Diverse Children: Exploratory Co-Design Study

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Abstract

Background: Being active benefits children and their parents, but there is a lack of co-designed resources that support families to engage in physical activity (PA) together.

Objective: This exploratory co-design study aimed to identify ways to optimize guidance resources intended to assist in being active together, and to evaluate the co-design approach it used.

Methods: Physiotherapist-researchers with experience and expertise in family PA drafted 2 evidence-informed prototypes. One prototype informed families about the holistic benefits of being active together, while the other helped families to plan their episode of PA. Twelve parents from 9 rural families and their neurodiverse or developmentally diverse children (n=13) were recruited as co-designers to ensure a wide range of considerations. Family co-designers took part in 2 to 3 workshops. They trialed the prototypes, telling researchers what worked well and how to improve them. Child and adult advisory groups oversaw the co-design approach. Each group met 3 times, with the child advisory group meeting prior to the adult advisory group. A child voice facilitator and advocate was used to support the child advisory groups and facilitate communication between child and adult advisory groups.

Results: Sixty-two changes were made to the prototypes in response to feedback from families and researcher observations. Key changes to resources recommended by children, parents, and researchers to increase user acceptability and usability included changing the ordering of the planning resource to reflect the way that most families used it, adding a "*hard words*" section to improve readability, support to normalize that no-one wins all the time, additional examples to cover each section of the resources, and encourage negotiation among families to ensure that the planned PA was mutually desirable. All families used the resources to successfully complete, or adapt, their planned session of PA together. Overall, co-designers and advisory group members perceived the co-design approach to be appropriate and responsive. However, the researchers identified a possible gap in final communication with the children regarding dissemination of results of the project which were provided to families via parents' email.

Conclusions: The co-design approach used in this study supported families, including neurodiverse and developmentally diverse children, to trial and provide feedback on PA resources. The large number of changes made to the resources from co-designer suggestions and researcher observations highlights the importance of gaining user feedback for consumer resources. Future research is needed to evaluate how these co-designed resources may impact family PA behavior and identity. The transparent co-design approach and evaluation highlighted limitations for research communication to children, which require careful consideration in future similar studies.

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KEYWORDS

co-design; physical activity; family; neurodiversity; parenting

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Introduction

The widespread benefits from regular physical activity (PA) are dose related, with the greatest health benefits observed among those who go from inactive to active [1,2]. National and international guidelines for PA emphasize minimum recommendations for PA volume and intensity [3-5]. Yet, despite decades of public health messaging on PA, regular child PA participation remains low worldwide [6]. For example, a 2022 report from the Active Healthy Kids Global Alliance graded 10 indicators related to PA across 57 countries. Aggregate grades include D for overall PA grade, C+ for PA engagement at school, and C− for family and peer PA engagement [6]. Low child PA participation rates are concerning, given the widespread health and well-being benefits childhood PA affords children throughout their childhood and adult life [7,8]. Children who are neurodiverse and developmentally diverse are at an even greater risk of inactivity due in part to slower development of fundamental movement and prosocial skills [9-11]. These populations include children with conditions such as autism, attention deficit hyperactivity disorder, and developmental coordination disorder, as well as those who are not meeting their developmental milestones. Diagnosis of conditions takes time, and many families, particularly those in rural areas, endure long waiting lists to access developmental assessments [12].

Parents shape their children's PA behaviors, which underlines the importance of supporting their endeavors. For example, medium-sized correlations have been found in studies of parental support behaviors and child PA [13,14]. There is general consensus in the literature that the following parental behaviors assist child PA: encouragement and talking about PA, logistical support, and cross-generational PA (X-gen PA; ie, parents or carers being active with their children) [13]. In 2022, Active Healthy Kids Australia suggested increasing child and parent engagement in PA *together* to provide modeling opportunities for children and reduce risks of chronic diseases (ie, diabetes) while increasing both populations' opportunities for a healthy life [15].

Research has found that X-gen PA provides more than physical and psychological health benefits [16]. For example, X-gen PA has been identified by both children and parents as an important instrument through which they can connect to each other socially and emotionally [16]. It facilitates communication, in a nonconfrontational context, and provides a bonding experience, even in contexts where verbal communication is not feasible (eg, high-intensity activity), possibly via mirroring of similar repetitive movements [16]. Parents view the support they provide during X-gen PA as much broader than just assisting their child's PA [16]. For example, they use it to teach their children how to work with other people and build resilience by getting through physically challenging circumstances together, as well as to role model healthy behavior and help their children to gain and practice sporting skills [16].

X-gen PA is a reciprocal partnership to which children, as well as parents, contribute [17,18]. Children may influence the commencement of an episode of PA with their parents, which requires consensus from all those involved [18]. For example, children may initiate episodes of PA with their parents by bringing their siblings with them to augment their request or ask to join in their parent's PA session [18]. It is evident that X-gen PA is a complex bidirectional phenomenon when viewed through the lens of socioecological models, such as those described by Bronfenbrenner [19] and James and Prout [20]. Yet, X-gen PA is often considered in PA research through a unidirectional model as one aspect of parental support for child PA [21,22]. This unidirectional model, where children's influence is not acknowledged and parents are considered the sole *gatekeepers* of family PA, may have contributed to the lack of children's voices in family PA research [18] and the narrow focus of PA promotion by targeting parents only [23].

A recent systematic review identified a lack of co-designed holistic resources that support families to engage in PA *together*, including among families with neurodiverse and developmentally diverse children [23]. This oversight is surprising as co-designing with end users ensures that resources are suitable for the populations they are targeting. In addition, co-designing with end users is recognized as one way of increasing health equity and literacy [24].

Family-centered practice describes another socioecological model that supports health professionals and researchers to work in partnership with families to enhance developmental outcomes for children [25]. It is strengths-based, acknowledging that all families have strengths that can be built upon, including that they are the experts on their *own* family [1,26]. Lundy's model of participation [27] was developed to help operationalize Article 12 of the Charter on the Rights of the Child [28], which states that children have a right to be heard on issues that affect them. The model describes 4 chronological elements that should be considered to support children's participation: space, voice, audience, and influence [27].

Children living in rural areas in Australia exhibit greater developmental vulnerability. For example, an overview of the 2021 Australian Early Developmental Census identified that only 55% of children in the geographic setting for this study were developmentally on track across all 5 domains: physical health and well-being, social competence, emotional maturity, language and cognitive skills (school-based), and communication skills and general knowledge [29].

The primary aim of the research was to identify ways to improve the usability and acceptability of guidance resources intended to increase knowledge of how to plan and engage in X-gen PA among rural families, including those with children who are neurodiverse and developmentally diverse. The secondary aim was to explore the authenticity of the co-design approach by evaluating the approach through the voices of children and parent co-designers, child and adult advisory groups, and researchers.

Methods

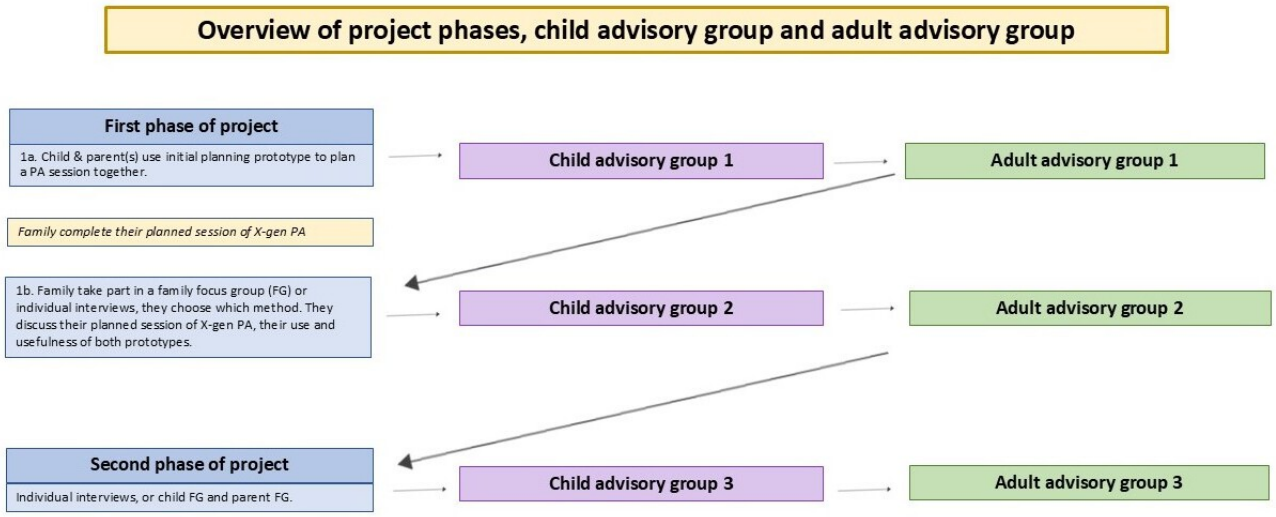
Overview

The research was conducted within a critical realism paradigm, which acknowledges both the existence of objective reality

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(ontological realism) and that co-designers' and researchers' understanding of that reality is situated and relative (epistemological relativism) [30]. The study used an exploratory, sequential, participatory research design [31,32] using multiple methods to iteratively inform resource co-design. The co-design process involved physiotherapist-researchers with experience and expertise in X-gen PA, along with neurodiverse or developmentally diverse children and the parents of these children. The physiotherapist-researchers contributed to the co-design process knowledge of considerations regarding X-gen PA gleaned from families more broadly based on prior research with families [16,18] with their own families' lived experiences with X-gen PA and their professional experiences. Participation and contributions of neurodiverse and developmentally diverse children and their parents in the co-design process enabled consideration of a range of additional issues for X-gen PA that may not have been as prevalent or as strongly recognized in many of the families involved in prior X-gen PA research. Children and parent co-designers attended 2 to 3 co-designer workshops where they trialed and provided feedback and suggestions on key elements of 2 X-gen PA prototype resources that were initially drafted by the physiotherapist-researchers, based on their prior understanding of X-gen PA (Figure 1). Additionally, child and adult advisory groups were established to provide guidance and feedback on the co-design approach (Figure 1). Both quantitative data (from surveys of participants) and qualitative data (child and parent co-designer suggestions and researcher observations) from workshops were collected and analyzed in this multimethod co-design research.

Figure 1. Co-design phases and advisory groups.



Setting

This study took place in a rural Local Health District (LHD) in NSW, Australia. Co-design workshops and child advisory group meetings were held in local library meeting rooms, while the adult advisory group meetings were online.

Drafting of Evidence-Informed Prototype X-Gen PA Guidance Resources

As a first step in the sequential co-design process undertaken in this study, 2 evidence-informed prototype X-gen PA guidance resources were drafted by the physiotherapist-researchers (KF, KA, and RP) in the research team. These drafts provided families participating in the co-design study with evidence-based prototypes to trial and critique, thereby facilitating a sequential approach to co-design in which the initial contributions of the practitioner-researchers, resulting in prototypes, provided a foundation for the contributions of children and parents and subsequent contributions of the researchers. Similar sequential approaches to co-design, which integrate research evidence and clinical and expert experience with lived experiences of consumers through a sequential co-design process, have been described elsewhere, for example, the Framework for Co-Design of Clinical Practice Tools [31]. A further example is the bidirectional strategy used in the co-design of a self-compassion mobile health intervention for people with cancer, which enabled the merging of "top-down" (research evidence based and clinical expertise based) and "bottom-up" (lived experience based) inputs in the co-design process [32].

In this study, the drafted prototypes took the form of booklets that provided families with guidance on building family capacity for planning and adapting PA to the X-gen PA context. Drafting of the prototypes was informed by evidence accumulated from previous research [16,18] and the following frameworks and behavior change theories: the International Classification of Functioning, Disability, and Health [33], family-centered practice [25], self-determination theory [33], socioecological frameworks [20], and strengths-based practice [1].

The first of these prototype resources, *Doing Physical Activity Together,* described the purposes behind X-gen PA and experiences of children and parents with X-gen PA, discussed current evidence of the benefits of being active together, and provided examples of types of PA that families might try doing together. The second prototype resource, *Planning Physical Activity Together,* covered aspects families might consider when planning a PA session together. It also guided families through a postsession review, through which they could identify aspects of the X-gen PA session that each participant liked and aspects they might wish to change in future PA sessions.

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The prototype resources sought to assist autonomous experiences by supporting children's and parents' rights to take part in planning and choosing aspects of X-gen PA [34]. Competence was addressed in the *Planning Physical Activity Together* prototype [33], which stepped co-designers through every aspect of planning an episode of PA together. In addition, the prototypes provided families with a common language to plan and discuss their X-gen PA. It was anticipated that this planning process would enable children to be active participants in decision-making and that the resources would build capacity for planning and adapting PA across both generations, which would be mutually reinforcing. Three quotes from children and parents involved in preceding X-gen PA research and suggestions from that prior research for X-gen PA were included in *You might like to try* sections of the prototypes to provide ideas for families and promote norms for X-gen PA. Two Australian First Nations mothers were paid as consultants to examine the initial proposed text in the 2 X-gen resource prototypes and provide feedback on their cultural appropriateness. No changes were identified as being needed by the 2 Australian First Nations mothers. This suggested that the prototypes were culturally safe for use by Australian First Nations families, should they choose to participate in the co-design process.

Child and parent co-designers subsequently commenced engagement with the prototype resources by using the planning resource to plan a session of PA together. This approach allowed all co-designers, irrespective of their experience of X-gen PA, to take part in the co-design study, as there was no requirement for previous experience of X-gen PA. Further details are provided below of the extensive involvement and contributions of children and parents in the subsequent stages of the co-design process.

Researchers, Partner Organizations, and Child Voice Facilitator and Advocate

Two researchers (KF and KA) facilitated all co-design workshops involving children and parents. Both were experienced physiotherapists, with more than two decades of experience working with children and families, as well as experience conducting research workshops and focus groups and with X-gen PA. The study involved a partnership with the Pediatric Department of an LHD, a private rural pediatric clinic, and a primary health network. The partners assisted with recruitment and provided advice for the project through representatives in project planning and on the adult advisory group. An experienced primary school learning support officer was recruited into the role of child voice facilitator and advocate (CVFA). The CVFA was a dual role created to provide both independent (nonresearcher) facilitatory support to the child advisory group and an advocacy role for the child's voice at adult advisory group meetings.

Child and Parent Co-Designers

Purposive sampling was used to invite and secure the participation of a diverse group of families who would likely use the co-designed resources. Pediatricians identified neurodiverse or developmentally diverse children aged between 5 and 12 years who also met other eligibility criteria for participation. The parents and carers of these children were subsequently informed about the study, and both the parents (or carers) and children were invited to participate. Exclusion criteria were those with a health condition that severely limited PA participation and family members who required an interpreter to take part. Parent consent and child assent for participation were obtained.

To acknowledge their time and expertise, child co-designers were given a suitable piece of PA equipment, and parent co-designers and CVFA received a credit card voucher following participation in each workshop or advisory group.

Co-Design Workshops

The co-design research approach was chosen to ensure that both child and parent voices, reflecting their lived experiences, contributed to the final X-gen PA guidance resources, together with the evidence-based understandings and lived experiences of X-gen PA among the researchers. Lundy's model of participation, encompassing the 4 elements of *space, voice, audience,* and *influence*, was used to inform the co-design research approach [27]. The checklist developed by Ireland's Department of Children and Youth Affairs [35] was used by the researchers to aid reflexivity on all elements of the approach (Multimedia Appendix 1).

Data collection periods involving participating children and families were determined by co-designers' preferences and availability and occurred during the first 3 school holiday periods in 2024 (Table 1), with phase 1 occurring in January, phase 2 in April, and the final child and adult advisory group meetings (Table 2) occurring during the July 2024 holiday period.

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Table . Data collection and activities with participating children and parents.

Study phase and activity	Participants	Description
Phase 1: January school holidays		
Initial questionnaires	Child and parent co-designers	Children completed a paper questionnaire about intergenerational physical activity (X-gen PA[a]), with researcher assistance where appropriate. Parents completed a paper questionnaire on X-gen PA and demographic information (eg, age, gender, and health conditions).
Workshop 1: planning	Child and parent co-designers working together	Co-designers provided feedback while working through the Planning Physical Activity Together prototype. Researchers observed and documented suggestions for improvement. Families left with their completed plan, both prototypes, and an agreed date for the second interview. Families completed their planned physical activity session together.
Workshop 2: reflecting	Child and parent co-designers working together	The session began with opportunities for co-designers to reflect on their experiences of completing the plan through drawing and writing activities. Beginning with child participants, co-designers described their physical activity session and provided further critique of the planning prototype and initial feedback on the Doing Physical Activity Together prototype.
Phase 2: April school holidays		
Workshop 3: doing	Child and parent co-designers separately	Children played a board game in which landing on a specific color corresponded to a section of the Doing Physical Activity Together prototype. Colored cards contained questions about each section. Parents reviewed the prototype one page at a time, suggested improvements, identified gaps, and highlighted aspects they liked.
Post–X-gen PA questionnaires	Child and parent co-designers	Children completed a paper questionnaire, with researcher assistance where appropriate. Parents completed a paper questionnaire.
Evaluation of co-design	Child and parent co-designers	Participants completed questionnaires based on the Lundy rights-compliant model [27]. The child questionnaire was adapted from the evaluation questionnaire in the Government of Ireland Participation Framework for Children and Young People Participation in Decision Making [36]. Parents completed a corresponding questionnaire.

[a]X-gen PA: cross-generational physical activity.

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Table . Summary of child and adult advisory group meetings.

Meetings	Child advisory group	Adult advisory group
Meeting 1	1. Introductions and game. 2. Discussion with researchers covering: What do child advisors do? What is research? Why should research hear from children? How would you like to tell us what you think? 3. Brainstorming and discussion on how child advocates can support the group. How do the children want the child advocate to inform the adult advisory group what they think?	1. Introductions. 2. Presentation of project. 3. Co-design approach and evaluation. 4. Draft terms of reference for the adult advisory group. 5. Briefing on the child advisory group from the child advocate. 6. Agree feedback to child advisory group (sent to child advisory group members via parent email). 7. Feedback invited from group on project.
Meeting 2	1. Introductions and game. 2. Review adult advisory group feedback. 3. Briefing on first phase of project. Watch video of researchers explaining some of the changes made to resource in response to child and adult advice. Score and provide feedback on how well researchers have listened. 4. Brainstorm what children want adult advisory group to know.	1. Introduction and attendance. 2. Review terms of reference of group. 3. Briefing and feedback invited on co-design during first phase of project. 4. Briefing on child advisory group from child advocate. 5. Agree feedback to child advisory group (sent to child advisory group members via parent email). 6. Discuss co-design approach in phase 1.
Meeting 3	1. Introductions and game. 2. Review adult advisory group feedback. 3. Researcher invited into group to remind group and discuss why hearing from children is important. 4. Briefing on second phase of project. Watch video of researchers explaining some of the changes made to resource in response to child and adult advice. Score and provide feedback on how well researchers have listened. 5. Brainstorm what children want adult advisory group to know. 6. Present children with participation certificates, thanking them for being child advisors.	1. Introduction and attendance. 2. Review terms of reference of group. 3. Briefing and feedback invited on co-design second phase of project. 4. Briefing on child advisory group from child advocate. 5. Agree feedback to child advisory group (sent to child advisory group members via parent email). 6. Where to from here? Brainstorming translation of project. 7. Group invited to contribute to evaluation of co-design approach.

Parents completed a short demographic survey at the beginning of workshop 1. The child and parent co-designers used the initial planning prototype *Planning Physical Activity Together* to plan a session of PA together, while a researcher observed and provided advice where appropriate. Child and parent co-designers left with copies of both prototypes. They returned following the implementation of their plan for an X-gen PA session. Achievements reported by the child and parent co-designers in completing X-gen plans were recorded, along with their initial experiences of using the resources and impacts they reported the resources had on their understandings of planning and doing PA together. Child and parent co-designers then provided feedback and gave their suggestions on the 2 prototypes. In phase 2, separate concurrent child and parent workshops were conducted, and co-designers were asked, as part of a small post–co-design survey, if using the resources had changed the ways they (parents and children) were active together and to evaluate the co-design approach (Table 1).

Child and Adult Advisory Groups

All child and parent co-designers were invited to join either the child or adult advisory group, respectively, to oversee the project and provide advice on the co-design approach (Table 2). Three child advisory group meetings were held during the research period. Adult advisory group meetings were held after each child advisory group meeting. Child advisory group meetings were facilitated by the CVFA (with online support from a project officer). The CVFA also attended adult advisory group meetings in their advocacy capacity, telling the adult advisory group what the child advisors wanted them to know and providing independent, nonresearcher representations of the child's voice, as requested by the children in the child advisory group. The CVFA reported back from the adult group to the child group via the children's parents' email addresses. Adult advisory group meetings included a parent co-designer, the CVFA, a pediatrician, a data support officer from the primary health network, and the physiotherapist-researchers involved in the project.

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Advisory group members were invited, during the second and third advisory group meetings, to comment on changes made to the prototype resources in response to data gathered in the co-design process. Child advisors watched a short video of how researchers had responded to changes suggested by child co-designers. The CVFA invited child advisors to then score how well the changes matched what child co-designers had told researchers, using a 5-point smile rating scale. They were then invited to say why they had given those scores.

Adult advisory group members were provided with tables, which listed *all* comments from all co-designers and all observations from researchers, together with the results of initial data analysis and any related changes made to the prototype resources. Subsequently, a brief overview of key changes made to the prototypes was provided during adult advisory group meetings before the advisory group members were invited to comment and ask questions. Adult advisory group members (excluding the physiotherapist-researchers) were invited to evaluate the co-design approach via a survey after the last advisory group meeting.

Reporting of Co-Design Approach

A reporting checklist was used to ensure that there was comprehensive reporting of the co-design approach while noting that exact replication is not an aim in the reporting of participatory approaches because they should be adapted to the specific context [23] (Multimedia Appendix 2).

Data Analysis

All co-design workshops were audio recorded and transcribed. All co-designers' suggestions and researchers' observations were tabulated and counted. Researchers met regularly during the data collection period to discuss all suggestions and observations, reaching a consensus on amendments to be made to the prototype resources in response to this feedback. Conventional content analysis (as described by Hsieh and Shannon [37]) was used to group suggestions and observations of all co-designers into themes, and a thematic analysis was completed on transcripts of workshops to identify key themes from participants' experiences, recommendations, and discussions, using the 6-phase approach to thematic analysis as described by Braun and Clarke [38]. Reflexivity during content and thematic analyses was supported by regular meetings between researchers, which allowed consideration of themes and alternate explanations. Demographic and evaluation surveys were analyzed using descriptive statistics and content analysis, as described earlier.

Co-Designed Resources

At the end of the study, co-designed versions of the resources were finalized, and a graphic designer was used to compile the final co-designed resources. An infographic was created to provide feedback to participants and distribute information about the study [39], and a website [40] was created to house and make publicly available the final co-designed resources and gather further feedback on them.

Ethical Considerations

Ethical approval for this study was obtained from the Sydney Children's Hospital Network Human Research Ethics Committee (HREC) (protocol 2023/ETH00995) and Charles Sturt University HREC (protocol H23804). Consent and child assent were obtained from all co-designers, including consent for publication.

Results

Child and Parent Co-Designer Demographics

Thirteen neurodiverse and developmentally diverse children (girls: n=6, 46.2% and boys: n=7, 53.8%, age range 5 - 11, mean 8.6 y, SD 1.79 years) and 12 parents (mothers: n=9, 75% and fathers: n=3, 25%) from 9 families took part in the co-design study. Ten (83%) of the 12 parents answered a prestudy survey. All parents reported that they had never previously been given resources or advice on being active with their child. Further demographic information is listed in Table 3.

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Table . Child and parent co-designer demographics.

Characteristic	Value, n
Parent age range (y)	
25 - 29	1
30 - 34	1
35 - 39	4
40 - 44	2
45 - 49	2
Parent health issues limiting X-gen PA[a,b]	
None	9
Yes	1
Child health issues limiting X-gen PA[c]	
None	8
Yes	2
Additional issues identified by parents as limiting engagement in physical activity with their child[d]	4 responses

[a]X-gen PA: cross-generational physical activity.

[b] Open-text comment: “Chronic fatigue, limits my energy levels.”

[c]Open-text comments: “Just need to be careful as he has a connective tissue disorder which means his joints are unstable. No hard contact sports, just gentle activities” and “No energy to be active. Gets tired easily.”

[d]“ADHD: boredom, hyperfixation and transitioning hinders us both.” “Work/school schedule especially during winter.” “[name of child] is no fun to play with eg, listening, sticking to rules, needs to control everything.” and “I need to lose weight to feel like doing more.”

What Were Families’ Experiences of Using the Prototype Resources?

All child and parent co-designers reported they were able to complete their planned session of X-gen PA. A parent said:

> *I liked how it [the planning prototype] was all set out and how we ended up with a really good plan of what to do.*

Families noted the prototype planning resource helped them to organize X-gen PA and gave them a structure and language to debate what the episode would look like by considering all aspects of it. A father described how the prototype resource was used successfully as a reference to cease the frequent rule changes that their child tended to impose:

> *It was so good, to have a reference, to be able to say "hang on a minute, this is what we decided." Game-changing actually.*

A couple of families had to adjust their plans, and they reported that these adjustments were accommodated without difficulty. For example, a mother said:

> *The planning tool helped us even when there was some adjustment in timing. There was no arguing, there was no ’yeah, but!*

There was consensus that the prototype resources were useful and user-friendly:

> *It’s good, it‘s really easy for [child name] to understand and fill in. I found it pretty user friendly. [Parent]*

Families noted that the prototype resources included aspects of X-gen PA they had not considered, such as *physical and emotional safety* and *stopping* in the prototype planning resource. And a parent noted the following about the prototype *doing* resource:

> *I thought this resource included things that I hadn' t consciously thought about. Like supporting child development for things like problem solving, social skills, communication... It puts a positive emphasis on trying to get out and do more activity together. Reading something like this reminds us why we should do it.*

Children said they “liked planning” and that the prototype resources were “good” as they gave them “different ideas of what to do.” The prototype *planning* resource encouraged co-participation in PA, as evidenced by one parent who observed that:

> *if we hadn‘t planned this, I would have just sat down and watched them.*

There was consensus among families that using the prototype planning resource allowed children to know exactly what was happening. Using the resource reduced confusion and questions from children, which allowed all child and parent co-designers to have a better experience. For example, one mother said:

> *I think it helped to stop a lot of the questioning that we get when we say we' re going to go and do something. We set it out, they know what they' re doing. … This allowed us to say it all at the beginning*

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> *and then it allowed for a calmer results because they were part of the process.*

Children concurred, for example, one child said:

> *It was really good because we had everything planned. I knew what we were doing.*

Some elements of X-gen PA covered in the prototype resources families had not considered planning before. For example, *how* to do the activity, *managing emotions*, and *stopping*. Families noted that planning improved their engagement and experience:

> *We usually just get in and just do it. And not thinking about how and what the word ' how' meant in that context. Normally if we go for a walk, it's just come on let's go for a walk but we haven' t really thought about it, we just do it. Thinking about how makes you think about what obstacles you do need to overcome to doing it.*
>
> *[Parent]*

And a child said: "I like having rules because then we argue less." Parents agreed, noting that planning enhanced their enjoyment by reducing arguments and allowing them to go "at a pace that works for them."

In the second co-design workshop, some children also demonstrated an appreciation of how managing emotions could be used during other PA. For example, a child said:

> *When I played handball at school, a boy lost and got really angry and bounced the ball really hard and hit his leg. He did not have a plan for keeping safe for big emotions.*

Likewise, child and parent co-designers commented that they found the *stopping* section useful but had not considered discussing or planning this aspect before. For example, a parent said:

> *Talking about stopping beforehand is a great idea because we were able to plan what it would look like.*

The importance of planning this aspect was underlined by the wide variation between child and parent time expectations. For example, a child said: "I could spend the whole day doing this." Parents noted how having an end point that was clear helped their children. One parent noted that it helped their child engage in the activity for longer periods, and another said:

> *[Child name] is autistic and he can be rigid and things need to be in a certain order, and change does not come easily. So that stopping one ... is huge for him, cause you heard him, "3 overs each at 6 balls."*

Parents also observed that knowing when PA will end helped them engage more fully with their children and the "confidence that it will end before everyone becomes tetchy and tired." This allowed the activity to end on a positive note, without conflict.

What Changes Were Made to the X-Gen PA Guidance Resources?

In total, 62 changes were made to the prototype guidance resources during the co-design process. Tables in Multimedia Appendices 3 and 4 detail the 35 changes suggested by child and parent co-designers and 27 changes made based on researcher co-designer observations. Textbox 1 provides a summary of the key changes from among these.

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Textbox 1. Summary of key changes made to resources based on co-designer contributions.

1. Planning resource was changed to reflect the order most families addressed their planning in

For example, *Where* and W*hat* were combined into one section and moved up to after *Who*

2. Suggestions of activities were added to sections that did not have them

- "The bits of the resource which have lots of suggestions are awesome ... because it triggers ideas and helps us get more out of planning with him" (Parent).

3. Examples were added to sections to help understanding

- Some children found some of the ideas hard to grasp. For example, *Managing emotions*, they talked about being sad if they got hurt. Amended resource to provide examples of why emotions may become big.

4. Negotiation in planning needed additional support

- Several aspects in resource amended. For example, emphasized importance of hearing from both children and parents in *who* section. In *Reviewing together*, encouraged participants to work with their activity partner to help improve each other's experience.

5. Support was required not just for planning the activity but considering the preparation too

- For example, packing swimming bag, remembering goggles.

6. Resource was amended to remind families of a simple definition of PA

- "I wouldn''t have thought that just handball was physical activity because to me physical activity is walking, running, swimming, anything that they label as fitness. So that was even an eye-opener, oh this is quite fun, and it's easy to do, and it's still being active!" (Parent)

7. Resource was amended to remind families that PA didn't need to take a long time

- Parents reported that using this resource helped them appreciate that being active with their child need not take a long time after some commented that the time to engage was more achievable than they had realized.

8. Simplified some language that children identified as hard

- "I think you can improve it by getting rid of some of the big words so it's easier for other children to read." (Child)
- For example, changed *routine* to *everyday*

9. Added *Hard Words* section

- Children showed very variable ability to read and understand some words but resources are for families to read together. Retained some *hard words*, eg, *agility, self-esteem*, they were highlighted in orange in the resource and an explanation provided in the *hard words* section at the end of the resource to support parents to explain them

10. Parents advised that they would like to normalize that no-one wins all the time

- Added to *Some families compete and measure against each other*
- I think it's really important just to remind them that "It's okay if you don't win, as long as you're better at—getting better within yourself."

Has Using the Resources Changed the Way That You and Your Parent or Child Are Active Together?

Five children and 3 parents (n=8) answered a post–co-design survey. Six of these co-designers (children: n=3, 37.5%, parents: n=3, 37.5%) answered *yes* to the abovementioned question. One child answered *no*, and one child answered *don't know*. Child and parent co-designers were invited to tell us more. Table 4 provides the themes and related examples arising in responses from child and parent co-designers.

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Table . Has using the resources changed how you are active together? Themes and examples based on responses from child and parent co-designers.

Themes	Child responses	Parent responses
Shared themes	*Do it more together (n=3)* • *We do more with them* (n=3).	*Do it more together* (n=1) • *I try to be more involved and play with them instead of just sending them to play on their own*
Child and parent only themes	*Plan PA more* (n=1) • *We talk about it more. I know what we are going to do.*	*Greater insight into child's interests* (n=1) • *It helped me see that what I consider a fun activity is not what [name of child] likes to do. That didn't occur to me.* *Increased child agency* (n=1) • *The kids feel like they have more agency over the activities we do together when we plan, rather than me picking the activity and us doing that.*

Was the Co-Design Approach Authentic?

Feedback From Advisory Groups During Co-Design

Child advisors during the second and third advisory group meetings were predominantly positive about the changes made to the prototype resources in response to child feedback. However, some changes attracted more approval than others, and scores given by child advisors ranged from 5 (a big smiley face) to 2 (a slight frown). For example, child advisors rated the addition of a suggestion that children and parents swap roles, and the child takes on the role of teacher or coach, in the *Being active together supports child development* section of the *Doing Physical Activity Together* prototype resource, with big smiley faces. A child advisor wrote: "This is because I understand this and it makes me want to say this to my parents."

They reported less enthusiasm for other changes. For example, making more space for writing in the blank plan by making it 2 pages instead of 1 was rated neutral to smiley face (3-4) by child advisors. A child advisor wrote: "It's not a big change but it is still a good change." Changes were made to simplify language and provide a small dictionary of *hard words* in response to child and parent feedback. One child advisor did not like the changes made to simplify the language that *they* understood. They scored this change with a slight frown (2), noting:

> *Because some of the words like "bonding" I know about and to me it's unfair that I know a word and you take it out.*

Likewise, support for changes made to the prototype resources was received from the adult advisory group members during the research. While adult advisers reported they appreciated this transparent approach, no additional advice or commentary was received from them.

Feedback Post Co-Design Process

All children who participated in the third co-design workshop answered the co-design evaluation survey (n=5), providing a score of 1 to 5 stars for each of 16 statements. Figure 2 shows the findings from the survey, in which questions were based on Lundy's framework of participation [40]. The statement, *I felt safe giving my ideas*, was scored 5 stars by all child co-designers. Only one statement received an average score lower than 4 stars. The statement, *I know how we will be told about what happens to our ideas*, scored an average of 3.6 stars (range 1 - 5).

The bars in the figure depict the lower and higher limits of the range of scores, and the line that dissects each bar indicates the mean of the scores.

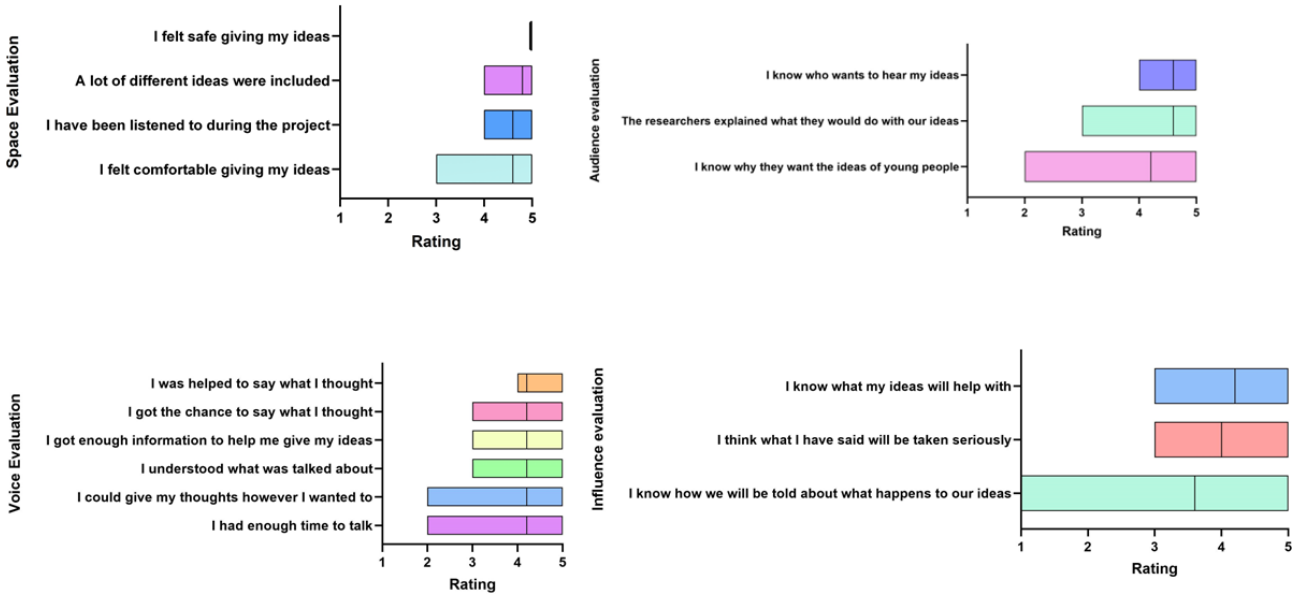
Questionnaire adapted from the Government of Ireland Participation Framework for Children and Young People Participation in Decision Making (Government of Ireland, 2021).

Three of 12 (25%) parent co-designers took part in the co-design evaluation at the end of the project (Textbox 2).

Three of 5 eligible adult advisory group members (60%) completed the questionnaire provided to them as part of the evaluation of the co-design process (Textbox 3).

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Figure 2. Child co-designer evaluation of co-design process (mean scores and range).



Textbox 2. Parent co-designer evaluation of co-design process (n=3).

1. All parent co-designers ranked the following statements on a 5-point Likert scale: 5=strongly agree

- I was given enough information to allow me to form a view about co-design
- I was given the experiences needed to form a view about co-design
- I was given enough time to express myself during co-design
- I felt comfortable giving my opinions about co-design
- I have been listened to by the researchers during the project
- I know what will happen to my opinions

2. What worked well in your co-design experience?

Two themes were found

- Co-design experience provided opportunities to share their experiences and opinions. One parent co-designer said, “I felt the whole process was valuable and gave me the ability to share my experiences and opinions. The resources worked well and it gave me some great ideas to bring to home life.”
- Two parent co-designers identified that the context and approach to co-design worked well. For example, a parent co-designer said, “Two way conversations and easy explanations.”

3. What could be improved from your co-design experience?

Nothing (n=3)

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Textbox 3. Adult advisory group evaluation of co-design process (n=3).

1. Did the study provide opportunities for children and parents to participate in co-design?

100% (n=3) replied Yes

Two themes identified invitation to comment on the answer above

- Engagement with children and parents (n=2)
- "Children involved in the advisory group were treated with respect and engaged with in a friendly manner. They appeared very comfortable to give their opinions and ideas."
- Multiple rounds of co-design (n=1)
- "There were several rounds of co-design sessions. This enables the refinement of themes from the sessions."

2. How much influence were the children and parents able to exert upon the co-design of the resources?

5-point Likert scale (1=*not much influence*, 5=*a lot of influence*).

33% (n=1) scored 4

66% (n=2) scored 5

3. What impact do you think the co-designed approach had upon the PA resources?

User-friendly end product (n=2)

Tailored to the study population (n=1).

4. What worked well with the co-designed approach? (Two respondents provided more than one answer).

Structured, user-friendly approach (n=1)

Time to allow children to fully engage (n=1)

Child advisory group well supported by child voice facilitator and advocate (n=1)

Transparent approach (n=1)

Communication between adult and child advisory groups (n=1)

5. What could be improved from your co-design experience?

Nothing (n=3)

Research Team Reflections Upon Co-Design Approach

The research team identified 2 elements of the co-design methodology that may have impacted child engagement in the study: the amount of information provided to child advisors and challenges in communicating with child advisors outside face-to-face sessions.

First, the purpose of doing the research and the importance of hearing from children were discussed with child advisors during the first child advisory group meeting but omitted from the second meeting of the child advisory group. This resulted in a child advisor voicing uncertainty to the CVFA during the second meeting about why adults wanted to hear their thoughts on the changes that were being made to the resources. Upon reflection, the researchers realized that while we included a brief recap of terms of reference at the beginning of each adult advisory group meeting, we had neglected to support child advisors in this way at the second child advisory group meeting. Thus, at the beginning of the third meeting of the child advisory group, a researcher was invited to join the group and facilitate a further discussion with child advisors about why their views were important.

Second, child advisors were sent an email update from the CVFA after each adult advisory group meeting. The intent of this communication was to close the communication loop and ensure that child advisors did not experience the frustration children have previously highlighted, that they are not informed about research progress and outcomes [27]. The email update was sent to each child's parent's email address to inform the child advisors of what the adult advisory group wanted to feed back to the child advisory group. Communicating with primary school children via their parents' email addresses was considered an important ethical approach, which ensured that parents were aware of and had control over interactions between the researchers and their children. However, it was found at the second child advisory group meeting that not all parents had shown their children this email or child advisors could not remember seeing or hearing about it. To address this issue, the feedback provided in the emails was reviewed with the child advisors at the beginning of the second and third child advisory group meetings. However, this finding does identify that the researchers had no way of knowing whether child co-designers were shown other emailed communication, such as the infographic sent to all families, via parents' email addresses, at the end of the project.

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Discussion

Principal Findings

This exploratory co-design study identified ways to increase usability and acceptability of guidance resources intended to increase family knowledge of how to plan and engage in PA together and evaluated the co-design approach it used. An asynchronous approach to co-design was taken to allow the development of theory-informed prototypes for families to trial and critique [41]. Key changes recommended by children, parents, and researchers to optimize the resources included changing the ordering of the planning resource to reflect the way that most families used it, adding a *hard words* section to aid readability, support to normalize that no-one wins all the time, additional examples of the types of PA families could do together, and assistance for negotiation among families to ensure that the planned PA was mutually desirable.

The secondary aim of the study was to evaluate the co-design approach. Overall, child and adult evaluators perceived the co-design approach to be appropriate and responsive and identified several elements of the co-design methodology that facilitated child and parent voices and increased methodological rigor. For example, the use of a CVFA to facilitate child advisory groups enabled safe spaces for children to contribute and evaluate changes made to the resources while ensuring independence and transparency of this aspect of the evaluation. Findings from the child evaluation and researcher observations resulted in 2 suggestions for co-design researchers to consider when conducting co-design research with children, which are discussed further later in this section.

Previous research has found that parents are already convinced about the physical health benefits of regular PA for their child but that has not changed their behavior in supporting their child's PA [42], and PA participation rates in children are still low worldwide [6]. It is also likely that some parents, who are not regularly active themselves, may not have the PA vocabulary necessary to enable, and undertake, successful episodes of PA with their children. Parent co-designers in this study discussed how the resources encouraged them to consider aspects of doing PA with their child that they had not considered before, such as how engaging in PA together supported their child's emotional and social development. It is hypothesized that the final co-designed resources [40] may provide families with greater insight into the wide range of health and well-being benefits of being active together. The resources were also written for both PA partners (children and their parents) to use together, as it is further hypothesized that planning and talking about PA together may influence family PA behavior and support for PA within families. However, both hypotheses will require further investigation with larger numbers of participants.

None of the participating families had previously received resources or advice on parents being active together with their neurodiverse and developmentally diverse children. The small sample size of this study means that this finding should be interpreted with caution, but it nonetheless is concerning because PA is an important intervention for these child populations [10]. Social PA interventions, such as X-gen PA, not only provide opportunities to practice physical skills and gain physical health benefits but also offer opportunities to practice prosocial skills, such as communication skills, taking turns, and self-regulation [10,43]. Provision of information to support families with neurodiverse and developmentally diverse children to take part in positive X-gen PA experiences is required. Development of paper-based or online resources, such as those created in this study, provides one possible way to deliver this support. Some families suggested that accessing the information via an interactive app would be fun, but it is acknowledged that the development cost and subsequent subscription costs of such an app might limit equitable access by excluding lower-income families [44].

The findings of this study suggest that the planning resource may help families consider together what obstacles they need to overcome to be active together. Importantly, parents reported they enjoyed their subsequent planned episodes of X-gen PA, indicating their children asked fewer questions and were more receptive to stopping PA at the end of an episode as planned, allowing for calmer experiences of X-gen PA and greater confidence that episodes would end without conflict. Basic psychological needs theory [45] may provide further explanatory insights into these experiences of success. The resources addressed all 3 needs that underpin the sustainment of intrinsic motivation for a behavior—relatedness, autonomy, and competence [45]. For example, planning stopping meant that children and parents gained insights into the often substantial differences between child and parent time expectations, resulting in conversations to plan mutually agreed-upon time frames for X-gen PA. Stopping of episodes of X-gen PA has previously been noted in the literature as an aspect of X-gen PA that children who were neurotypical found frustrating due to greater parental control over the cessation of a PA episode [18]. Creating a structured environment for children with neurodiversity, such as planning PA, has been identified as a key strategy to help children with neurodiversity manage their behavior [46]. Planning stopping also gave children with neurodiversity knowledge and preparation time to transition from one activity to another, which can help children with neurodiversity manage their emotions [46].

Previous parenting research has found that planning PA opportunities was identified as a key self-regulation strategy that parents who identify as an active parent perform for their family [47]. Research suggests that both role and social identities play a part in maintaining health-enhancing behaviors such as PA [44,48]. Role identity research has found a positive link between PA frequency and having a strong exercise identity [49]. Social identity theory acknowledges that people identify themselves by both their personal identity *and* a wide variety of social identities [49]. Thus, it is hypothesized that encouraging and supporting children to have both a voice and influence over the child-parent PA partnership may positively influence both a child's identity as an active person and foster a shared "active family" identity more than resources directed solely toward parents and carers, in which children are assumed to be the passive recipients of parental decision-making.

Two recommendations for family co-design have emerged from the process evaluation of our exploratory co-design study. First,

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it is important to remind child advisors at the beginning of each child advisory group meeting why children's voices are important to hear [27,28] and of the purpose behind the child advisory group (eg, terms of reference). We note that establishing agreed terms of reference has been identified in recent research on co-design studies as one factor that may enhance co-designer cooperation and understanding of their roles as co-designers [50]. Second, this study found that communicating to children via their parents' email addresses did not ensure that child advisors were provided with information about research progress and thus we are unable to determine whether child co-designers saw the infographic depicting the research outcomes that was written for families [39]. The HREC approved the researchers to communicate with the child co-designers via their parents' email addresses, and we acknowledge the importance of ensuring children's safety and privacy. However, not closing the communication loop with children has been identified in previous research as a source of frustration by children [27]. Our study suggests there may still be a role in sending out research summaries by mail, perhaps addressed to the whole family, to increase the likelihood of children accessing research outcomes. Previous research has found that children enjoy receiving research outcomes in the mail and suggest sending research in multiple formats, such as summaries, coloring books, and posters [51].

Limitations

The small number of co-designers and advisory group members in this study was recruited from a single rural Australian LHD, using a purposive sampling approach. We acknowledge that readers will need to determine the transferability of our findings to other populations; thus, we have provided detailed methodology, including descriptions of settings and participants. We hope our transparent approach will allow readers to consider the relevance of the study's findings to other populations and contexts.

Fewer child and parent co-designers took part in the second phase than in the first phase of the study. A gap of two and a half months (school term) between phases is likely to have contributed to this reduction in numbers. In future research, we recommend, where possible, recruiting more child and parent co-designers to reduce the impact of attrition [51] and completing studies without such long time gaps to maintain momentum and interest. However, it should be noted that we used holiday periods because parents informed us in this study that engagement was more likely during holidays, as term-time schedules are too busy. As this study was conducted in Australia (southern hemisphere), it was not possible to conduct the study in one (summer) holiday period due to the impact of Christmas during this time, but conducting the study over a continuous 6-week period would have been ideal. It should be noted that the reduction in engagement in the second phase of the study subsequently impacted the number of children and parents who provided an evaluation of the co-design approach at the end of the study, as child and parent co-designers were invited to complete paper-based evaluations at the end of the second phase workshop. Future studies could also consider a continuous evaluation approach through the use of a short survey at the end of each workshop. Finally, the possibility of desirability bias should be noted. Steps were taken to address this risk by empowering co-designers and advisory group members, such as by employing a nonresearcher (the CVFA), doing activities that promote collaboration to disrupt power hierarchies (eg, playing games and anonymous feedback) [52], and use of multiple methods to provide different ways for co-designers to collaborate and express themselves.

The final co-designed resources are freely available under a Creative Commons License [40]. Further research is needed to test the usefulness of the co-designed X-gen resources in a broader rural population. It is suggested that such research could examine the impact of the resources on family PA literacy, family cohesion, and PA identity, and their use during holidays rather than their impact on an individual's weekly PA total.

Conclusions

In this study, child and parent co-designers provided multiple suggestions to improve the usability and acceptability of guidance resources that had been compiled by experienced physiotherapists, underlining the importance of consumer involvement in resource design. The co-design methodology supported discussion and planning of X-gen PA among rural families with neurodiverse and developmentally diverse children. Future research is needed to evaluate whether these resources can positively impact family PA behavior in the longer term and across broad populations. Evaluating co-design approaches is an important way to provide transparency of the processes involved and to protect consumers against tokenistic co-design approaches. This study highlighted the need for consideration of how to convey study findings to child co-designers.

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Data Availability

Most of the data generated or analyzed during this study are included in this published article and its Multimedia Appendix files. Under the ethics approvals for the study, the rest of the data are not available for broader sharing or use in other research due to privacy constraints.

Authors' Contributions

Conceptualization: KF, RP, KA
Data curation: KF
Formal analysis: KF, RP, KA
Investigation: KF, KA, MS
Methodology: KF, RP, KA, JB, MS
Project administration: KF, KA
Writing – original draft: KF, RP, JB, KA, MS
Writing – review and editing: KF, RP, KA, JB, MS

Conflicts of Interest

None declared.

Multimedia Appendix 1
Elements of co-design approach that facilitated family voices evaluated using Lundy's voice model checklist for participation.
[PDF File, 203 KB - pediatrics_v9i1e92658_app1.pdf]

Multimedia Appendix 2
Checklist for sufficiency of reporting of co-design approach.
[PDF File, 160 KB - pediatrics_v9i1e92658_app2.pdf]

Multimedia Appendix 3
Child and parent co-designers' suggestions and researcher co-designers' observations on Planning Physical Activity Together resource.
[PDF File, 370 KB - pediatrics_v9i1e92658_app3.pdf]

Multimedia Appendix 4
Child and parent co-designers' suggestions and researchers' observations on Doing Physical Activity Together resource.
[PDF File, 376 KB - pediatrics_v9i1e92658_app4.pdf]

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Abbreviations

CVFA: child voice facilitator and advocate
HREC: Human Research Ethics Committee
LHD: Local Health District
PA: physical activity
X-gen PA: cross-generational physical activity

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Motives of Children for Digital Gaming and Physical Activity and Their Parents' Perceptions: Cross-Sectional Matched-Pair Study

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Abstract

Background: Physical activity (PA) is essential for the healthy development of children. However, the pervasive presence of digital technologies has made digital gaming (DG) a prominent part of children's everyday lives. As children grow up immersed in these digital environments, concerns about reduced PA have intensified. Given that adults, particularly parents and guardians, play a central role in guiding children's behavior, their understanding of children's motivational drivers for both PA and DG is of particular relevance.

Objective: This study aimed to explore the motivational differences underlying children's engagement in either PA or DG. Specifically, the study investigated five distinct motivational scales (recreation, social interaction, coping, competition, and skill) to determine which motives primarily drive behavior in each context. Also, it assessed whether adults accurately perceive these motives in children.

Methods: Data were collected during events using an on-site questionnaire based on the Videogaming Motives Questionnaire. Both children and their accompanying adults completed parallel assessments regarding motives for PA and DG. The final sample included 94 participants forming 49 parent-child pairs. A 3-way mixed ANOVA with group as a between-subjects factor and activity and motive as within-subjects factors was conducted to examine group, activity, and motive effects and their interactions. To further explore these effects, a series of 2 × 5 repeated measures ANOVAs were conducted to examine the interaction between activity type and motivational dimension across groups, followed by separate multivariate tests per motive.

Results: A significant interaction effect between activity type and motivational dimension emerged in the children's data ($F_{4,45}$=3.93, P=.008, partial η^2=.259). Further analyses showed that motive competition was rated significantly higher for DG than for PA ($F_{1,48}$=4.38, P=.04, partial η^2=.084). Among adults, separate multivariate tests for each motivational dimension revealed the largest difference in perceived motive coping ($F_{1,48}$=4.72, P=.01, partial η^2=.123), with PA rated higher than DG. Additionally, a significant difference emerged for motive competition ($F_{1,48}$=4.10, P=.05, partial η^2=.079), indicating higher ratings for DG compared to PA.

Conclusions: The findings emphasize the complexity of children's motivational profiles, suggesting that engagement in DG is not necessarily a sign of diminished interest in PA but rather reflects alternative, equally compelling motivations. This nuanced understanding challenges simplistic dichotomies and supports the need for balanced perspectives on children's activity preferences. Importantly, no statistically significant differences were detected between children's self-reported motives and adults' perceptions of their children's motives, suggesting a general tendency toward similar ratings rather than clear evidence of alignment. These insights can inform the development of more tailored strategies for promoting both physical and digital engagement in a healthy and complementary manner.

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KEYWORDS

video gaming; digital gaming; physical exercise; parental; leisure time activities; adolescence

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Introduction

Overview

Children and adolescents are not only the custodians of future societies but also key to achieving sustainable development. Investing in their health, education, and well-being is essential for ensuring economic stability, social cohesion, and environmental resilience in the decades to come [1]. Physical activity (PA) is widely recognized for its numerous health benefits, particularly in childhood and adolescence [2]. Regular engagement in PA has been shown to improve cardiovascular health, enhance cognitive development, and foster social well-being [3,4]. Moreover, recent research further supports the cognitive benefits of PA in children, showing that structured sport-based interventions (eg, decision-making drills) can significantly enhance problem-solving and creative thinking abilities in young athletes [5]. Additionally, participation in sports contributes to lifelong physical literacy, encouraging active lifestyles into adulthood [3,6]. Nowadays, the increasing presence of electronic devices has made them an integral part of our daily lives and especially of children and young people, who grow up surrounded by these "new" technologies [7]. Smartphones, tablets, and computers are commonplace, and most young people use them for a variety of purposes, including digital gaming (DG) [7]. Indeed, large national datasets show that sedentary behavior, which often includes screen time, accounts for a significant proportion (around 50% - 60%) of children and young people's waking hours [8]. The widespread daily use of electronic devices and regular participation in DG form a crucial context for understanding parental concerns about potential negative effects, such as addiction and reduced PA [9]. Given the significant time invested in sedentary screen-based activities, understanding and promoting engagement in PA is increasingly important for the health and well-being of the young age groups [10,11]. Recent findings among physically active university students demonstrate that even short-term interventions can enhance both physical and cognitive performance, underscoring the enduring interplay between activity, recovery, and cognitive function beyond adolescence [12]. With the rise of digital technologies, children's leisure activities have evolved, and DG has become an integral part of contemporary youth culture. While DG has often been scrutinized for its association with sedentary behavior, with some research linking excessive DG to negative health outcomes, such as increased obesity risk and decreased PA levels [13], emerging research suggests potential positive cognitive, emotional, and social effects [14-16]. Indeed, Granic et al [14] argue for a more balanced perspective on video games, suggesting that their increasingly complex, varied, realistic, and social nature may offer real-world psychosocial benefits. They summarize research suggesting benefits across cognitive domains, such as improved attention and visual skills, as well as motivational, emotional, and social gains from DG experiences.

Research by Barnett et al [17] highlights a contrast in perspectives between parents and children, particularly regarding active video games (AVGs) and basic movement skills. While parents often held skeptical views, perceiving AVGs as not a substitute for "the real thing" and having limited benefits for skill development or transfer to real life, children held a more expansive view of reality and reported using AVGs as a learning tool, perceiving skill acquisition as highly transferable [17], especially in the context of alterations needed in society over time [18]. This difference in perception of rather active digital games, wherein parents have expressed concerns regarding screen time and sedentary behavior [13] and have delineated a distinction between the "virtual" and "real" world [17], contrasts with children's perspective of DG as a meaningful social space that fosters autonomy and connection [19]. Considering the increasing complexity and interactivity of modern video games, research needs to move beyond simply labeling them as "good" or "bad" and develop equally complex models to understand their influence on players and which underlying motives contribute to their universal appeal and encourage participation of the young population.

Conflict of Leisure Time—Motivations for PA and Gaming

Understanding what drives engagement in both PA and DG is increasingly pertinent in contemporary society. Gaming in a digital form has become a dominant form of leisure behavior among youth, raising concerns about its potential to displace time that could otherwise be spent on PA. A study by Salmensalo et al [20] found that Finnish vocational students who primarily used PCs for DG were more than twice as likely to exhibit insufficient levels of moderate-to-vigorous PA, suggesting that the DG context and platform may play a role in reinforcing inactivity. Although total DG time was not significantly associated with physical inactivity, the results suggest a conflict hypothesis, which could state that time spent on digital entertainment can compete with PA pursuits. This may be particularly relevant for younger populations, such as children, who face a limited amount of discretionary leisure time. As digital games continue to evolve in complexity and immersive potential, children may increasingly be drawn to screen-based engagement at the expense of PA, creating a behavioral tension between immediate digital gratification and the long-term health benefits of active lifestyles. Related to PA, the primary motivations encompass a range of factors, including the pursuit of improved physical and psychological well-being [21,22], the experience of enjoyment and pleasure [23,24], and the desire for social interaction and support [21] or competition [25]. These motivations can vary depending on individual characteristics such as age and gender [15,21,26,27], as well as the activity undertaken [23].

Similarly, the motivations for engaging in DG are multifaceted, extending beyond mere entertainment or recreation to include the satisfaction of psychological needs such as competence, autonomy, and socialization [15]. Individuals are often driven by the sense of achievement within games [17], the opportunities for social connection and competition [28], and the potential of immersion and escapism into virtual worlds [17]. To comprehensively assess these multifaceted motivations behind DG [15], instruments like the Videogaming Motives Questionnaire (VMQ) have been developed [29] to identify and measure the various underlying motives for playing digital games. An examination of these underlying motivations is

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critical for designing effective implications to promote healthy behaviors and for better understanding the profound influence of digital entertainment in our lives [23].

Divergences in Perceptions

A substantial point of divergence exists in the value and purpose attributed to nonactive DG by parents compared to children [7,9,17]. Parents often hold largely negative perceptions of DG, with concerns frequently centering around violent content and the potential for addiction. Further evidence indicates that evening blue light exposure can negatively affect sleep quality, motor function, and cognitive performance in young individuals, highlighting the potential risks of excessive screen use for children's overall well-being [30], which might be seen negatively by parents as well. This aversion can be attributed, at least in part, to what has been termed a "generational difference," which hinders parents' ability to relate to DG [9].

This perspective is in contrast to the multifaceted motivations that children have for engaging with video games. As stated, children engage in DG for the sake of enjoyment, stress reduction, social interaction, the management of boredom, and competition [31]. Martucci et al [15] further delineate a comprehensive array of DG motivations, encompassing recreation, social interaction, coping, violent reward, fantasy, cognitive development, customization, and competition. Moreover, initial findings suggest that children perceive DG as more recreational and skill-enhancing than their parents do [32]. While parents may primarily focus on the perceived negative impacts of DG, existing research highlights potential benefits of DG that parents might overlook [14,33,34]. These include improvements in cognitive skills, motivation, emotion regulation, and social domains. For instance, certain games have been shown to enhance attention and spatial reasoning skills, promote persistence, provide a secure environment for managing negative emotions, and facilitate social interaction [14,35]. Rhodes et al [36] also address a related concern, highlighting that parents perceive screen time, whether active or sedentary, as a potential substitute for other activities they deem more valuable, such as homework, socializing, and sleeping. This observation suggests a more extensive set of concerns among parents regarding the opportunity cost of time allocated to DG.

In contrast, Ng et al [37] found that for children who play sports video games, it can be an important part of their overall "Physical Activity Relationships," potentially linking to their interest in watching sports and participating in PA, for example, children who actively play soccer are also attracted to soccer simulations like EA Sports' EA FC [38]. This finding suggests that some children may perceive a connection between the virtual world of sports-gaming and the real world of sports, a link that parents may not fully recognize or value. Although previous studies have examined differences in perceptions between parents and children in the contexts of DG and PA, these domains have largely been investigated in isolation. For example, Franzò et al [39] identified a discrepancy between how parents and children perceive the emotional impact of DG, with parents expressing more concern and children reporting a more nuanced view. Similarly, Kutner et al [40] found that while children view DG as a socially meaningful activity, parents tend to emphasize its potential negative effects, such as interference with academic performance and reduced socialization. In the realm of PA, Tay et al [41] explored children's motivations for engaging in PA, noting that parental support and access are crucial factors. Ostermeier et al [42] further highlighted parental concerns about decreased PA levels during the COVID-19 pandemic and the importance of peer influence in children's reengagement with active routines. Despite the value of these findings, there remains a notable gap in the literature: to date and to the best of our knowledge, no study has systematically investigated how parent-child perception differences operate simultaneously across both DG and PA domains. Given the increasing relevance of both behaviors in youth development and health, integrative studies bridging these perspectives are warranted [42].

While parents often perceive DG as excessive, violent, or potentially addictive, and thus harmful to their child's well-being [9], children are more likely to see it as a meaningful part of their social world, offering opportunities for autonomy, social connection, and identity development [19].

In conclusion, the perceptions of DG and PA might differ significantly between parents and children. While parents often express concern about DG, focusing on its potential negative impacts, lack of "real-world" value compared to PA, and a generational gap in understanding—children tend to be motivated by fun, social interaction, and skill development. They may also perceive a stronger connection between virtual and real-world PAs. We hypothesize that children are expected to show similar motivational patterns for PA and DG, with only minor differences across specific motives, as the structure of the motives for both activities appears to be similar. Moreover, we hypothesize that parents will perceive higher motivational relevance for PA compared to DG in their children, particularly in dimensions related to PA or social engagement. Lastly, certain motivational dimensions—such as coping or competition—will be rated significantly higher for DG than for PA by children. This study seeks to investigate these divergent perceptions by examining whether parents underestimate the potential positive aspects of DG and how children view both DG and PA as integral parts of their daily lives. By exploring these possible perception discrepancies, this study aims to contribute to a better understanding of DG's role in child development. Based on the hypotheses, two research questions (RQs) were formulated.

RQ1: Do children report different motivational patterns for engaging in PA compared to DG, and which motivational dimensions are more strongly associated with each activity type?

RQ2: To what extent do parents' perceptions of their children's motives for PA and DG align with the children's self-reported motives?

Methods

Recruitment

Participants were recruited at two separate events: the Frühjahrsmesse (spring fair) 2024, held from March 14-17, 2024, in Innsbruck, Austria, and Gamers Heaven, which took

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place on September 21-22, 2024, in Telfs, Austria. The aim was to collect data from a broad and diverse sample representing Tyrolean society. The Frühjahrsmesse is an established annual fair featuring exhibitors and family-oriented attractions, while Gamers Heaven was held for the first time and specifically targeted individuals interested in DG. In total, 162 participants participated in the questionnaire on-site using a Samsung Galaxy Tab A (T515) for data collection due to its portability. The complete questionnaire is available in Multimedia Appendix 1 (original-German) and Multimedia Appendix 2 (translated-English), and the item-level statistics are provided in Multimedia Appendix 3. After excluding incomplete or unmatched responses, the final analytical sample comprised 94 participants (49 children and 45 adults), with four adults each participating with two children, resulting in a total of 49 parent-child pairs. The demographic characteristics of the analyzed sample are presented in Table 1. It should be noted that the child sample showed a substantial gender imbalance, with boys comprising the clear majority of participants, which should be considered when interpreting the motivational patterns reported.

Table . Demographic description of the sample.

	Age (y), mean (SD)	Gender, n (%)	PA[a]>5 h/wk, n (%)	DG[b]>5 h/wk, n (%)
Children (n=49)	12.6 (2.9)	10 (20.4) female	14 (28.6)	32 (65.3)
Adults (n=45)	44.4 (5.7)	25 (55.6) female	8 (17.8)	—[c]

[a]PA: physical activity.

[b]DG: digital gaming.

[c]Not applicable.

To link responses from children and adults, both were instructed to enter a matching code at the beginning of the questionnaire. This code was based on a combination of letters and numbers derived from shared personal information: the first letter of the place of birth, the first and last letters of the mother's surname, the first letter of the father's surname, and the sum of birth day and birth month. If an adult accompanied more than one child, their responses were matched with each respective child's data set. The average time to complete the questionnaire was 23.8 (SD 16.9) minutes.

Since this study aimed to explore motives across both domains, the questionnaire was built upon the VMQ [29], which was adapted for PA. The VMQ is a validated tool for assessing DG motivations. Prior studies have indicated the presence of psychological drivers, such as competition, skill development, and enjoyment, that are relevant to PA and DG activities [43]. This study adapts the VMQ to measure children's self-reported motivations for PA and DG, as well as their parents' perceptions, offering a dual-perspective approach to better understand these behavioral patterns. Based on the VMQ, children completed assessments that evaluated 5 psychological scales related to their engagement in PA and DG: recreation, social interaction, coping, competition, and skill. The questionnaire was independently translated from English to German by three researchers. Discrepancies in wording were subsequently discussed collaboratively to reach a consensus, ensuring that the meaning and intent of each question remained as close to the original as possible. Validated for video gaming [29], the questionnaire was modified to PA by replacing the word "video gaming" in the questions with "sport," as a child-friendly synonym for PA. It should be noted that the term sport was deliberately used in place of PA to ensure conceptual comparability with DG, as both represent structured, goal-directed, and voluntarily chosen activities. Hence, the motive scales were designed to be quasi-identical and were administered separately for PA and DG contexts, respectively, to allow for consistent and comparable measurement across the two domains. Moreover, parents were asked to report their perceptions of their children's motivations regarding PA and DG, specifically in relation to the underlying motives driving these behaviors. This allowed for comparisons between both children and parents within each activity type and within each group across the two activity types. The questions were presented in a randomized order within the items, with the starting sequence also varied; for example, some participants began with the PA section followed by the DG section, while others completed the sections in the reverse order.

Ethical Considerations

Prior to participation, written informed consent was obtained from all parents. Participants were informed about the study procedures, the voluntary nature of participation, and their right to withdraw at any time without providing a reason and without any negative consequences. Data were collected anonymously using a tablet-based survey. To allow withdrawal of data after survey completion without recording identifiable information, participants generated a self-created identification code based on predefined rules (eg, initials of parental names and calculated birth date components). This code was not linked to any personal identifiers and could not be traced back to individual participants by the research team. Confidentiality of all participant information was strictly maintained. Participants did not receive any financial or material compensation for their participation. The study was approved by the Board for Ethical Questions in Science at the University of Innsbruck (Certificate 44/2021). All taken procedures were performed in accordance with the Declaration of Helsinki (1964).

Statistical Analysis

Data were collected from children and their parents, with paired data structures employed to ensure that individual child-parent connections could be accurately matched. This approach allowed for direct comparisons between corresponding participants within each family, facilitating more precise analyses of the relationships between PA and DG behaviors. A 3-way mixed

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ANOVA was conducted with group (children vs adults) as the between-subjects factor and activity (PA vs DG) and motive (5 motivational dimensions) as within-subjects factors. This design allowed testing for overall group differences, main effects of activity and motive, as well as their 2- and 3-way interactions to examine how motivational patterns varied across activities and age groups.

Moreover, to exploratorily examine differences between children and parents across 5 motivational scales in detail, as well as activity-related differences (PA vs DG) within each group, four separate 2-way repeated measures ANOVAs (2 × 5 design) were conducted. Although a linear mixed-model approach could account for random effects of matched dyads, the ANOVA strategy was chosen due to its interpretability, established robustness with balanced designs, and the primary interest in specific within- and between-group comparisons per motivational scale. The chosen approach allowed for a clear examination of within-subject effects (activity type and scale) and between-group effects (children vs parents), while also enabling follow-up post hoc comparisons. The paired nature of the data was accounted for by conducting repeated measures designs within each group. If Mauchly's test indicated violations of the sphericity assumption, the Greenhouse-Geisser correction was applied. Moreover, all individual post hoc comparisons were corrected for multiple testing using the Bonferroni procedure, ensuring control of the family-wise error rate. To control for inflation of the Type I error rate due to multiple testing across the four ANOVAs, the α level was adjusted to .0125 using the Bonferroni correction. Partial eta-squared (η^2) was reported to quantify effect sizes, and internal consistency of each scale was assessed using Cronbach α. All analyses were performed using SPSS (version 29.0.2.0; IBM Corp).

Sample Size

To determine the required sample size, an a priori power analysis was conducted using G*Power (version 3.1.9.7) for a repeated measures ANOVA with a within-subjects design [44]. The analysis was based on an expected medium effect size of f=0.25, which corresponds to empirical estimates reported by Granic et al [14] video game intervention research, particularly regarding outcomes such as cognitive flexibility, emotion regulation, and persistence. The significance level was set at α=.05 and statistical power at 1–β=.80. The analysis assumed two measurement points (eg, DG and PA motives) and a correlation among repeated measures of 0.5. Under these parameters, the required sample size was calculated to be 34 matched pairs (ie, 68 individuals) to detect a within-subjects effect with sufficient power.

Results

Internal Consistency of Questionnaire

To assess the reliability of the scales used to measure motivational constructs in both PA and DG contexts, Cronbach α coefficients were calculated for each scale. For PA, internal consistency was acceptable to excellent across all scales, with α values as follows: recreation (7 items) α=.780, social interaction (11 items) α=.910, coping (8 items) α=.828, competition (6 items) α=.810, and skill (6 items) α=.731. Similarly, for the DG context, reliability coefficients indicated strong internal consistency: recreation (7 items) α=.841, social interaction (11 items) α=.918, coping (8 items) α=.867, competition (6 items) α=.808, and skill (6 items) α=.782. These results suggest that all subscales demonstrate adequate to excellent internal consistency, indicating reliable measurement of the respective motivational dimensions in both domains.

Comparison of Motives for PA and DG Across Children and Adults

The Greenhouse Geisser-corrected 2 (group: children vs adults) × 2 (activity: PA vs DG) × 5 (motive) mixed ANOVA revealed a significant main effect of motive, $F_{3.416,327.981}$=46.93, P<.001, partial η^2=.328, indicating substantial differences across motivational dimensions. The main effect of activity was not significant, $F_{1,96}$=0.19, P=.66, partial η^2=.002, suggesting similar overall motivation levels between PA and DG.

Importantly, a significant activity × motive interaction emerged, $F_{3.474,333.540}$=7.48, P<.001, partial η^2=.072, indicating that differences in motivation between PA and DG varied depending on the specific motive. Post hoc pairwise comparisons confirmed that motives differed significantly from one another (all P<.001), with recreation and competition being rated higher than coping, social, and skill motives overall.

Neither the main effect of group ($F_{1,96}$=0.07, P=.79, partial η^2=.001) nor any interaction involving group reached statistical significance. Thus, motivational profiles were broadly similar between children and adults, both in overall intensity and in how they differentiated between PA and DG motives.

To examine the robustness of the findings across recruitment sites (Frühjahrsmesse and Gamers Heaven), separate 2 (group: child vs adult) × 2 (activity: PA vs DG) × 5 (motive) mixed ANOVAs were conducted for each location [45]. The analyses revealed highly consistent patterns, with significant main effects of motive at both sites (all P<.01) and no significant main or interaction effects involving group. The activity × motive interaction was significant at the Frühjahrsmesse but not at Gamers Heaven. Overall, the motivational structure was comparable across sites, confirming the robustness of the main results. In sum, across both age groups, participants distinguished between motivational dimensions, and these motives varied between PA and DG. However, children and adults showed comparable patterns. Because the 3-way mixed ANOVA did not yield any interactions involving the group factor, the subsequent analyses were conducted solely to provide a more detailed description of the within-group motivational patterns for PA and DG. For this purpose, separate 2 × 5 mixed ANOVAs were calculated for children and adults. These follow-up analyses are descriptive in nature and are intended to illustrate group-specific profiles. All inferential conclusions are based on the results of the abovementioned 3-way model.

Comparison of Motives for PA and DG Among Children

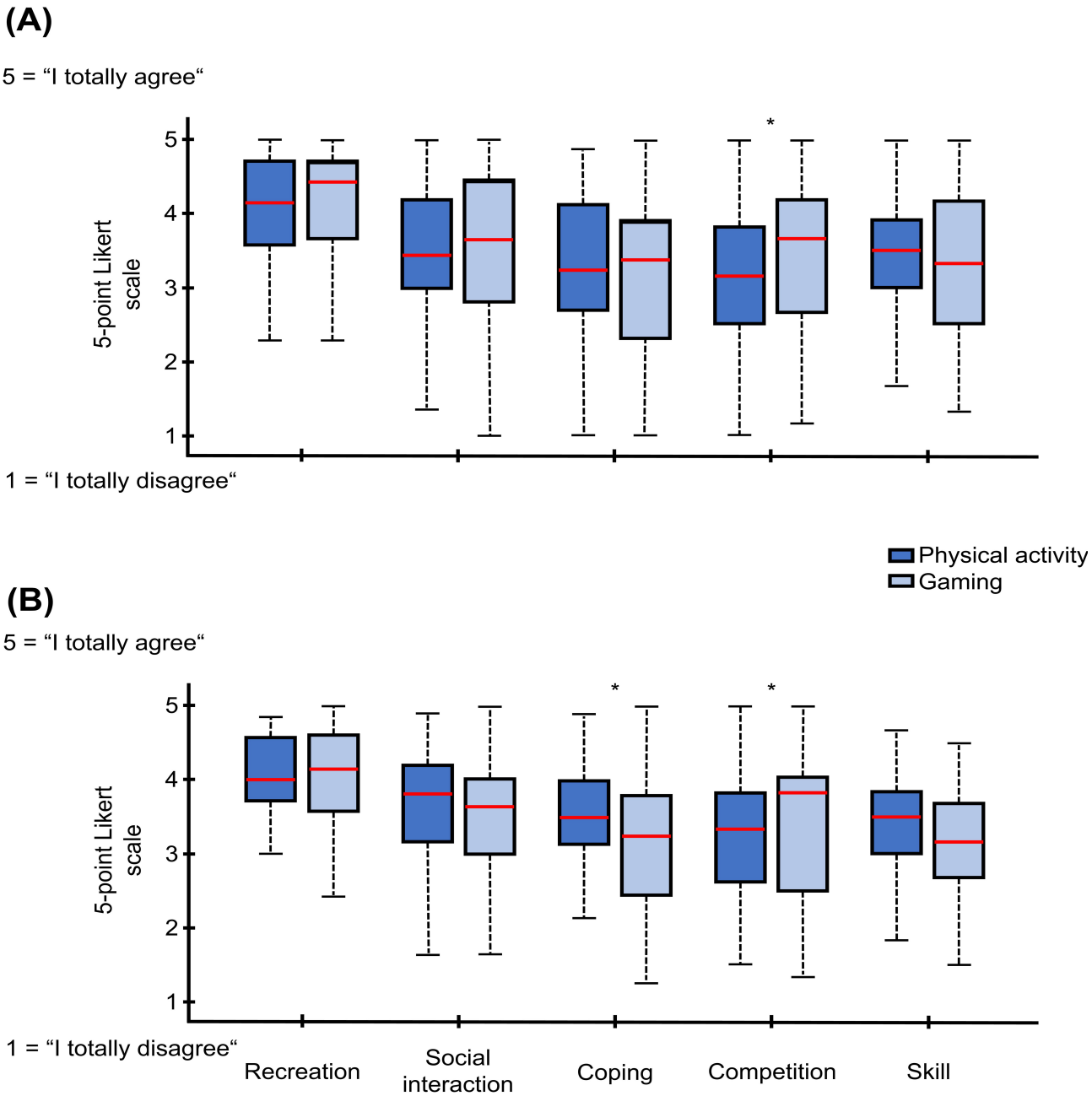
Multivariate tests revealed a significant main effect of motives, $F_{4,45}$=34.34, P<.001, partial η^2=.753, indicating substantial differences across motivational dimensions. The main effect of

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activity was not significant between PA and DG. However, a significant interaction between motives and activity emerged, $F_{4,45}$=3.93, P=.008, partial η^2=.259, indicating that the difference in motives ratings between PA and DG varied depending on the motive. The repeated measures ANOVA confirmed the significant main effect of motive, $F_{3.43,164.57}$=24.41, P<.001, partial η^2=.337. An almost significant motive × activity interaction was also observed, $F_{3.43,164.57}$=3.43, P=.02, partial η^2=.067. The main effect of activity remained nonsignificant, P=.78, across all correction methods.

Simple multivariate tests conducted for each motive revealed that only competition showed a significant group difference, $F_{1,48}$=4.38, P=.04, partial η^2=.084, as children rated DG as significantly more competition-oriented than PA. The results are demonstrated in Figure 1A.

Figure 1. Differences between physical activity (dark blue) and digital gaming (light blue) in relation to the motives recreation, social interaction, coping, competition, and skill are displayed. (A) The differences of children are presented. (B) The results of the adults. Answers to the questions of each motive were given on a 5-point Likert scale. The asterisks (*) indicate significant differences of the post hoc results, which failed to reach significance after Bonferroni correction.



Comparison of Motives for PA and DG Among Adults

For adults, multivariate tests revealed a significant main effect of motives, $F_{4,45}$=20.68, P<.001, partial η^2=.648, indicating substantial differences across motivational dimensions. The main effect of activity was not significant, $F_{1,48}$=1.40, P=.24, partial η^2=.028. Importantly, the interaction between motive and activity was significant, $F_{4,45}$=6.23, P<.001, partial η^2=.356. This suggests that the difference in motivation between PA and DG depends on the specific motive being assessed. The within-subject tests confirmed the main effect of motive,

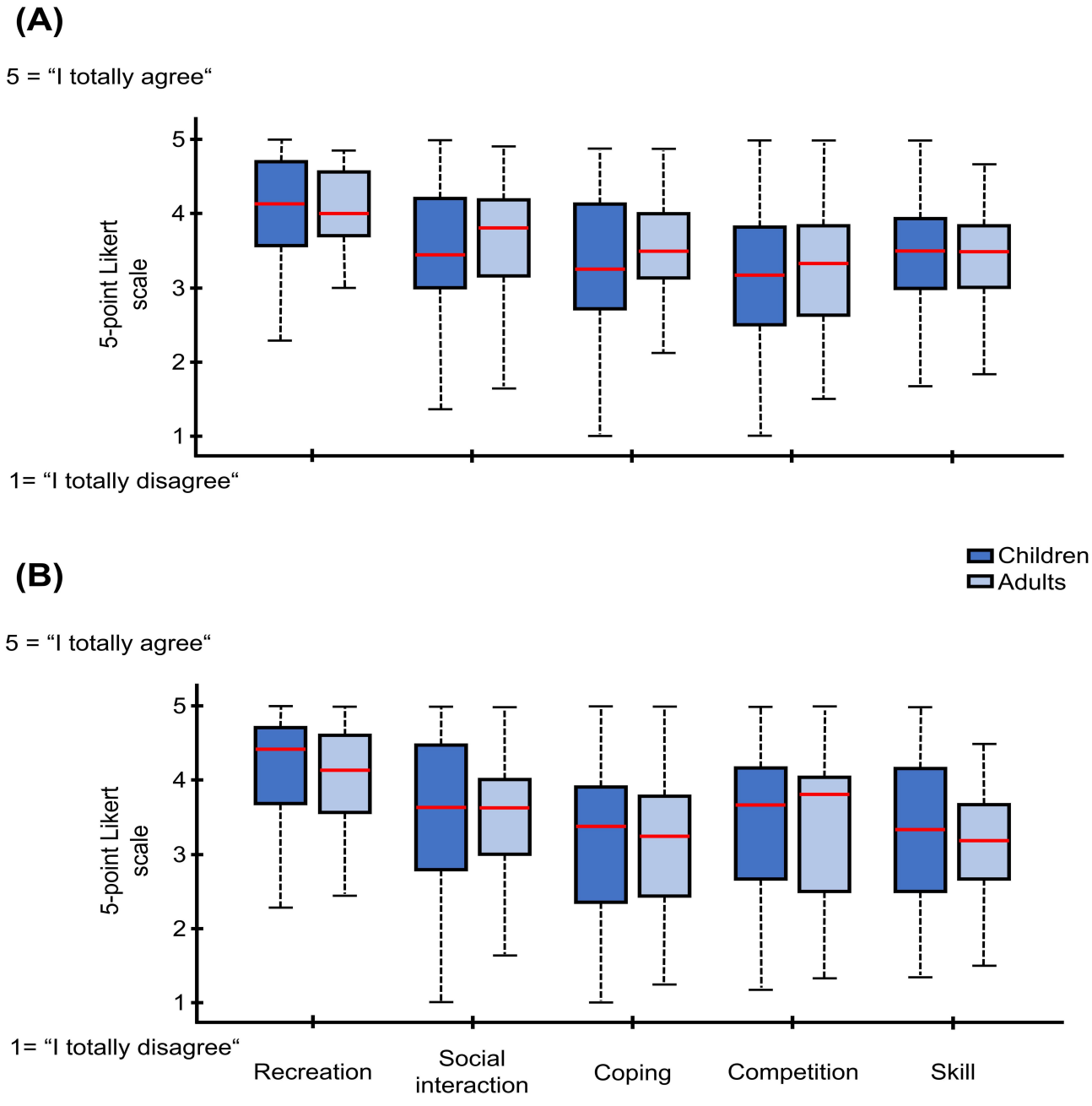
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$F_{3.06,146.71}$=23.36, P<.001, partial η^2=.327. The interaction effect was also significant, $F_{3.37,161.71}$=4.78, P=.002, partial η^2=.090, indicating that motives varied across domains between PA and DG. The main effect of activity remained nonsignificant (P=.24). Separate multivariate tests for each individual scale showed that the largest difference for adults between PA and DG occurred in perceived coping, $F_{1,48}$=4.72, P=.01, partial η^2=.123. Additionally, a significant difference was found for perceived competition, $F_{1,48}$=4.10, P=.05, partial η^2=.079. Other scales did not show significant group differences (all P.15). The results are displayed in Figure 1B.

Comparison of PA Motives Between Children and Adults

Related to PA, multivariate tests revealed a significant main effect of motives, $F_{4,45}$=29.19, P<.001, partial η^2=.722, indicating substantial differences in motives across the five domains. In contrast, the main effect of group was not significant, $F_{1,48}$=0.21, P=.65, partial η^2=.004. The motive × group interaction also did not reach statistical significance, $F_{4,45}$=1.97, P=.12, partial η^2=.149. To further explore potential group differences on individual motivational scales, multivariate tests were conducted separately for each scale. None of the 5 motivational dimensions showed statistically significant differences between children and adults. A visualization of the results is shown in Figure 2A.

Figure 2. Variances between children (dark blue) and adults (light blue) in relation to the motives recreation, social interaction, coping, competition, and skill are demonstrated. (A) The differences related to PA are presented. (B) The results of DG. Answers to the questions of each motive could be given on a 5-point Likert scale.



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Comparison of DG Motives Between Children and Adults

By investigating whether motivational profiles differ between children and adults across DG, a significant multivariate main effect of motive was observed, $F_{4,45}$=43.16, P<.001, partial η^2=.793, indicating substantial differences across motivational dimensions. The main effect of group was not significant, $F_{1,48}$=0.95, P=.334, partial η^2=.019. Moreover, the interaction between motive and group also failed to reach significance, $F_{4,45}$=0.32, P=.88, partial η^2=.026. Separate multivariate tests were conducted to explore potential differences between activity types for each motivational scale individually. None of the 5 scales reached statistical significance. The results are demonstrated in Figure 2B.

Discussion

Principal Results

The present study aimed to explore motivational differences in children's engagement in PA versus DG and the extent to which parents accurately perceive these motivations. Drawing on 5 distinct motivational dimensions—recreation, social interaction, coping, competition, and skill—we addressed two research questions concerning motivational patterns, intergenerational perception alignment, and differential associations of specific motives with activity type.

A notable and unexpected finding of the present study was that the analyses did not detect evidence of discrepancies between children's self-reported motives and their parents' perceptions, despite prior literature suggesting meaningful gaps between self- and proxy-reports [7,9,17]. In contrast to this established work, our results showed no statistically reliable divergence between self- and parent-reported motives across activity domains. Importantly, this pattern should not be interpreted as evidence of true parent-child alignment. Following the principles of null hypothesis significance testing, the finding represents an absence of statistical evidence for a difference—not confirmation of equivalence in motivational understanding.

To examine whether this result might reflect a sampling artifact (eg, parents at a gaming-focused event like Gamers Heaven being more attuned to DG), we conducted sensitivity analyses [45] separately for the Frühjahrsmesse and Gamers Heaven subsamples. The motivational patterns were highly consistent across locations: both subsamples showed strong main effects of motive and, critically, no group-related main or interaction effects. The activity × motive interaction presented to be significant at the Frühjahrsmesse but not at Gamers Heaven, which is likely attributable to reduced statistical power due to the much smaller number of matched pairs at the latter site. However, an equally plausible interpretation is that the gaming-affine Gamers Heaven sample may differ systematically from the spring fair sample in ways that influence motivational patterns. In general, this consistency indicates that the absence of parent-child differences should not be attributed solely to recruitment-site characteristics or increased parental familiarity with DG. Nonetheless, several contextual factors may have contributed to the lack of detectable divergence, including shared situational cues during data collection, relatively high parental involvement in the activities assessed, and the inherently observable nature of motives such as recreation or competition. At the same time, subtle differences may exist but remain undetected due to measurement limitations, shared method variance, or limited statistical power for small effects [46]. These considerations emphasize the need for cautious interpretation: the present results indicate that no discrepancies were detected within this sample, but they should not be taken as evidence of robust parent-child congruence in motivational perceptions.

Motivational Aspects of PA and DG

Regarding RQ1, if children report different motivational patterns for engaging in PA compared to DG, the results indicate that children do not report systematically different motivational patterns across the 5 dimensions when comparing PA to DG. However, some tendencies emerged that warrant attention. In particular, competition was rated more strongly as a motive in relation to DG than PA, suggesting it may play a distinct role in driving DG activities. This suggests that the motive of competition—known to be relevant in both PA [25] and DG [28]—may be more strongly fulfilled in DG contexts than in PA settings for children. A possible underlying explanation is the accessibility of modern networked play against human opponents, as seen in formats such as Battle Royale games (eg, "Fortnite") [47] or competitive modes like the Weekend League in "EA FC" [48]. While attending local area network parties back in the days used to require considerable effort, including transporting DG hardware to physical venues, today's competitive DG experiences can be accessed conveniently from home. While the relatively small sample size may limit the generalizability of the findings, the presence of statistically significant effects even under conservative testing procedures indicates that the observed differences are unlikely to result from random variation alone. Thus, although caution is warranted in interpreting marginal effects or visual trends, the detected significant results can be considered meaningful within the scope of the present design and sample characteristics.

Interestingly, the majority of motivational means of children were in general slightly higher for DG across the board, except for motives skill (Figure 1A) and recreation (Figure 2A), which showed reverse patterns. The gaming industry designs games to be highly engaging and, arguably, even addictive [48-50], potentially addressing psychological motives such as recreation and coping. However, while game mechanics can be programmed, genuine social interaction cannot—yet it showed a higher mean value, albeit without reaching statistical significance. The ability to communicate with peers in real time while playing may further enhance the appeal of DG by strengthening social motives. In summary, games have evolved rapidly in recent years, offering a wide variety of experiences that fulfill a range of important psychological needs. Notably, recreation, interpreted as a general intrinsic or personally valued motivation, consistently received the highest ratings across both activities and groups. This supports the notion of a possible "leisure time conflict," where both active and passive behaviors are motivated by similarly strong internal drivers, potentially competing for the child's limited free time [20]. These findings

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point to the complexity of children's motivational structures and emphasize that DG as an activity may not necessarily arise from a lack of motivation for PA but from competing, equally compelling motives.

Finally, we examined whether certain motivational dimensions were more strongly associated with either activity. Again, the motive competition emerged as the most activity-specific, being more strongly endorsed for DG by both children and parents. This aligns with prior research suggesting that DG behavior is often motivated by comfort, ease, or relaxation [51,52]. The convergence between generational views on competition adds confidence to this interpretation and underscores its relevance as a potential target for interventions aiming to reduce DG time. Other motives showed relatively balanced activation across PA and DG, further supporting the idea of overlapping and competing motivational structures in leisure contexts. The findings highlight the potentially overlapping nature of children's motivations for PA versus DG activity. The general alignment between children's self-perceptions and their parents' beliefs is promising for family-based intervention approaches. Importantly, the consistently high endorsement of intrinsic motivations like recreation across both activity types reinforces the idea that children are not necessarily passive recipients of screen-based content but are actively motivated by various factors—factors that may also be leveraged to promote PA if carefully aligned.

Focusing on RQ2, to what extent do parents perceive their children's motives for PA and DG correctly, the analysis did not detect statistically significant differences between children's self-reported motives and their parents' perceptions. While this indicates a lack of evidence for systematic discrepancies, it should not be interpreted as evidence of full alignment. The overall pattern suggests that parents' perceptions broadly resembled children's self-reports, though the degree of correspondence may vary across motives, which was not anticipated in that form based on existing literature [7,9,17]. We could not find results, which suggests that parents in the tested sample are generally detached from the reasons why children engage in either activity. In the context of PA, parents are generally considered to be fairly accurate in understanding their children's motives and behaviors [53]. It is plausible that this may also apply to the context of DG, suggesting that parents might be able to perceive and interpret the reasons why their children engage in video games with a comparable level of insight. This could be particularly true for more observable or socially shared motives, such as competition or social interaction, which are easier for parents to recognize. However, some nonsignificant trends pointed to potential perceptual differences. Specifically, the motives of social interaction, coping, and skill were perceived by parents as more relevant for PA than indicated by the children's self-reports, although these differences did not reach statistical significance. This trend may reflect generational assumptions or aspirational biases—parents might attribute more socially or developmentally valued motives like social interaction or skill development to active behavior [9,54]. Although not statistically robust, these trends merit further exploration, especially considering their potential impact on parental support for children's activities and a better understanding of parents related to DG nowadays.

Limitations

Several limitations should be acknowledged. First, although the VMQ [29] was originally validated for video gaming contexts, it was applied to both DG and PA settings in this study. This decision was made as the questionnaire closely aligned with the research questions, and the included motives overlapped substantially with those known to be relevant in PA. It should be noted that the term "sport" was used instead of "physical activity" to ensure conceptual comparability with DG, as both represent structured and intentionally chosen activities. However, this substitution narrows the construct to organized or leisure sport and does not capture the full range of everyday PA (eg, active play, active transport, unstructured movement). As such, the present findings primarily reflect motives for sport participation rather than PA in a broader behavioral sense. Future studies should therefore complement this approach by assessing motivation across the full spectrum of children's PA behaviors. Moreover, the motivational scales used in this study were not validated against objective behavioral measures. Thus, while the results reflect participants' self-reported motives, future research should examine how these relate to actual behavioral engagement in PA and DG. However, future research should aim to validate the VMQ across both contexts. Second, while the sample size was relatively modest, it closely matched the a priori power analysis, which indicated that 68 participants would be sufficient to detect moderate effects. The use of ANOVA and the observed moderate effect sizes (eg, partial η^2) further support the robustness of the findings, especially after Bonferroni-corrected alpha level. Third, a potential sampling bias cannot be entirely ruled out, as data were also collected at the "Gamers Heaven" event, which is an event for analog and DG-affine people. However, efforts were made to minimize bias by approaching a broad and casual family audience directly on site. Finally, the study was limited to the region of Tyrol, which may constrain the generalizability of the results to other populations. However, it presents a first matched-data approach showing the potential competing motives related to PA and DG of children. Lastly, the gender distribution differed between groups, with a lower proportion of female participants among children compared to adults. This imbalance should be considered when interpreting the results, as gender-related differences may have influenced motivational patterns.

Conclusions

These findings highlight the nuanced and multifaceted nature of children's motivational structures. Rather than indicating a lack of interest in PA—or in this study, sport—DG may emerge as a response to equally compelling, but distinct, motivational drivers. This complexity underscores the importance of further investigating these trends—particularly in relation to how they shape parental support for different types of activities. A deeper understanding of contemporary DG motives may also enhance parents' ability to relate to and support their children's engagement in both digital and physical pursuits.

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Acknowledgments

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Data Availability

The datasets generated and analyzed during this study are not publicly available due to institutional data protection policies and participant privacy considerations. However, deidentified data may be made available by the corresponding author upon reasonable request.

Authors' Contributions

FW contributed to the investigation, methodology, conceptualization, data curation, formal analysis, and writing of the original draft. NG and RMA contributed to the investigation, methodology, conceptualization, and writing sections of the original draft. NG, RMA, and SK were involved in data curation, as well as in the review and editing of the manuscript. MS was responsible for funding acquisition, project administration, resource provision, and supervision. All authors critically revised the manuscript, approved the final version for submission, and agree to be accountable for all aspects of the work.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Original questionnaire.
[DOCX File, 71 KB - pediatrics_v9i1e80129_app1.docx]

Multimedia Appendix 2
Translated questionnaire.
[DOCX File, 54 KB - pediatrics_v9i1e80129_app2.docx]

Multimedia Appendix 3
Item-level scale statistics.
[DOCX File, 49 KB - pediatrics_v9i1e80129_app3.docx]

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Abbreviations

AVG: active video games
DG: digital gaming
PA: physical activity
VMQ: Videogaming Motives Questionnaire

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Adolescents' Preferences, Experiences, and Views of 2 Online Programs for Anxiety and Depressive Symptoms: Qualitative Interview Study

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Abstract

Background: Anxiety and depression are among the most prevalent mental health problems affecting adolescents. Digital mental health interventions have emerged as promising means of addressing these challenges. Understanding adolescents' experiences and perspectives, and incorporating them into intervention design, can enhance their relevance, engagement, and effectiveness, ensuring interventions meet young people's needs.

Objective: This qualitative study aimed to identify how adolescents aged 16-19 years engaged with 2 distinct interventions (Bite Back [Black Dog Institute] and Project YES [Youth Empowerment & Support; Lab for Scalable Mental Health and Koko]). It explored (1) barriers and facilitators to engagement, (2) young people's preferred design features and content, and (3) perceptions of their potential usefulness and helpfulness.

Methods: Adolescents aged 16-19 years living in the United Kingdom were eligible to take part and were recruited through a university and a charity using convenience sampling. The final sample comprised 22 participants aged 18-19 years. They were asked to use Bite Back and Project YES for 30 minutes each over a 2-week period. Following this, 1-hour semistructured online interviews were conducted between January and March 2025. Anonymized transcripts were managed in NVivo (version 14; Lumivero) and analyzed using a pragmatic, inductive thematic analysis.

Results: Seven themes were identified that captured young people's views on factors influencing engagement, preferred design features and content, and the perceived usefulness of digital mental health interventions. Participants' views were shaped by whether the content felt age-appropriate, culturally relevant, and relatable, and by how clear and transparent the interventions were. Interactive, visually appealing, and tailored features were generally preferred. Although most participants found Bite Back helpful, useful elements were identified in both interventions.

Conclusions: This study contributes to the growing understanding of how young people engage with digital mental health interventions by identifying a set of interconnected factors that influence young people's experiences. It highlights the importance of designing interventions that align with young people's stage of life, culture, and experiences. Even small age differences appeared to influence how relevant the interventions felt to the individual. Furthermore, involving young people in co-design and ensuring clear, accessible communication may support trust and engagement, ultimately enhancing the benefits of such interventions.

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KEYWORDS

Interviews; digital interventions; mental health interventions; DMHIs; mental health; young people; digital mental health interventions

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Introduction

Background

The prevalence of mental health problems is estimated at almost 14% among individuals aged 15-19 years, representing the highest rate across all age groups up to 24 years [1]. According to the Global Burden of Disease study by the Institute for Health Metrics and Evaluation (IHME), anxiety and depression account for approximately 40% of these cases [2]. Adolescents with anxiety or depression often experience persistent sadness, irritability, low energy, or hopelessness [3-7], which can lead to social withdrawal, school avoidance, poor academic performance, and various health-related challenges [8-11]. When such difficulties occur during adolescence, a period of critical developmental changes, including identity formation, emotional regulation, and evolving social relationships [12-18], they can negatively shape future well-being. Without appropriate support, these challenges may persist into adult life, negatively affecting employment opportunities, interpersonal relationships, and overall quality of life [19-25].

Early intervention is essential, both to prevent the worsening of symptoms and to reach young people during a critical developmental stage, particularly as an increasing number of adolescents are experiencing anxiety and depression [26-30]. However, public mental health services frequently involve long waiting times [31,32]. In the United Kingdom at the end of 2023, only about one-third of adolescents with referrals to Child and Adolescent Mental Health Services (CAMHS) were able to access support within a year [33]. These delays highlight a gap between the growing demand for mental health services and the limited capacity of available professionals [34], creating barriers to accessing care. This problem can disproportionately affect individuals from ethnic minority groups or disadvantaged socioeconomic backgrounds, who may be more likely to experience such mental health difficulties [35,36]. Digital mental health interventions offer a promising avenue to bridge this gap, reduce inequalities, and deliver timely, accessible support to those who need it most.

The widespread use of digital devices, with as many as 96.5% of young people aged 12-17 years owning a smartphone in the United Kingdom [37], has paved the way for new approaches to delivering mental health support. Among these, digital interventions have emerged as valuable tools for helping young people manage anxiety, depression, and other mental health challenges [38]. Such tools can further offer the privacy, convenience, and flexibility that many young people seek [39-41], making mental health support more accessible. In addition to meeting the needs of young people, digital mental health interventions also offer a cost-effective approach [42] that could help alleviate the burden on mental health services by complementing existing care. By improving mental health literacy, these tools can also equip adolescents with skills required to better manage their symptoms and recognize when to seek professional help [43,44].

A wide range of digital mental health interventions has been developed in recent years, including those targeting anxiety and depression in adolescents [45-49]. These interventions are primarily delivered through mobile apps (eg, We Click [UNSW Sydney Brain Sciences] [50], CARE [Child and Adolescent Research in Emotion Lab] [51], and MoodHwb [Cardiff University] [52]), websites (eg, Grasping the Opportunity [53], An Enhanced Psychological Mindset Session [54], and MoodGYM [55]), or online platforms (eg, BetterHelp and Thriveworks). They draw on a variety of theoretical frameworks, such as positive psychology (eg, Bite Back [Black Dog Institute] [56]), mindfulness (eg, CARE [51], Tita [University of Turku] [57]), and growth mindset (eg, Project YES [Youth Empowerment & Support; Lab for Scalable Mental Health and Koko] [58] and Shamiri [Shamiri Institute] [59]), among others, but cognitive behavioral therapy (CBT; eg, Stressbusters [team from Manchester, The Institute of Psychiatry, London and Australia] [60], CATCH-IT [Competent Adulthood Transition with Cognitive Behavioral, Humanistic, and Interpersonal Training; University of Chicago] [61], and SPARX [The University of Auckland] [62]) remains the most commonly used framework. Digital interventions can address a broad spectrum of mental health challenges, such as eating disorders [63], posttraumatic stress symptoms [64], or sleep problems [65,66]. Some tools are intended for individuals with neurodevelopmental disorders [67] or chronic diseases [68], whereas others are aimed at the general population or at individuals experiencing elevated symptoms, as a form of prevention [69] or early support [70]. Some serve as a medium for delivering conventional therapy [71] or are designed to complement traditional approaches by offering additional resources or activities between sessions (eg, ChilledOut Online [Macquarie University] [72]), whereas others are intended to function independently, without direct support from a mental health professional [73].

Despite the growing number of such interventions, there remains a significant gap between their development, rigorous evaluation, and application in real-world settings. While many digital mental health interventions are publicly accessible, a substantial number have not undergone empirical evaluation [45,74,75], raising concerns about their effectiveness and safety. At the same time, few digital interventions targeting anxiety and depression that have been evaluated in research studies are actually implemented or widely accessible outside research settings [69,73,76]. Additionally, such interventions are still seldom developed with the involvement of the target population, which may limit their effectiveness [77-80]. This highlights a need for co-designed, practical interventions that are both evidence-based and accessible to adolescents beyond controlled research environments.

While assessing the effectiveness of an intervention is crucial, the success of digital mental health interventions also depends on how adolescents engage with them in real-world contexts. Even the most well-designed tools can fall short if they fail to capture users' attention, meet their needs, or resonate with their lived experiences. Research has shown that adolescents often disengage from digital interventions due to issues such as limited interactivity, concerns about privacy, or unclear and unrelatable content [81-83]. Engagement itself is a complex construct that goes beyond simple metrics such as usage frequency or duration. It is important that user interactions with the intervention are

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meaningful and sufficient to support positive behavior change [84]. Therefore, investigating targeted user experiences with the interventions is essential to ensure that digital mental health interventions are effectively engaging and consequently beneficial for those experiencing mental health difficulties [85].

Existing qualitative evidence has highlighted that adolescents value interventions that feel relevant to their age, culture, and experiences [81-83,86,87]. Interactive and personalized features, ease of use, privacy, flexibility, and confidentiality further support engagement with interventions [82,83,87,88]. Concerns about privacy and perceptions that interventions are overly text-heavy or too clinical have been identified as barriers to engagement [82,89]. This supports the view that qualitative research plays a vital role in understanding adolescents' experiences and perspectives on digital mental health interventions. User feedback obtained through qualitative methods helps ensure that interventions remain engaging, relevant, and responsive to the specific needs of adolescents [90]. Thus, understanding individual perspectives can provide deeper insights into what makes digital interventions acceptable, meaningful, and helpful, and further inform the refinement of intervention content and design beyond what quantitative measures alone can capture.

This qualitative study aimed to examine young people's views and experiences of 2 distinct digital mental health interventions (Bite Back [56] and Project YES [58]) designed to address anxiety and depressive symptoms. Both interventions were used as reference points for adolescents and were not directly compared to one another because they differ considerably in design and content. The study explores key factors that influence how young people in the United Kingdom interact with these interventions, including specific features and content they may find beneficial or unhelpful, their preferences, and perceived usefulness and effectiveness. By examining the views of users who differ slightly in age and culture from the original target user population, this study seeks to contribute to our understanding of potential barriers to implementation and the need for adaptation of user-centered digital mental health interventions, supporting efforts to enhance their accessibility, relevance, and impact for a wider range of young people.

Research Questions

This study was guided by the following research questions: (1) What are the barriers and facilitators to engagement with 2 distinct interventions (Bite Back and Project YES) among UK users aged 16-19 years? (2) What are young people's preferred design features and content when comparing Bite Back and Project YES? (3) What are young people's perceptions of the potential usefulness and helpfulness of Bite Back and Project YES for their mental health?

Methods

Ethics and Preregistration

Ethical approval was granted by the University of Bristol ethics board (reference number 21829), and the qualitative study protocol was registered on the Open Science Framework (OSF) [91]. This paper adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [92].

Participants

This qualitative study explored participants' experiences of 2 distinct mental health interventions through 1-hour semistructured online interviews, analyzed using pragmatic thematic analysis. Adolescents aged 16-19 years living in the United Kingdom, with access to a smartphone or laptop and an internet connection, were eligible to take part in the study. Twenty-two adolescents aged 18-19 years were included in the final sample. Those who reported experiencing mental health symptoms that severely impacted their lives or who had ever been hospitalized due to mental health–related reasons were excluded from the study. These criteria were chosen primarily to complement the "Sleep Well" study, which recruited a nonclinical sample of mostly 16-18-year-olds. This age range was slightly expanded to include young people just above the age range in which Bite Back and Project YES had previously been evaluated, to explore how these interventions were experienced by slightly older adolescents.

Procedure

Convenience sampling was implemented due to recruitment challenges, and as a result, purposive sampling based on age and ethnicity was not feasible. Most recruitment was facilitated through a university's experimental-hours scheme, through which psychology students can earn course credit for participation in research. Five mental health charities working with adolescents were approached; only 1 agreed to assist with recruitment, while the remaining charities were unavailable. Interested adolescents first completed an online eligibility questionnaire. Those who met the inclusion criteria were invited to a brief video call with the researcher (via Microsoft Teams). During this call, which was not recorded, participants verified their nationality and age by presenting a valid photo ID. Eligible participants then received a Qualtrics (Qualtrics International Inc) link to the consent form and additional well-being, anxiety, and depression questionnaires. No relationship with participants was established prior to the start of the study. Participants received a £20 (£1=US $1.26 as of March 2025) Love2shop voucher or 2 experimental hours credits to compensate them for their time spent using the interventions and participating in the interview.

Participants provided consent and completed questionnaires (see Standardized Measures section) before they gained access to the interventions. They were then invited to engage with Bite Back and Project YES for a total of approximately 1 hour (30 minutes with each intervention) over a 2-week period, in the order they preferred. This duration was chosen to ensure that all participants had comparable exposure to both interventions while taking into account their academic commitments and the single 30-minute-session design of Project YES. As both interventions were freely available external programs, the actual time spent using the interventions was not formally tracked. Following this 2-week period, participants took part in a 1-hour, semistructured online interview that explored their views and preferences regarding these interventions.

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Sample Size Justification

To determine a sample size for this study, the concept of "information power" was applied [93]. This study incorporates relatively narrow aims and a fairly specific sample, focusing on UK adolescents aged 16-19 years and their views and experiences of 2 distinct digital mental health interventions. However, the use of convenience and purposive sampling to recruit participants may limit how targeted the sample could be. In addition, the study is not guided by a single established theoretical framework. Although the data were generated through 1-hour semistructured interviews that support rich interview data, both PK and MC were novice interviewers with some prior interviewing experience. Inductive thematic analysis is used to identify patterns across participants' accounts. Taken together, these factors indicate that a sample size of 20 participants was considered adequate to provide the necessary information power to fully address the research questions.

Interventions

Bite Back and Project YES were chosen through a systematic review [73] that was conducted as part of the "Sleep Well" study (ISRCTN14480620) [94], which focused on creating stepped care that aimed to help adolescents with their sleep, anxiety, and depressive symptoms. Within this review, both Bite Back and Project YES were identified as promising interventions based on effectiveness, risk of bias, and real-world applicability, and were the only freely available options in this category [73]. This evaluation was conducted independently, with none of the authors having any investment in either intervention.

Bite Back

Bite Back is a web-based positive psychological program developed at the Black Dog Institute in Australia. This interactive and self-guided 6-session program was designed to promote well-being and enhance resilience among young people aged between 12 and 18 years. Bite Back was not originally developed in collaboration with its intended user group. This intervention was openly accessible and has been evaluated through randomized controlled trials, demonstrating significant improvements in well-being, resilience, and life satisfaction as well as reductions in anxiety and depression symptoms in a nonclinical sample [56]. The Black Dog Institute in Australia offers further information about the Bite Back program on its website [95]. However, following completion of the study, the program itself is no longer accessible.

Project YES

Project YES is a freely available web-based program created by researchers at the Lab of Scalable Mental Health at Northwestern University, United States. This self-guided program comprises 4 single sessions, approximately 30 minutes in duration: Project Personality, the Action Brings Change (ABC) Project, Project CARE, and Project RISE. The sessions were based on the growth mindset, behavioral activation, self-compassion, and minority stress theories and were developed to support the mental health of young people aged 11-17 years. A recent randomized controlled trial demonstrated significant reductions in symptoms of anxiety and depression, hopelessness, and restrictive eating [58]. While the original version of the intervention was not developed with input from the target user group, subsequent adaptations of the intervention have been co-designed with young people [96]. More information about Project YES, which remains openly accessible, can be found on the Lab for Scalable Mental Health website [97].

Data Collection

Overview

Data collection took place between January and March 2025 and was conducted by 2 female researchers (PK and MC). Interviews were automatically recorded via Microsoft Teams. Participants took part in a one-hour, one-to-one semistructured online interview guided by a topic guide (Multimedia Appendix 1), which was developed by the research team based on the research questions and content of both interventions. The topic guide was refined after the first few interviews to ensure clarity and relevance. Participants were initially asked about their experiences with Bite Back, followed by questions about Project YES. The topic guide comprised open-ended questions exploring participants' experiences using the interventions, including engagement, usability, perceived helpfulness, and suggested improvements. If time permitted, an additional think-aloud component was included, in which participants were presented with screenshots of selected pages from the interventions and prompted to spontaneously verbalize their thoughts and impressions. This component aimed to elicit additional insights into specific elements of the interventions that participants might not have recalled spontaneously but could discuss when visually prompted. Recorded interviews were transcribed, and all identifiable information was removed to ensure participant anonymity. Following transcription, video and audio recordings were securely deleted.

Standardized Measures

Standardized questionnaires administered at baseline, before participants engaged with the interventions, along with demographic data (ie, age, gender, ethnicity, and parents' highest level of education) were used to better understand and describe the study sample. This information allowed us to contextualize participants' views and experiences of the interventions and to indicate the range of mental health presentations represented within the sample. The following measures were used:

Well-Being

Mental well-being was assessed using the Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS) [98,99]. The SWEMWBS is a short version of the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS). The SWEMWBS is a self-administered questionnaire consisting of 7 items that assess mental well-being using a 5-point Likert scale. Higher scores suggest more positive mental well-being. A reliability of α=.86 was reported for 16-19-year-olds [99].

Anxiety and Depression

Anxiety and depression symptoms were assessed using the Revised Children's Anxiety and Depression Scale–25 (RCADS-25) [100]. The RCADS-25 is a short version of the RCADS. The RCADS-25 is a self-administered questionnaire

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consisting of 25 items that assess anxiety and depressive symptoms using a 4-point Likert scale (never, sometimes, often, and always). A higher score indicates more severe symptoms, with a cutoff point of 65 suggesting borderline clinical symptoms. A reliability of α=.86 was reported for 6- to 18-year-olds [101]. Although traditionally validated for individuals aged 8-18 years [100], emerging research has demonstrated its validity in 19-year-olds, supporting its appropriateness for this study population [102]. Thus, to maintain methodological consistency across the entire sample of 16- to 19-year-olds, this tool was selected as the sole measure.

Data Analysis

An inductive thematic analysis [103] using a pragmatic epistemological approach was adopted, allowing the researcher to actively construct themes from qualitative data while ensuring that the findings reflected participants' perspectives without using a preexisting framework. The themes remained closely grounded in participants' views and experiences and, consistent with a pragmatic approach, focused on findings of practical relevance for intervention development and improvement. Data analysis was conducted independently by the primary researcher (PK), who had prior training in qualitative research methods. All authors were involved in discussing and refining the coding framework to enhance the credibility of the findings. The process followed the step-by-step approach to thematic analysis outlined by Braun and Clarke [103]. This involved familiarization with the transcripts, development of initial codes, and an iterative process of grouping and refining patterns across the dataset until the final themes were established. NVivo (Lumivero) software was used to manage the data [104].

As a researcher with a background in psychology and an interest in improving young people's mental health, the primary researcher (PK) approached this study with a strong belief in the potential benefits of digital interventions. While PK had no affiliations with the digital mental health tools studied in this project, her personal interests may have influenced how she interpreted participants' experiences, particularly if she unintentionally elicited or prioritized positive feedback. PK strove to balance her personal interest in improving mental health with an open-minded approach to understanding young people's views and preferences. The potential influence of the researcher's positionality, prior assumptions, and values about the topic was addressed through ongoing reflection, grounding interpretations in the interview data, and actively looking for examples that did not fit the developing patterns.

Results

Participants' Characteristics

The results are based on 22 interviews. Most participants were White (n=16, 73%), 5 (23%) identified as Asian or Asian British, and one (5%) identified as having a mixed ethnic background. Participants were either 18 years old (n=8, 36%) or 19 years old (n=14, 64%). The majority were women (n=18, 82%), and most had no prior experience with online mental health interventions (n=15, 68%). Almost all participants had low-severity scores for depression (n=19, 86%), anxiety (n=20, 91%), and total RCADS-25 (n=19, 86%) scores, indicating that symptom levels were within the nonclinical range. Participants' mean SWEMWBS score was 23.35 (SD 3.13), with higher scores indicating more positive mental well-being [105]. Detailed participant characteristics are presented in Table 1.

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Table . Participants' characteristics (N=22).

Characteristics	Values, n (%)
Age (years)	
18	8 (36)
19	14 (64)
Gender	
Men	4 (18)
Women	18 (82)
Ethnicity	
White	16 (73)
Asian or Asian British	5 (23)
Mixed or Multiple ethnic groups	1 (5)
Parents' highest education level	
Secondary school up to 16 years	2 (9)
Higher or secondary or further education (A-levels, BTEC[a], etc)	4 (18)
College or university	8 (36)
Postgraduate degree	8 (36)
Mean SWEMWBS[b] score, mean (SD)	23.35 (3.13)
RCADS-25[c]	
Depression	
Low severity	19 (86)
Medium severity: borderline clinical threshold	1 (5)
High severity: above clinical threshold	2 (9)
Anxiety	
Low severity	20 (91)
Medium severity: borderline clinical threshold	1 (5)
High severity: above clinical threshold	1 (5)
Total score	
Low severity	19 (86)
Medium severity: borderline clinical threshold	2 (9)
High severity: above clinical threshold	1 (5)
Has previous experience with online mental health programs	7 (32)
Device used to access Bite Back and Project YES[d]	
Laptop	21 (95)
Phone	1 (5)

[a]BTEC: Business and Technology Education Council.

[b]SWEMWBS: Short Warwick-Edinburgh Mental Wellbeing Scale.

[c]RCADS: Revised Children's Anxiety and Depression Scale.

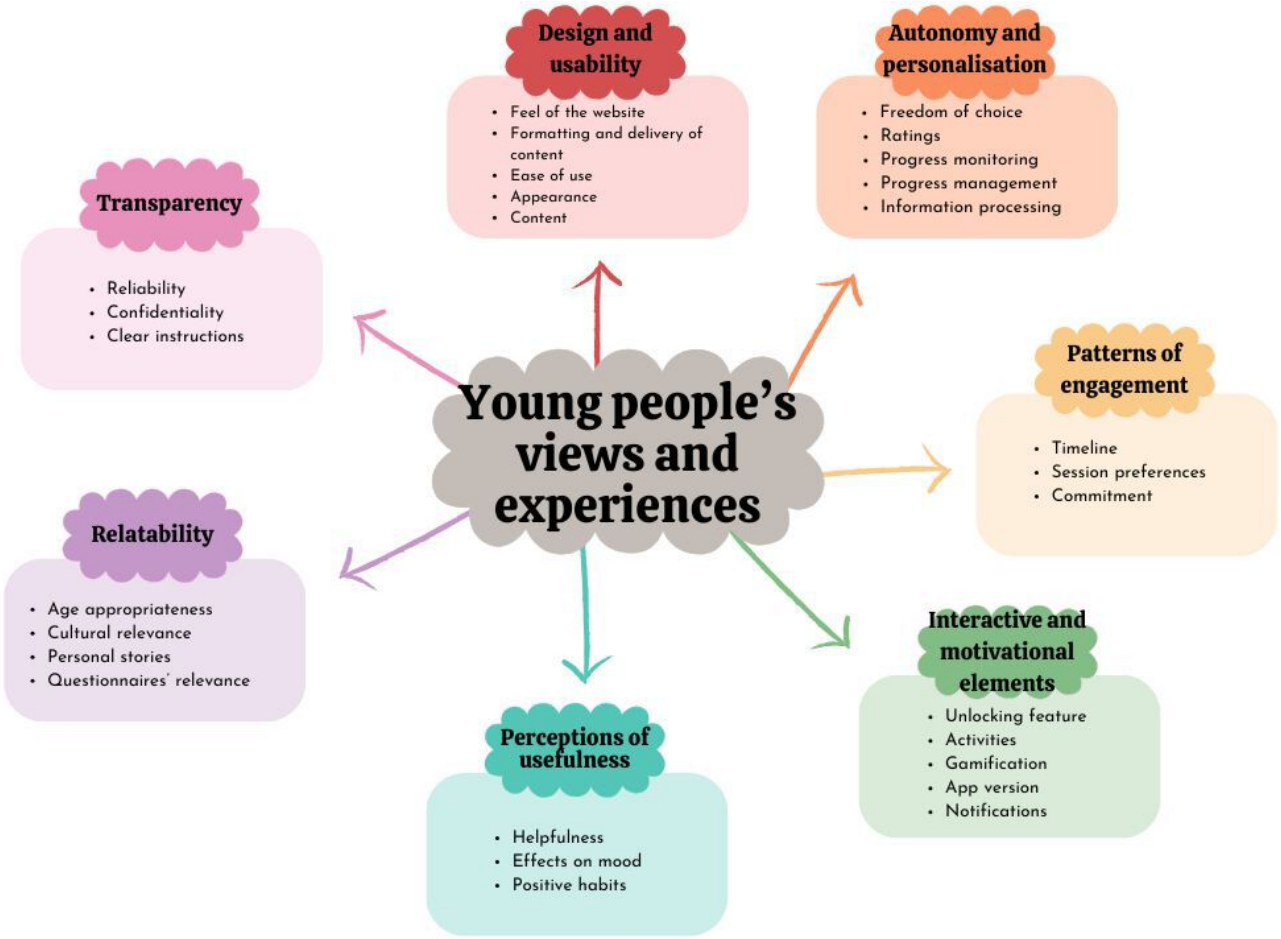
[d]YES: Youth Empowerment & Support.

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Theme 1: Relatability

Relatability refers to whether participants felt that the interventions were relevant to their age, personal experiences, and the cultural references used within the content. Interventions targeted at younger audiences, those containing culturally mismatched information, or those failing to reflect participants' lived experiences could affect young people's engagement. See Figure 1 for an overview of all identified themes.

Figure 1. Visual representation of themes.



Participants frequently reflected on whether the tone, language, and content of the interventions felt appropriate for their stage of life. Many felt that some parts were targeted toward a younger audience, such as secondary school students. They reported that the information was overly simplified or that the language felt too basic. While most participants found this off-putting, others appreciated content that was accessible, clear, and welcoming to a range of age groups. A few described how more complex or mature content would have made it feel more suitable for them and encouraged them to continue using the intervention.

> *So just felt like it was aimed at someone much younger than me who might need help understanding certain terms.* [Participant 19, female, 19 years old, about Project YES]

> *I mean, I can imagine maybe people like my age or slightly older will probably be the age where people start thinking, oh, this is a bit childish, but for me personally, I liked it.* [Participant 15, female, 19 years old, About Project YES]

> *I think it might have been slightly younger than my age demographic, maybe by a few years, but that didn't make it boring or anything. I still thought it was quite good.* [Participant 12, female, 19 years old, about Bite Back]

> *Cause of how simply they were trying to describe things like your strengths or like your social connections, […] like defining everything and then that's what made it seem like less age appropriate.* [Participant 19, female, 19 years old, about Bite Back]

Familiarity with cultural references also influenced how relatable participants found the interventions. Some individuals found it difficult to connect with content that included Australian or US-based brands, examples, or language rather than references that felt familiar within a UK context. However, not all participants mentioned such cultural discrepancies.

> *It's very I think Australian, not British. And lots of the token things where you could choose which brands you liked. I don't think I recognized any of the brands.* [Participant 11, female, 18 years old, about Bite Back]

> *Like it's targeted toward, like, an American audience like it asked: Are you in high school? […] Are you this and I'm not. So, it did obviously feel a bit […] distance from that!? It's like I did feel like it wasn't*

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> *made for like a tailored British audience.* [Participant 8, male, 19 years old, about Project YES]

Some participants indicated that other people's experiences made the intervention feel more personal. However, others pointed out that, although the stories felt like a valuable component of the intervention, they became less impactful when unrelated to their current stage of life.

> *I think it makes it a bit more specific, and it also gives you actual real-world examples of it instead of just concepts that are floating about. […] But then because there was so many of them and a lot of them were very similar, they were all in like kind of a similar setting, similar situations that got a bit repetitive and boring* [Participant 1, male, 18 years old, about the personal stories in Project YES]

> *Some stories I probably connected to, and I understood, whereas other ones that I was less connected to, I got bored so […]. Yeah, but the relevance of the story to my own experiences was a big factor in whether I felt engaged with it* [Participant 8, male, 19 years old, about Project YES]

> *Maybe if they used like examples that were a bit more relevant to someone who's older.* [Participant 9, female, 19 years old, about both interventions]

Some participants queried the inclusion of questionnaires at the beginning of the interventions. They expressed uncertainty about their purpose and how, or whether, the responses were used. For these participants, the questionnaires felt unnecessary and uninformative. Although questionnaires in both interventions were not used for tailoring, Bite Back users received some feedback depending on their scores, which some participants valued. However, most participants did not question the relevance of these questionnaires.

> *It was sort of like you just did the quiz at the start and then it was not mentioned again. Yeah, 'cause, I think it would provide more relevance to you actually having to do it at the start rather than just doing the quiz and then like forgetting about it* [Participant 12, female, 19 years old, about Project YES]

> *One part I liked about the Bite Back one was that they did give you a quiz at first and then gave you a score. So, I think Project YES could probably do something like that. I liked it because it kind of gave me an idea about like how I was about like each specific topic and then from that, I can like move on to the activities and the videos* [Participant 3, female, 18 years old, about both interventions]

Theme 2: Transparency

Transparency relates to the clarity of instructions, openness about participants' data use, and the reliability of the interventions' content. A lack of clarity around what the tasks involved or where participants' information was going could affect adolescents' willingness to fully engage with the interventions.

A few participants highlighted that the statistical content provided in Project YES made the information feel more legitimate and helpful. This was the only aspect of either intervention that participants specifically identified as contributing to a sense of reliability.

> *I kind of like the statistics. I think 'cause it made it kind of seem more legitimate when they added all of that.* [Participant 9, female, 19 years old, about Project YES]

> *Like I think it can make you feel a lot like, […] say if you're doing this and you think you're a minority or you think you're like really strange or something and then you see statistics that like, oh, most people think this or most people are in the same boat. I do think it makes you feel more like you're not just a weirdo* [Participant 1, male, 18 years old, about Project YES]

Several participants expressed uncertainty about what would happen to the information they shared. Some felt uneasy when the intervention did not clearly explain how their responses would be used or stored. This lack of clarity could lead to discomfort, which might act as a potential barrier to engagement.

> *During the session, it didn't really explicitly say where the information was going, and that was quite off putting* [Participant 11, female, 18 years old, about Project YES]

> *I had to put like I don't know like my post code and all these other information. Why does a mental health intervention need me to make an account and put my address and my phone number in. So yeah, it put me off* [Participant 8, male, 19 years old, about Bite Back]

A few participants suggested that clearer guidance on how to begin and navigate the interventions would be helpful. They described moments of uncertainty about how to start tasks or move through sessions. These suggestions highlight the importance of having explicit, well-structured instructions to support smoother engagement.

> *[What could have made it easier to use?] Perhaps making it more clear like that is going to be over a few weeks and what it's actually trying to do and how it's going to help you.* [Participant 14, female, 19 years old, about Bite Back]

> *Perhaps like for example with the name thing again, like it might have been a bit easier if there was like instructions at the top saying like oh, only put one name.* [Participant 13, female, 18 years old, about Bite Back]

Theme 3: Design and Usability

Design and usability refer to the structure, presentation, and navigation of the interventions. Adolescents commented on the visual appeal, clarity of layout, and how easy it was to use and understand the content. A user-friendly layout, inviting appearance, and clarity of delivery could influence how adolescents interacted with the interventions.

Participants addressed the tone and presentation of the interventions. Bite Back was generally described as inviting,

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welcoming, and engaging, while Project YES was occasionally seen as more like a formal survey or test. Some participants who described feeling this way about Project YES also noted that it made them feel bored. A welcoming and well-structured website may influence the level of user participation.

> *I felt quite a nice, like, warm, like, welcoming feel to it.* [Participant 13, female, 18 years old, about Bite Back]
>
> *I felt like I was just doing a survey, but how it was like structured, it felt like a test rather.* [Participant 19, female, 19 years old, about Project YES]

Participants commented on the formatting and structure of the interventions. Bite Back was described by some as professional and well-designed. A few participants noted that the weekly format and content organized in smaller chunks made the sessions feel shorter and easier to follow. A few also noted that the weekly format made it easy to forget about the intervention. One participant said they would have preferred that the content take up more space on the screen.

> *It wasn't just like reading words, there was audios and interactive activities with the typing and everything.* [Participant 12, female, 19 years old, about Bite Back]
>
> *It had the weeks, so it was like the sections that you could do. I thought it was nice because it organized them into little chunks.* [Participant 4, female, 19 years old, about Bite Back]
>
> *I think it was quite good. I quite like the reading because it wasn't like that much to read. While sometimes you might find yourself like having to read like an entire page and then you get lost. I liked how concise the information was.* [Participant 19, female, 19 years old, about Bite Back]

In contrast, participants described Project YES as having a simpler design. Some said the platform was not user-friendly and mentioned that scrolling through pages was a long process. The presentation was occasionally compared to a textbook or "Wikipedia" page, and some felt that the large number of slides with minimal information elongated the experience. Suggestions included reducing the amount of text and making it more interactive.

> *I feel like it's just plain black and white, it has like a little photo. It gives very for me textbooky or like Wikipedia vibe.* [Participant 9, female, 19 years old, about Project YES]
>
> *I think it was quite focused on like questionnaires and things like that. I think it would have been, it could have been more interactive.* [Participant 12, female, 19 years old, about Project YES]

Both interventions were described by many participants as easy to use. Bite Back was reported as having clear instructions, a straightforward interface, and short, accessible activities. Some said it was easy to start using and to return to the page if they had to leave. However, a few participants mentioned that logging back in required effort, and one noted that signing up took time. Others described needing to refresh the website or listen again to audio to be able to move to the next week's session when the connection was lost.

> *I thought the interface, was very easy to use. It wasn't too, like overwhelming with information or anything like that.* [Participant 2, female, 18 years old, about Bite Back]
>
> *It wouldn't let me click on to the next page like, even though I listened to the whole audio, I clicked to go to the next page and it wouldn't let me on. So I had to listen to audio again.* [Participant 8, male, 19 years old, about Bite Back]

Several participants said Project YES was easy to start using because no login was required, and some described the interface as clear and the navigation as straightforward. Others, however, said it was less easy to use, with one reporting difficulty navigating through the sessions and another stating it took more effort to use than Bite Back. A few participants also mentioned that getting through the sessions was a long process. Difficulties with logging in or navigating could create barriers to participants' engagement with the interventions.

> *I think it was easy. I don't remember having to go through the same login process as I did with Bite Back, so that was good.* [Participant 11, female, 18 years old, about Project YES]
>
> *It was quite easy once you like started doing the session. So then it's kind of like, there's not much to like, accidentally click on. It's like you just go next, next.* [Participant 19, female, 19 years old, about Project YES]

Visual elements such as colors, fonts, and images contributed to how appealing and approachable the interventions felt. Participants described the colors and variety of fonts as uplifting and inviting. Images, especially cartoons or symbolic visuals, were positively received when they complemented the session content.

> *I like the colors, it just makes it seem less depressing.* [Participant 19, female, 19 years old, about Bite Back]
>
> *I think Project Yes doesn't really have that much kind of like colors or things that you know really attract a person. The visual elements are really important.* [Participant 6, female, 18 years old, about Project YES]

Participants expressed mixed views on the content of both interventions. Some described the content in both interventions as familiar or "common sense," reporting that it often felt like a repetition of information they already knew. While a few participants found this repetitive or not educational, others appreciated the opportunity to revisit known material and considered it a helpful reminder. Several participants mentioned that the concepts were explained using simple language. For some, this contributed to perceptions that the content was overly simplified or infantilizing. However, there were some participants who valued the inclusion of psychological concepts that were explained simply or described the content as scientific.

> *I thought it just covered like the generic, like mental health advice type of stuff you would see on like*

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> *YouTube or in assemblies in school.* [Participant 9, female, 19 years old, about Bite Back]
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> *It's still very useful information. It, I believe, would help a younger individual because when we're younger we see things a lot differently and I believe that it would help them.* [Participant 22, female, 18 years old, about Project YES]

Theme 4: Autonomy and Personalization

Autonomy and personalization refer to features that allow participants the freedom of choice, control, and flexibility within the interventions. Participants referred to existing features such as selecting sessions, receiving feedback, and viewing progress. Suggestions to save progress and comments on format preferences reflected a desire for greater control over when and how they interact with the material.

Most participants liked or were positively surprised by the feature that allowed them to choose which session to work on in Project YES. Some said that having this choice made the intervention feel more tailored to them.

> *It felt like a more personalized approach rather than just forcing everyone to do the same activity, you can pick whichever one you think suits you.* [Participant 12, female, 19 years old, about the choice of sessions in Project YES]
>
> *You can choose whether you want to do this one or this one. It depends on how you're feeling. I like that a lot.* [Participant 8, male, 19 years old, about Project YES]

Participants described the use of scores and ratings in Bite Back as a reflective and engaging feature. Several reported that receiving a score helped them learn more about themselves, visualize their progress, or feel more motivated to continue. Questions were generally viewed as clear, age-appropriate, and easy to use. However, one participant noted that receiving a low score could potentially be demotivating for some users.

> *Like this it can maybe put someone down and not want to carry on, because if they answer no, I'm not thankful. I'm not thankful and they see 5 out of 25 as the score. They're not particularly going to be happy with that.* [Participant 14, female, 19 years old, about Bite Back]
>
> *It kind of tells you how you're doing in that sort of environment. Like for example, I was doing really good in like the friends one but I'm not really good at like, the mindfulness one. […] I like how that was like, personalized.* [Participant 8, male, 19 years old, about Bite Back]

Participants referred to Bite Back's progress bar as a feature that helped them track their progress through a session. While not all participants mentioned it, those who did described it as helpful and motivating. Some said it gave a clear sense of progression and an end point to work toward. A few mentioned missing a similar feature in Project YES.

> *It's nice to know how far through you are, it's good motivation to keep going.* [Participant 11, female, 18 years old, about the progress bar in Bite Back]
>
> *I feel like it's always nice to see when you're making progress on something, even if it's like small. So I thought that was quite nice to see because I was like, oh, look at me, I'm doing well.* [Participant 13, female, 18 years old, about Bite Back]

Some participants suggested that the ability to save their responses to tasks could improve their experience with the interventions. A few mentioned that it would be helpful to revisit previous answers as a way to reflect on or recall how they felt at a particular time.

> *I feel like I would have also liked if they like, sent it to you. Obviously if they kept anonymous, but it would just be nice to have it there saved.* [Participant 9, female, 19 years old, about the activities in Project YES]
>
> *I think it would have been maybe nice to just have it like saved somewhere so you have the option of going back, because then maybe if you were […] having like a really bad day, you could go back to it and be like OK, […] what was I?! I'm having a bad day today. What was I grateful for at that time. It can give you a nice little reminder.* [Participant 1, male, 18 years old, about the activities in Bite Back]

Participants expressed varied preferences for how information was delivered. Some preferred reading text over listening to audio or watching videos, noting that reading was quicker, easier to process, or better suited to their learning style. However, many participants appreciated having multiple formats available, such as audio, video, and text, and described this as helpful or accessible. The ability to revisit the same content in different formats, such as having text that repeated video content, was seen by some as useful, while others felt that such repetition should be avoided. Several participants mentioned that bullet points would make the text easier to follow, particularly if they missed parts of a video.

> *A text that came after, it just repeated the video, and I would much prefer to skim over the text than watch the video.* [Participant 11, female, 18 years old, about Bite Back]
>
> *I quite liked the little audios that were there that you could like, listen to as you're reading along, was just easier.* [Participant 9, female, 19 years old, about Project YES]

Theme 5: Patterns of Engagement

Patterns of engagement describe how participants interacted with the interventions over time. This theme includes when and how they used the content, which sessions they continued with or disengaged from, and how they perceived the interventions in terms of accessibility and commitment.

Participants described varying patterns in when and how long they engaged with the interventions. Some completed multiple sessions in one sitting, often influenced by having free time or

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wanting a distraction. Others reported using the interventions in response to specific emotional states, such as feeling stressed, down, or frustrated. The time spent on each session ranged from 20 to 40 minutes, which many participants viewed as an appropriate or optimal duration. A few appreciated the short and manageable structure of both interventions.

> *When the website was used] It was in the morning just to sort of set myself up for the day. By practicing something different, because that's […] when my anxiety peaks. And so it was nice to have, like, a routine in the morning with something to do, to practice, just to sort of like, take the time for myself and chill out.* [Participant 2, female, 18 years old, about Bite Back]

> *Used the website] when I had nothing else to do, like it wasn't really like something I picked up to do because I needed like a break.* [Participant 19, female, 19 years old, about Bite Back]

Participants noted that not all sessions were equally appealing, and some expressed a desire for more flexibility in how they moved through the interventions, as this influenced how far they progressed. Several mentioned wanting to skip sessions they found less engaging, particularly the mindfulness session in Bite Back, which was sometimes seen as requiring a specific mindset. A few participants reported stopping their use of the intervention when they reached this session, suggesting that being unable to move past less preferred content could discourage continued engagement.

> *I wanted to unlock Level 3 without having to do 10 minutes of meditation.* [Participant 11, female, 18 years old, about Bite Back]

> *Like they're forced to fill in the sentences to move on.* [Participant 3, female, 18 years old, about Project YES]

A few participants described the interventions as low-commitment or a more accessible alternative to more formal support services, such as university counseling.

> *It's much like lower commitment than trying to like get a hold of the university counseling service.* [Participant 11, female, 18 years old, about Bite Back]

> *It's an easy thing to get into because it's like not asking for huge commitments. You can just do one week if you want or you can do like multiple of the like the week modules. Which I think's good.* [Participant 7, female, 19 years old, about Bite Back]

Theme 6: Interactive and Motivational Elements

Interactive and motivational elements refer to intervention features that could encourage engagement and support a more active experience. This theme includes both the elements present in Bite Back and Project YES, as well as participants' suggestions for enhancing interactivity and motivation. It encompasses subthemes such as the unlocking feature, activities, gamification, an app version, and notifications.

Participants expressed mixed views about the unlocking structure of sessions in Bite Back. Several described it as motivating, noting that progressing through the weeks felt like achieving small goals or even like playing a game. Some said it encouraged consistency and ensured they moved through the content gradually. However, a few participants preferred having all sessions available from the start so they could choose content most relevant to them. One participant noted that the unlocking structure shortened their time spent using the intervention.

> *I think I'd rather have access to all of the weeks because there were certain weeks that for me I quite liked like the I think there was mindfulness, one which was really good, but then maybe on a specific day, I didn't really want to be doing the, say, gratitude one. If I was in a specific mood and I wasn't really feeling that. So I think it would be nice if they all were. Maybe if you were encouraged to do them in order, but they weren't locked.* [Participant 4, female, 19 years old, about Bite Back]

> *I did enjoy the whole concept of unlocking like a new week or like you couldn't start one before. I felt like I was almost playing a game, but then it was like a fun game, like AI. Well, I've done this now and now I've been rewarded with next week's and like a star.* [Participant 13, female, 18 years old, about Bite Back]

Participants expressed a range of views about the activities included in both interventions. Many found the interactive components engaging and reflective, with some describing them as encouraging deeper thinking about personal experiences or relationships. Activities involving giving advice were often highlighted as particularly engaging and meaningful, though a few participants noted that these tasks could feel irrelevant when based on scenarios they had not personally experienced. In Bite Back, short, varied activities were generally well received, with participants appreciating their manageable length and real-life applicability. In contrast, some participants felt the tasks in Project YES became repetitive, overly focused on writing, or difficult to complete. Suggestions included incorporating a greater variety of scenarios and making the tasks more general so that more people could relate to them.

> *So the activities were all very like, made me reflect and stuff like that.* [Participant 9, female, 19 years old, about Bite Back]

> *I quite like the thing about […] giving the advice cause although it was effortful, I feel like it's almost like encouraging you to give advice to yourself if you were in that situation. So, I think that did stand out.* [Participant 12, female, 19 years old, about Project YES]

Some participants suggested that incorporating game-like features could make the interventions more engaging. One participant said that receiving a reward at the end of a session would feel motivating and similar to playing a game.

> *Maybe including something like a game where you do the interventions and then it progresses through like a game sort of thing and then you get rewarded at the end or something like that.* [Participant 12, female, 19 years old, about Bite Back]

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Several participants suggested that having access to the interventions through a dedicated mobile app would improve convenience and usability. An app-based format was seen as a way to encourage more consistent use by reducing barriers such as having to log in via a browser or remembering to return to the website after taking a break.

> *An app form would be quite interesting. I think an app like if it's just on your phone, could be more accessible to people.* [Participant 9, female, 19 years old, about Bite Back]

> *I think an app would be convenient so that I don't have to keep going back on my laptop and then opening it, and I can just use it on my phone.* [Participant 3, female, 18 years old, about Bite Back]

Most participants identified notifications as a potentially helpful feature for supporting consistent engagement with the interventions. They suggested that reminders could encourage them to return to the platform regularly, helping them stay on track with sessions and avoid forgetting about the program over time.

> *Like they said to have those activities to like repeat them every week or every day, if they had like a little maybe reminder like notification option, I think that could be useful.* [Participant 9, female, 19 years old, about challenges in Bite Back]

> *Just notifications on your phone and then it will remind you because obviously we're all human. Like we're forgetful, people are going to forget and stuff.* [Participant 15, female, 19 years old, about Project YES]

Theme 7: Perceptions of Usefulness

Perceptions of usefulness capture participants' reflections on how the interventions supported their mental health and well-being. Adolescents discussed overall helpfulness, impact on mood, and how the interventions encouraged positive habits.

Most participants perceived Bite Back as more helpful than Project YES. Many said they would be willing to recommend it to younger friends or family members. However, there were some participants who found Project YES beneficial, while others felt that both interventions offered useful elements. A few expressed a desire to revisit Bite Back to explore additional sessions.

> *It's kind of like an easier way of like grounding yourself compared to like other forms.* [Participant 19, female, 19 years old, about Bite Back]

> *It's easier to like actively engage in, whereas the other one [Project YES] was just like […] reading quite a few stories and things. Whereas the other one [Bite Back] was more like relating it to your own life, if that makes sense. So that was more engaging.* [Participant 5, female, 19 years old, about Bite Back]

> *[Which platform did you find more helpful?] Overall Project YES, but I think some of the activities in Bite Back were really good. I think if you could transport them then Project Yes would be perfect.* [Participant 4, female, 19 years old, about Project YES]

Several participants mentioned that using Bite Back made them feel calmer and more positive afterward and indicated that the intervention was a good starting point for improving their well-being. Some also reported positive changes after using Project YES.

> *There was definitely a more sense of like calm, I guess.* [Participant 19, female, 19 years old, about Bite Back]

> *Yes, after I used it, I did feel like a sense of accomplishment because of giving the advice and helping others.* [Participant 6, female, 18 years old, about Project YES]

When recommending Bite Back to others, some participants emphasized its potential to support the development of positive daily habits, even though not all reported forming these habits themselves.

> *I probably just tell them that it's good for keeping those like positive habits.* [Participant 9, female, 19 years old, when recommending Bite Back to a friend]

Discussion

Principal Findings

This qualitative study used 2 distinct and widely available digital mental health platforms (Bite Back and Project YES) to help understand what supports or hinders young people's engagement, what design features they prefer, and how useful they find these interventions. Participants frequently reflected on whether the tone, language, and content of the interventions felt age-appropriate, culturally relevant, and connected to their personal experiences. Clarity of instructions, transparency around data use, ease of navigation, and flexibility in how the interventions could be used also appeared to influence engagement. Participants generally preferred features that were interactive, visually engaging, and personalized, and many valued being able to track progress or choose content. Bite Back was often described as helpful, although some participants also found Project YES beneficial and identified useful elements in both interventions. These findings highlight a number of factors that may influence how young people engage with and perceive digital mental health interventions.

Facilitators and barriers to engagement were shaped by multiple, interconnected factors. Relatability and transparency were among these, with participants preferring interventions that used culturally relevant, age-appropriate content that aligned with their stage of life, supporting previous research emphasizing the value of content that resonates with adolescents' lived experiences [81-83,86,87]. It is important to note that although participants in this qualitative study were only slightly older than the intended user age group, many described the content and design of both interventions as age-inappropriate. This indicates that even small age differences may affect perceived relevance and adds to existing research showing that developmental stage matters in digital mental health intervention design [106,107]. This highlights the need to involve young

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people across different adolescent age ranges in intervention development, especially when designing interventions targeting broader age groups. Although tailoring content to very narrow age bands may enhance relevance, this is not always practical in real-world settings. A more feasible approach may involve developing interventions that are adaptable to different developmental stages. In the future, artificial intelligence may offer scalable ways to personalize content dynamically based on age, preferences, or individual needs. Transparency regarding the purpose of the interventions, confidentiality, and instructions was of particular importance to participants, supporting previous research identifying transparency as a key factor in building trust and engagement [81]. Participants expressed a need for clear explanations on what happens to their data, how they could benefit from such interventions, and the purpose of certain tasks. The way transparency is communicated could matter, while clear information might foster trust, overly detailed or complex explanations might be overwhelming and may conversely hinder engagement. This suggests that interventions should balance providing essential information in a clear and accessible manner while avoiding information overload, ensuring young people feel informed and confident in engaging with digital mental health interventions.

Autonomy and personalization, patterns of engagement, and interactive and motivational elements were also identified as important factors influencing engagement, further aligning with previous research demonstrating their role in supporting young people's use of digital mental health interventions. Participants valued the ability to track their progress and choose the order or type of content they engaged with [82,87], supporting a sense of control and relevance. Patterns of engagement indicated a general preference for shorter sessions [82,83,87], with some participants expressing that digital mental health interventions felt less demanding and required less commitment than student counseling services. Most participants engaged with the interventions only once without returning, describing differences in motivation for when to use them, which was often shaped by their mood, available time, or daily routines. This highlights the need for interventions to allow flexible use that aligns with adolescents' lives, in line with broader research showing that ease of access and fit with everyday routines can influence how young people engage with digital mental health platforms [82,83,86,87,108]. Some participants suggested that the existing feature of session unlocking could help sustain motivation and recommended additional elements such as gamification, a mobile app version, or notification reminders to further encourage uptake and engagement. However, preferences varied, with some participants expressing the need for notifications as reminders and an app version for ease of access. Some participants preferred having all sessions unlocked to be able to choose those that were most appropriate for them, which is consistent with findings from the broader literature [82]. This reflects the importance of offering customizable interactive features to cater to individual preferences.

Participants preferred design features and content that offered clear and simple information, were easy to navigate, and featured a colorful, pleasing appearance. The ability to choose the order of sessions and to track progress was valued [82,87], which might have provided a sense of control and accomplishment. Informative content was appreciated, particularly when it was available in various formats, such as text, audio, or video, allowing participants to engage with material in ways that suited their preferences. These findings indicate that visually pleasing design, flexible use, and access to content in multiple formats are valued by young people and may further influence their engagement with digital mental health interventions. This is consistent with broader mHealth design research, which highlights navigation, presentation of information, personalization, and aesthetics as features associated with stronger user engagement [109].

Participants described the interventions as grounding and as a good starting point for improving well-being, with some expressing willingness to revisit them in the future. Participants' views on the usefulness of the interventions suggest that even when an intervention includes therapeutic, evidence-based content, this may not be enough on its own for young people to find it helpful. This aligns with previous qualitative research highlighting the importance of perceived usefulness in sustaining young people's engagement with digital mental health interventions [81,108].

All themes identified in this study are interconnected and collectively may shape how young people engage with digital mental health interventions and what they perceive as helpful within them. Design features and content preferences may influence whether young people find interventions appealing, practical, and worth returning to, which in turn may affect how much they benefit from using them. This highlights the importance of involving the target group in intervention development to ensure that interventions reflect young people's needs and preferences. Overall, the findings support a broader body of research suggesting that helpfulness and engagement are shaped not only by intervention content, but also by whether digital mental health tools feel relevant, easy to use, and trustworthy to young people in practice [110].

Strengths and Limitations

The use of a think-aloud component in an interview setting is a relatively novel approach and was generally perceived as a helpful technique for aiding recall and encouraging reflection on the interventions. Most participants noted that the prompts made it easier to remember and discuss specific aspects they might have otherwise overlooked, which could have enhanced the depth of feedback they provided. However, some participants found it challenging, suggesting that while think-aloud can enrich data collection, it should be introduced carefully to ensure participants feel comfortable sharing their perspectives.

Convenience sampling resulted in a participant pool that primarily consisted of university-educated individuals, including psychology students, who did not have elevated anxiety or depression and who might have greater familiarity with mental health concepts and digital tools, potentially shaping their perspectives. Although the study initially intended to use purposive sampling based on age and ethnicity, recruitment challenges contributed to the limited participation of individuals aged 16-17 years. As a result, 16-17-year-olds were not represented in the final sample, which meant that potential

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age-related differences in preferences and engagement with digital mental health interventions could not be explored. This is particularly relevant as the examined interventions have been evaluated with slightly younger adolescents (Bite Back for aged 12-18 years, Project YES for aged 11-17 years), which may have influenced how participants perceived and interacted with the content. Furthermore, as the interventions were designed to support young people experiencing symptoms of anxiety or depression, our participants' generally low symptom levels may have affected how useful they found these interventions.

Participants were asked to use each intervention for approximately 30 minutes over a 2-week period. This decision was made to ensure consistency in the amount of time participants spent using each intervention, as Project YES was designed to be completed in a single 30-minute session, while also accommodating participants' academic schedules. While this approach allowed participants to experience and compare both interventions within the same timeframe, it provided limited exposure to Bite Back, which is designed as a 6-week program (around 10 minutes per session), and may not have allowed participants sufficient time to fully engage with its features and content. Additionally, the short engagement period within a longer timeframe may have affected participants' recall of content for both interventions, potentially influencing their perceptions and the depth of their feedback. To mitigate these limitations and aid recall, a think-aloud component was included, although it is acknowledged that the shortened engagement period may still have impacted the depth of participants' experiences with the interventions.

Implications for Development and Research

This study highlights the importance of involving young people in the co-design of digital mental health interventions to ensure content is age-appropriate, relatable, and engaging. In particular, future designs should consider the varying needs across different age ranges, as even small differences in age can affect how content is perceived and whether it feels relevant. Transparent communication about data use and the purpose of interventions should be clear and accessible while avoiding information overload. Future qualitative research could explore accessible and informative ways of communicating essential information, such as data use or the purpose of tasks, to build trust while maintaining engagement within digital mental health interventions.

Conclusion

This study contributes to the growing body of knowledge by identifying 7 interconnected themes that could shape how young people engage with digital mental health interventions. These findings emphasize that young people value interventions that feel relevant to their age, culture, and stage of life, and that are transparent about their purpose, data use, and content. Even slight differences in age appeared to influence how appropriate the interventions felt to participants, highlighting the importance of involving young people in the design process to ensure interventions reflect their needs and preferences and clearly convey information that could support their engagement.

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Declaration of Generative AI and AI-assisted technologies in the writing process

During the preparation of this work, PK used ChatGPT in order to verify the text's grammatical accuracy (spelling and grammar). After using this tool/service, the author reviewed and edited the content as needed and takes full responsibility for the content of the publication.

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Data Availability

The datasets generated or analyzed during this study are available on Open Science Framework [91].

Conflicts of Interest

None declared.

Multimedia Appendix 1
Topic guide.
[PDF File, 862 KB - pediatrics_v9i1e84384_app1.pdf]

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Abbreviations

ABC: Action Brings Change
CAMHS: Child and Adolescent Mental Health Services
CARE: Child and Adolescent Research in Emotion Lab
CATCH-IT: Competent Adulthood Transition with Cognitive Behavioral, Humanistic, and Interpersonal Training
CBT: cognitive behavioral therapy
COREQ: Consolidated Criteria for Reporting Qualitative Research

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IHME: Institute for Health Metrics and Evaluation
OSF: Open Science Framework
RCADS: Revised Children's Anxiety and Depression Scale
RCADS-25: Revised Children's Anxiety and Depression Scale – 25 items
SWEMWBS: Short Warwick-Edinburgh Mental Wellbeing Scale
WEMWBS: Warwick-Edinburgh Mental Wellbeing Scale
YES: Youth Empowerment & Support

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Examining the Characteristics of Adolescents Recruited to a Novel Digital Treatment for Eating Disorders: Baseline Assessment in an Open Feasibility Trial

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Abstract

Background: Digital interventions for eating disorders have the potential to increase access to care and broaden the range of treatment options for adolescents. However, little is known about the characteristics of those who seek these interventions. Identifying such characteristics will help ensure that these interventions meet the needs of the target population, highlight potentially underrepresented groups, and support clinicians in assessing clinical suitability for individual patients.

Objective: This study aimed to examine the characteristics of adolescents seeking digital treatment for eating disorders within routine clinical care and to explore whether the key components of the novel digital treatment align with the characteristics of the adolescents it is designed to support.

Methods: This study used baseline data from an open feasibility trial of a novel digital treatment for eating disorders within routine clinical care. Participants were adolescents aged 15 to 18 years with a diagnosis of atypical anorexia nervosa, atypical bulimia nervosa, binge-eating disorder, or eating disorder, unspecified. Baseline assessment included demographic characteristics, eating disorder symptomatology, psychosocial impairment, emotional dysregulation, anxiety, depression, negative self-evaluation, and motivational factors.

Results: A total of 25 adolescents participated in the study, all of whom were women. The mean age was 16 (SD 0.87) years. Half of the adolescents had previously received face-to-face treatment for an eating disorder. The sample was transdiagnostic with some variation in distribution. The adolescents reported severe eating disorder symptoms, marked psychosocial impairment, emotional difficulties, elevated negative self-evaluation, and high levels of internal pretreatment motivation.

Conclusions: The findings from this study underscore the relevance of digital interventions to complement or extend traditional eating disorder care for adolescents. This study emphasizes the importance of designing digital treatments that are sensitive to normative biases, address the multifaceted nature of eating disorders, and are tailored to the needs and preferences of a transdiagnostic population. The present findings are important insofar as they may inform whether the key treatment components align with the characteristics of adolescents seeking digital treatment for eating disorders within routine clinical care.

Trial Registration: ClinicalTrials.gov NCT06306586; https://clinicaltrials.gov/study/NCT06306586

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KEYWORDS

eating disorders; adolescents; digital treatment; routine clinical care; developing novel intervention; characteristics of help-seeking

Introduction

Eating disorders are a group of complex clinical conditions characterized by pathological concerns about shape and weight, as well as disturbed eating and weight-control behaviors [1]. Impaired physical health, disrupted psychosocial functioning, and reduced life expectancy are some of the severe consequences of eating disorders [2,3]. The disorders are highly prevalent worldwide, especially in adolescents [4,5], with overall estimates suggesting that approximately 1 in every 20 children and

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adolescents are affected [6]. Several evidence-based treatments are available for adolescents [7], with family-based treatment and enhanced cognitive behavioral therapy having the strongest evidence base [8].

Despite the severity of eating disorders and the availability of evidence-based treatments, most individuals who meet the criteria for a clinical eating disorder do not seek help [9,10]. Eating disorders are therefore frequently undetected and untreated [3,11], with particularly low help-seeking rates among adolescents, where only 10% to 20% access treatment [12-14]. Individual barriers to help-seeking behavior include poor mental health literacy, stigma surrounding eating disorders, denial of the disorder's severity, as well as distorted body ideals enforced by social media [9,15]. Systemic factors contributing to the existing treatment gap are limited therapist availability, the cost of treatment, geographic isolation from available services, long waitlists, and poor eating disorder literacy among primary care providers [9,16]. Moreover, of those who seek help, a substantial number do not respond to the treatments currently available [17,18]. High dropout rates (29% - 73%) [19,20] and low remission rates (40% - 50%) indicate that a substantial proportion continue to exhibit high levels of eating pathology at the end of treatment [17,21]. Additional factors have been identified as contributing to the complexity of treating eating disorders. The disorders' complex interplay of psychological, biological, and social factors [15,22], the underlying mechanisms being unknown [23], and the high psychiatric comorbidity (>70%) [24] could be among the reasons. Furthermore, eating disorder treatments often have a categorical approach, despite diagnostic migration being common and diagnoses varying across individuals [25]. In addition, treatments often follow standardized protocols and manuals, which do not account for unique individual factors influencing an eating disorder [26]. As a result, individuals with eating disorders can feel alienated from treatment [27,28]. Given the aforementioned challenges in treating eating disorders, there is a pressing need to both improve access to existing evidence-based treatments and develop novel interventions that address the multifaceted nature of these conditions [17,23,26,29].

A promising approach is the use of treatments delivered via computers or smartphones, often referred to as digital interventions or digital treatments [30,31]. The accessibility of these treatments positions them as a valuable component within the spectrum of services for eating disorders, particularly considering the numerous barriers associated with traditional treatments [32]. Digital interventions can increase access to care and have demonstrated effectiveness in improving symptoms of eating disorders while also being cost-effective [7,33]. While endorsing many of these advantages, most individuals with eating disorders still prefer face-to-face treatment [34]. Moreover, despite a growing evidence base, only a limited number of digital interventions have been specifically developed for adolescents with eating disorders [31]. At present, the few available app-based interventions, such as TCApp and Recovery Record, have primarily been evaluated as adjuncts to standard treatment rather than as standalone interventions [35,36]. In addition, digital interventions also face challenges related to uptake and engagement [30,37], and one contributing factor may be expert-driven development processes that do not sufficiently reflect the preferences and goals of the intended users [38,39].

To address these challenges, there is a need to develop novel digital interventions for adolescents with eating disorders [17,31] based on the perspectives of those who will use them [37,40]. This is particularly important given that adolescents differ from adults in their developmental needs, preferences, and contexts, making simple adaptations of adult interventions insufficient [41,42]. At the same time, digital interventions may not be acceptable or suitable for all individuals, underscoring the importance of understanding which adolescents engage with such approaches and who may benefit most [34,37]. Such knowledge can also help identify underrepresented groups and inform necessary adaptations to ensure that interventions fit into adolescents' everyday lives [37,43]. The involvement of adolescents in the development of such interventions remains relatively limited, raising concerns about whether existing tools adequately reflect their needs and preferences [44,45]. Furthermore, only a small number of digital interventions have been developed and evaluated within routine clinical care, where treatments are delivered under real-world conditions with heterogeneous patient populations and varying clinical practices [16,38,46]. As a result, it remains unclear which adolescents are reached by digital interventions in these settings and whether those who engage with them correspond to the intended target population. Addressing this gap is essential for evaluating the feasibility and clinical relevance of digital treatments. Assessing sample representativeness within feasibility trials can provide important insights into whether interventions reach the populations they are designed for and help identify potential barriers to implementation. This study therefore aimed, as part of a feasibility trial of a novel digital treatment, to examine the characteristics of adolescents seeking digital treatment for eating disorders within routine clinical care and to explore whether the key components of the novel digital treatment align with the characteristics of the adolescents it is designed to support.

Methods

Study Design

An open feasibility trial of a digital treatment for adolescents with eating disorders was conducted in routine clinical care. The trial was guided by the UK Medical Research Council's framework for developing and evaluating complex interventions and followed CONSORT (Consolidated Standards of Reporting Trials) standards for feasibility trials (Checklist 1) [47,48]. In line with these recommendations, 4 key progression criteria were assessed to evaluate feasibility across multiple domains: sample representativeness, adherence, acceptability, and preliminary efficacy. In this study, we specifically report findings related to sample representativeness as an indicator of feasibility. Sample representativeness was examined in relation to overall eating disorder psychopathology to better understand which adolescents sought digital treatment and the extent to which the participants reflected the intended target population. This was assessed by analyzing baseline characteristics from the feasibility trial and evaluating how well the key components

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of the intervention corresponded to the clinical profile of the sample. The study used baseline data from participants included in the feasibility trial between March 2024 and May 2025. In accordance with feasibility trial design, no formal sample size calculation was conducted.

Study Setting

Adolescents receiving the digital treatment were patients at child and adolescent psychiatric outpatient clinics in Norway, specifically within the catchment area of Haukeland University Hospital and Helse Fonna. These clinics are part of the state-funded Norwegian specialist health care system and are located within the Western Norway Regional Health Authority, serving a population of approximately 122,000 youth under 18 years [49].

Study Population

Inclusion Criteria

The following inclusion criteria were applied for the feasibility trial: (1) diagnosed with atypical anorexia nervosa, atypical bulimia nervosa, binge-eating disorder, or eating disorder, unspecified [50,51]; (2) aged between 15 and 18 years; (3) on a stable dose of medication for a psychiatric disorder for 6 weeks; (4) has a mobile phone with internet access; and (5) speaks and writes Norwegian.

Exclusion Criteria

The following exclusion criteria were applied: (1) diagnosed with anorexia nervosa, bulimia nervosa, or avoidant or restrictive food intake disorder (ARFID); (2) having a comorbid medical condition or disorder known to influence eating or weight (ie, pregnancy, cancer); (3) psychotic disorders, acute suicidality, substance abuse, substance dependence, or a severe depressive episode; and (4) receiving inpatient treatment for a psychiatric disorder or face-to-face psychological treatment. This trial was the first to examine a digital intervention for adolescents with eating disorders within routine clinical care in Norway. During the planning phase, concerns were raised about including participants with anorexia nervosa or bulimia nervosa due to the increased risk of medical instability. Although a more flexible inclusion strategy based on clinician judgment was considered, it was not implemented due to concerns about maintaining internal validity. As a result, adolescents with anorexia nervosa and bulimia nervosa were excluded from the trial. Patients with ARFID were excluded since the clinical picture is different from that of other eating disorders [50].

Procedure

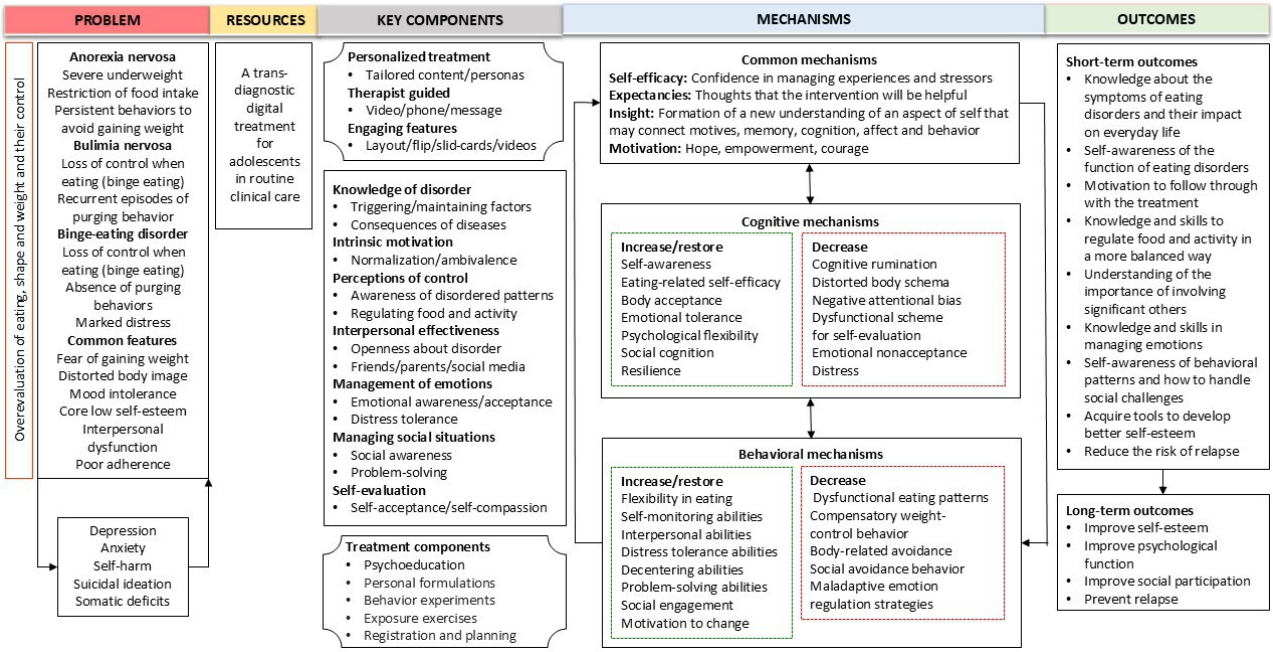
Participants were recruited from 8 child and adolescent psychiatric outpatient clinics. Information about the study was disseminated through meetings with clinic managers, emails to staff, and flyers placed in waiting rooms. Interested participants were provided with a link to the study website for information about the study and a brief preliminary online screening. The online screening captured information on disordered eating, eating-related behaviors, functional impairment in daily life, as well as key inclusion criteria such as age, internet access, and language. Eligible participants were given the opportunity to leave their contact information and were contacted by telephone to confirm inclusion and exclusion criteria. A diagnostic assessment was conducted by trained clinicians within the research group using the Mini-International Neuropsychiatric Interview (MINI) [52] and Eating Disorder Assessment for *DSM-5* (EDA-5) [53]. As the *International Statistical Classification of Diseases, Tenth Revision* (*ICD-10)* is the standard diagnostic framework in Norway, final diagnoses and all inclusion and exclusion criteria were determined according to *ICD-10* [51]. While MINI was used as a diagnostic instrument, the EDA-5 served to systematically assess eating disorder symptoms and support clinical judgment, rather than as an independent diagnostic tool. In response to slow recruitment, additional promotion of the study was carried out via upper secondary schools and advertisements on social media. As the study was conducted in routine clinical care, all participants had to be eligible for specialized care in accordance with national priority guidelines [54]. Participants who were not already patients at an outpatient clinic were required to visit their general practitioner to confirm medical stability and obtain a referral. Eligible participants were given access to the native treatment application, in which they signed consent forms, with those aged 15 years required to provide additional parental consent.

Intervention

The intervention was developed in line with the person-based approach (PBA) [55]. PBA is a methodological framework for understanding the most effective way to apply appropriate behavior change techniques in the specific context of the intervention and its intended users [55]. In line with PBA, adolescents with lived experience of eating disorders [27], mental health professionals, and the existing evidence base helped us identify key issues, needs, and challenges the intervention should address. Drawing on this in-depth understanding, key components were identified and systematically embedded into the design of the intervention. A logic model was created to describe how the key components of the intervention should lead to positive behavior change and better health (Figure 1). During development, the key components were incorporated and user-tested to refine the digital treatment to meet user requirements. This model serves as background for the second aim of this study: exploring whether the following key components of the novel digital treatment align with the adolescents it is designed to support: eating disorder symptomatology, psychosocial impairment, emotional difficulties (emotion dysregulation, anxiety, and depression), negative self-evaluation, and motivational factors.

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Figure 1. Logic model.



The development process resulted in a therapist-guided digital treatment delivered through a smartphone app. The intervention is based on a transdiagnostic cognitive behavioral framework targeting mechanisms that maintain eating disorders, alongside elements from emotion regulation approaches to enhance distress tolerance [56,57]. The treatment consists of eight modules delivered in a fixed sequence: (1) What is an eating disorder? (2) Motivation and change, (3) Balancing food and activity, (4) Involving others, (5) Management of emotions, (6) Managing social situations, (7) Improving self-esteem, and (8) Preventing relapse. Modules were released weekly, although 2 were designed to be completed over a 2-week period (modules 3 and 5). Adolescents received weekly clinician support through scheduled telephone consultations lasting approximately 15 to 30 minutes. In addition, they could send asynchronous messages to clinicians to address technical or practical issues. During the feasibility trial, the intervention was incorporated into the existing workflows of participating Child and Adolescent Mental Health Services (CAMHS) outpatient clinics. The clinicians delivering the intervention were employed within CAMHS and were assigned approximately 10% of a full-time position, corresponding to a caseload of around 3 patients each. Standardized guidelines were developed to support clinicians in delivering the intervention. Clinicians also received brief introductory training on the digital platform and treatment procedures. In addition, they participated in fortnightly 1-hour group supervision sessions led by an experienced clinical psychologist.

Measures

Data were collected using self-report questionnaires administered online. Sociodemographic data (age, gender, living situation, engagement at school and with friends) were gathered using a questionnaire developed specifically for this study. The selected measures have been applied in adolescent and eating disorder populations, used in evaluations of digital interventions for this group, and are consistent with international consensus recommendations on patient-centered outcome measures in eating disorders [58,59].

Eating Disorder Examination—Questionnaire Short (EDE-QS)

Eating disorder symptoms were measured using the EDE-QS [60]. EDE-QS is a 12-item questionnaire with a 4-point response scale that assesses symptom severity over the preceding 7 days. Scores range from 0 to 36, and higher scores indicate greater symptom severity. A score of 15 or above serves as a cutoff point for distinguishing between eating disorder cases and noncases [61]. The questionnaire has high internal consistency (Cronbach α=0.91) [60].

Clinical Impairment Assessment Questionnaire (CIA)

CIA was used to assess the severity of psychosocial impairment due to eating disorder features [62]. CIA consists of 16 items covering impairment in different domains of life that are typically affected by eating disorder psychopathology. Three subscales are computed, representing personal, social, and cognitive impairment that can result from eating disorders. Global scores range from 0 to 48, with higher ratings indicating a higher level of impairment [62]. A global score of 16 or above represents a cutoff for clinically significant impairment [62]. Normative data from a clinical adult female sample in Norway indicate mean scores of 14.01 (SD 4.31) for the personal impairment subscale, 9.54 (SD 3.97) for the social impairment subscale, and 8.97 (SD 3.81) for the cognitive impairment subscale [63]. In this study, the normative data have been rounded to the nearest whole number to report the number of participants with a mean score that matches the clinical sample. The questionnaire has high internal consistency (Cronbach α=0.97) [62].

Difficulties in Emotion Regulation Scale (DERS-18)

The DERS-18 was used to assess clinically relevant difficulties in emotion regulation [64]. Participants answer on a 5-point

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Likert-type scale ranging from 1 (“almost never”) to 5 (“almost always”). Scores range from 18 to 90, with higher scores indicating greater emotion dysregulation [64]. DERS-18 consists of 6 subscales measuring difficulties in the flexible, multidimensional regulation of emotion: lack of awareness of one’s emotions (awareness), lack of acceptance of one’s emotions (nonacceptance), lack of access to effective emotion regulation strategies (strategies), lack of ability to manage one’s impulses during negative emotions (impulse), lack of ability to engage in goal-directed activities during negative emotions (goals), and lack of clarity about the nature of one’s emotions (clarity) [64]. DERS-18’s internal consistency is very high (Cronbach α=0.90) [65]. DERS is ideal for use in clinical research studies that require multiple assessment points and is frequently used in treatment outcome research [65]. Due to the different versions of the DERS, it is difficult to collapse findings across studies [65]. In one study from 2022, DERS scores were organized by depression subgroups [66]. For the DERS-18, total mean scores were 35.88 (SD 8.69) for normal subgroup, 42.68 (SD 10.50) for mild depression, 48.39 (SD 10.15) for moderate depression, and 56.13 (SD 10.08) for severe depression [66]. In this study, we used the same putative depressive symptomatology subgroups to organize our sample’s difficulties with emotion regulation. We used the moderate depression subgroup as a cutoff for difficulties within each domain. The reported cutoff scores have been rounded to the nearest whole number.

Generalized Anxiety Disorder-2 Scale (GAD-2)

Anxiety symptoms were measured using the 2-item version of the GAD-2 [67]. GAD-2 measures symptoms over the last 2 weeks, scored on a 4-point Likert scale ranging from 0 (“not at all”) to 3 (“nearly every day”), with a cutoff score of 3 or above [68].

Patient Health Questionnaire-2 (PHQ-2)

Symptoms of depression were measured using the 2-item version of the PHQ-2 [69]. PHQ-2 measures symptoms over the last 2 weeks and is scored on a 4-point Likert scale ranging from 0 (“not at all”) to 3 (“nearly every day”) [70]. The standard cutoff score of PHQ-2 is 3 or above; however, a cutoff score of 2 or above may represent an optimal threshold for adolescents [71].

Rosenberg Self-Esteem Scale (RSES)

The RSES was used to measure negative self-evaluation [72]. RSES measures self-competence and self-liking using 10 items, answered on a 4-point Likert-type scale—from “strongly agree” to “strongly disagree.” The scale ranges from 0 to 30, and scores between 15 and 25 are within the normal range; scores below 15 suggest low self-esteem [72]. The questionnaire’s Cronbach α was 0.92, indicating excellent internal consistency [72].

Total Burden of Symptoms

To capture the overall level of symptom burden among participants, a composite score ranging from 0 to 6 was calculated. For each standardized measure, 1 point was assigned if the participant’s score exceeded the established clinical cutoff. The total score therefore reflects the number of measures for which the participant scored above the cutoff, with higher scores indicating a greater overall symptom burden.

Treatment Motivation

In addition to the standardized measures, the participants were given a 6-item questionnaire to explore motivational factors for participating in a novel treatment. As no suitable validated instrument was available, the questionnaire was developed specifically for this study, drawing on the Short Motivation Feedback List [73] and grounded in self-determination theory [74]. Four items were rated on a 5-point Likert scale ranging from “Strongly disagree” to “Strongly agree” and were designed to capture both the level and type of motivation (internal vs external). These items assessed reasons for participating in treatment, including intrinsic motivation (eg, wanting to engage in treatment) and externally driven motives (eg, perceived expectations from others). The remaining 2 items asked participants to rate, on a scale from 0 to 100, how much effort they expected to invest in the treatment and the extent to which they would involve others for support when needed.

Data Analysis

Data were analyzed using SPSS (version 29). Given the descriptive nature of this study, data are presented in terms of frequencies, percentages, means, and standard deviations.

Ethical Considerations

This study was approved by the Regional Committees for Medical and Health Research Ethics in Norway (REC-639031). In addition, the study was conducted in line with the Haukeland University Hospital’s guidelines for ethics and privacy considerations. Informed consent was obtained via the smartphone app.

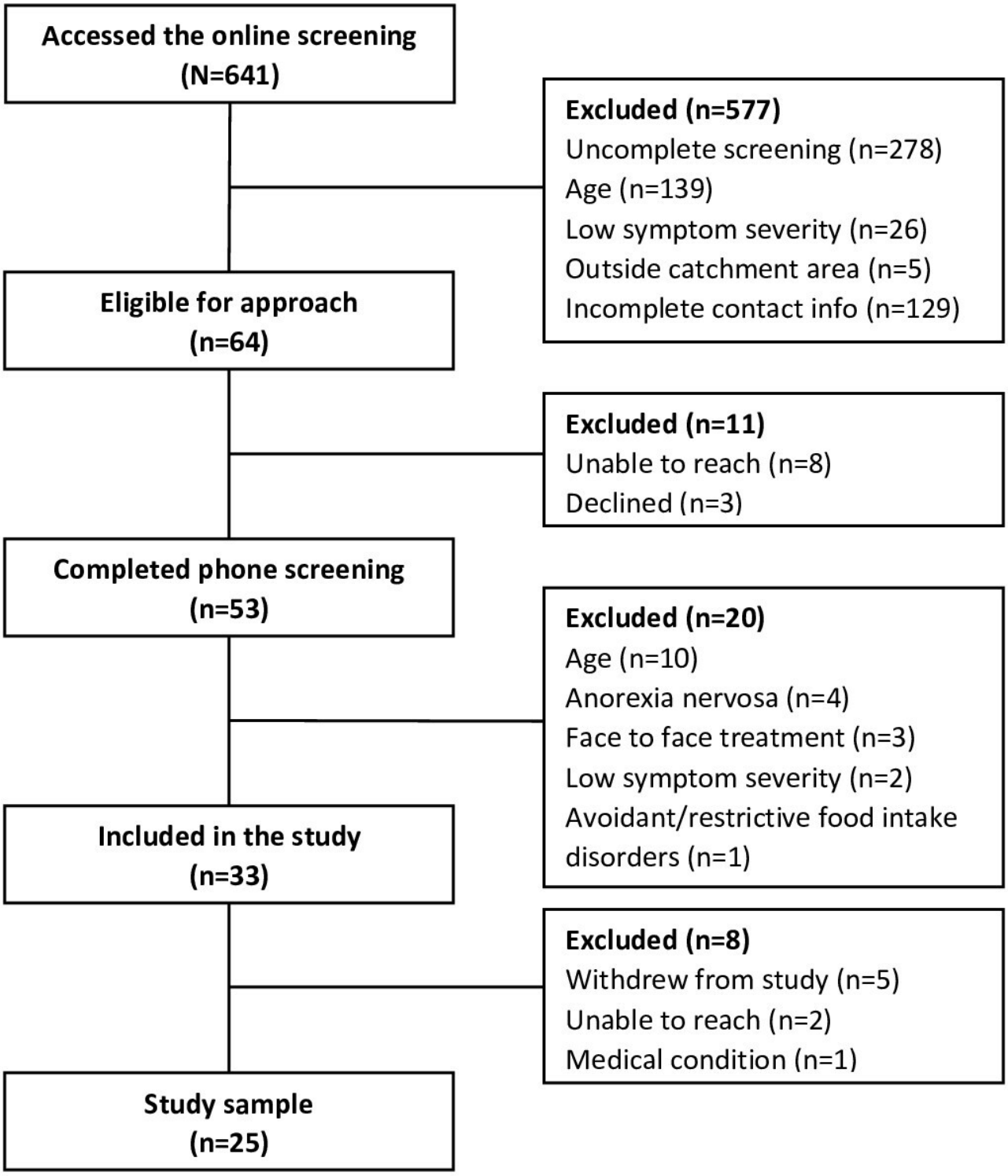
Results

Recruitment

Following 14 months of recruitment, baseline data were used for this study as the project neared completion. A total of 641 individuals accessed the online screening portal (Figure 2) between March 2024 and May 2025. Of these, 577 individuals were ineligible due to incomplete screening, being outside the age range, not meeting diagnostic criteria for an eating disorder (low symptom severity), or living outside the catchment area. In addition, 129 individuals met the criteria for the online screening but could not be contacted as they did not leave their contact information. Of the 64 adolescents eligible for approach, 11 were excluded because they were unable to be reached or declined participation. Of the 53 adolescents contacted by telephone, 20 were excluded from the study due to age (n=10), a primary diagnosis of anorexia nervosa (n=4), receiving face-to-face psychological treatment (n=3), low symptom severity (n=2), or ARFID (n=1). After inclusion, 5 adolescents changed their minds regarding participation, 2 were unable to be reached, and 1 was excluded due to a medical condition. Twenty-five adolescents completed the baseline screening and enrolled in the study. These were recruited through CAMHS (n=15), upper secondary schools (n=5), and social media (n=5).

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Figure 2. Recruitment flowchart.



Sociodemographic Characteristics

All participants were women (Table 1). The mean age of the study sample was 16 (SD 0.87, range 15-18) years. Over half of the sample were living with both parents (60%). All participants were engaged in school (100%), and almost all (96%) were engaged with friends on a regular basis.

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Table . Sociodemographic characteristics of adolescents seeking digital treatment (N=25).

Characteristics	Values
Gender, n (%)	
Men	0 (0)
Women	25 (100)
Nonbinary	0 (0)
Age (y), mean (SD)	16.48 (0.87)
Living situation, n (%)	
Both parents	15 (60)
50/50 residential	3 (12)
One parent	4 (16)
Alone	1 (4)
Other living agreement	2 (8)
Engaged in education, n (%)	
Reduced time	5 (20)
Full-time	20 (80)
Engaged with friends[a], n (%)	
Daily	6 (24)
Weekly	11 (44)
Monthly	7 (28)

[a]For the sociodemographic characteristic "Engaged with friends," N=24 (96%).

Diagnoses and History of Present Illness

Most of the adolescents were diagnosed at inclusion with atypical anorexia nervosa (40%), with the second largest group being eating disorder, unspecified (28%) (Table 2). The rest of the sample was equally distributed between atypical bulimia nervosa (16%) and binge-eating disorder (16%). The mean age at eating disorder onset was 13 (SD 1.68, range 9 - 16) years. Half of the adolescents had previously received face-to-face treatment for an eating disorder (52%, 13/25).

Table . Diagnoses and history of present illness of adolescents seeking digital treatment (N=25).

Characteristics	Values
Diagnoses (inclusion), n (%)	
Atypical anorexia nervosa	10 (40)
Atypical bulimia nervosa	4 (16)
Binge eating disorder	4 (16)
Eating disorder, unspecified	7 (28)
Prior eating disorder treatment, n (%)	
Yes	13 (52)
No	12 (48)
Age of disorder onset (y), mean (SD)	13.00 (1.68)

Motivational Factors

The adolescents' motivational factors for participating in a novel digital treatment are summarized in Table 3. Most of the adolescents' responses to items 1 and 3 were in the higher categories, 4 ("agree") and 5 ("strongly agree"), indicating high internal treatment motivation. When asked to rank (0% - 100%) how much effort they would put into carrying out the treatment, the mean score was 83% (SD 14.34%), ranging from 50% to 100%. Regarding the involvement of others, the mean score was somewhat lower (52%, SD 33.18%), with a range from 0% to 100%.

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Table . Motivational factors among adolescents seeking digital treatment (N=25).

Item number	Items	Median (IQR)	n (%)	n (%)	n (%)	n (%)	n (%)
	How much do you agree with the following statements:		Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree
1	I am participating in treatment because I want to.	5 (4-5)	1 (4)	0 (0)	1 (4)	10 (40)	13 (52)
2	I am participating in treatment because others think I should.	3 (3-4)	1 (4)	4 (16)	8 (32)	9 (36)	3 (12)
3	I am participating in treatment because it will help me live a better life.	4 (4-5)	2 (8)	0 (0)	1 (4)	12 (48)	10 (40)
4	I am participating in treatment to avoid disappointing others.	2 (2-3.5)	5 (20)	9 (36)	5 (20)	5 (20)	1 (4)

Eating Disorder Symptoms

The distribution of eating disorder symptoms was in the severe range, with a mean EDE-QS score of 21.56 (SD 6.80) [61]. Table 4 provides an overview of the distribution of symptoms, range, cutoff, and mean.

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Table . Distribution of eating disorder symptoms, psychosocial impairment, emotional difficulties, and negative self-evaluation (N=25).

Measures	Range	Cutoff[a], n (%)	Mean (SD)
Eating Disorder Examination—Questionnaire Short (EDE-QS)			
Total score	8-33	21 (84)	21.56 (6.80)
Clinical Impairment Assessment Questionnaire (CIA)			
Global score	8-47	22 (88)	28.08 (10.71)
Personal impairment	5-18	3 (52)	13.08 (3.89)
Social impairment	1-15	9 (36)	7.80 (4.10)
Cognitive impairment	2-14	10 (40)	7.20 (3.52)
Difficulties in Emotion Regulation Scale-18 (DERS-18)			
Total score	32-85	17 (68)	53.72 (13.92)
Awareness	4-13	21 (84)	10.00 (2.48)
Nonacceptance	3-15	18 (72)	8.92 (3.39)
Strategies	3-15	11 (44)	7.24 (3.64)
Impulse	3-15	15 (60)	7.52 (3.68)
Goals	5-15	15 (60)	11.16 (2.88)
Clarity	3-15	15 (60)	8.88 (2.86)
Generalized Anxiety Disorder-2 Scale (GAD-2)			
Total score	1-6	17 (68)	3.44 (1.69)
Patient Health Questionnaire-2 (PHQ-2)			
Total score	0-6	20 (80)	2.60 (1.56)
Rosenberg Self-Esteem Scale (RSES)			
Total score	0-28	19 (76)	11.76 (6.33)

[a]Participants with scores exceeding the clinical cutoff on measure were identified. For the CIA subscales and the DERS-18, normative data were used due to the lack of clinically validated cutoff scores (62 and 66).

Psychosocial Impairment

The global impairment score was high at 28.08 (CIA) [62] (Table 4). The impairment subscales show difficulties across the personal, social, and cognitive domains [63].

Emotional Difficulties

To explore the adolescents' emotional difficulties, emotion dysregulation and symptoms of anxiety and depression were assessed (Table 4). The sample's abilities to regulate emotions indicate moderate to severe difficulties within this domain, with a total mean DERS-18 score of 53.72 (SD 13.92) [66]. The adolescents had difficulties in all the 6 DERS-18 subscales. In addition, they reported anxiety symptoms above the cutoff (GAD-2 score 3.44, SD 1.69) [68]. The mean score for depression was below the cutoff (PHQ-2 score 2.60, SD 1.56) [70]; however, using an optimal cutoff score for adolescents of 2 or above, the score exceeded the threshold [71].

Negative Self-Evaluation

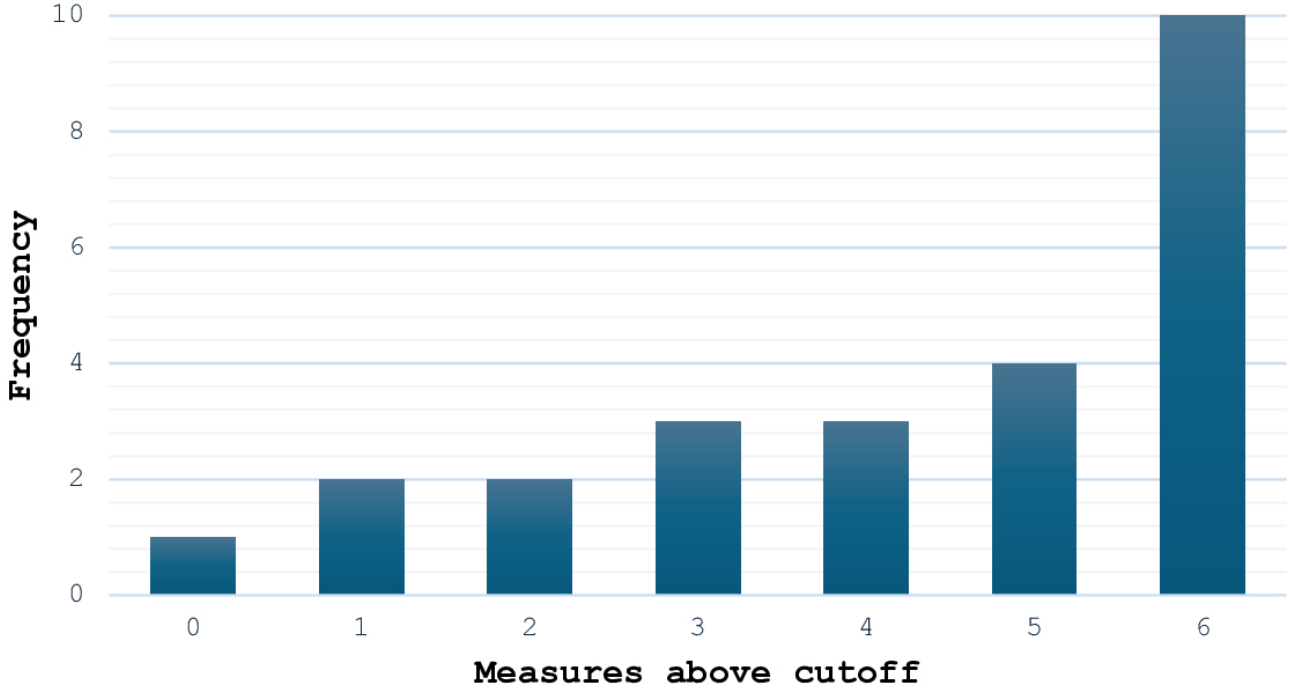
To evaluate the sample's level of negative self-evaluation, we measured the adolescents' self-esteem (RSES mean score 11.76, SD 6.33), which was in the range indicating severely low self-esteem [72].

Total Burden of Symptoms

The total burden of symptoms was calculated (Figure 3). Median response scores ranged from 0 to 6, with the median score on 5 measures above the cutoff.

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Figure 3. Total burden of symptoms above established cutoffs among adolescents seeking digital treatment (N=25). Each standardized measure exceeding its clinical cutoff contributes one point to the total symptom burden score. A score of 1 indicates one measure above cutoff, and a score of 2 indicates 2 measures above cutoff, and so forth.



Alignment Between Key Components and Adolescents' Characteristics

The second aim of this study was to explore whether the key components of the novel intervention (for more details, see Figure 1) align with the characteristics of the adolescents recruited for this study. Table 5 shows an overview of the key components, the results from measuring these characteristics, and an evaluation of the alignment.

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Table . Alignment between key components of the digital treatment and adolescents' characteristics.

Key components	Measure	Result	Evaluation	Alignment
Eating disorder symptomatology	• EDE-QS[a]	Majority above clinical cut-off	Indicates that the treatment targets core symptoms relevant to the adolescent population.	Yes
Impairment	• CIA[b]	High level of global impairment	Suggests that the intervention's focus on functioning is well-matched with the sample's needs.	Yes
Emotional difficulties	• DERS-18[c] • GAD-2[d] • PHQ-2[e]	High levels of anxiety, depression, and emotional dysregulation	Supports the relevance of the treatment in addressing emotional difficulties across all these domains.	Yes
Negative self-evaluation	• RSES[f]	Severe low self-esteem	Confirms the importance of components addressing self-image and self-worth.	Yes
Motivational factors	• Six-item questionnaire	High level of pretreatment motivation	Levels observed were higher than anticipated. Variability across individuals suggests that tailored engagement strategies may still be necessary to optimize uptake and adherence.	Partial

[a]EDE-QS: Eating Disorder Examination—Questionnaire Short.

[b]CIA: Clinical Impairment Assessment Questionnaire.

[c]DERS-18: Difficulties in Emotion Regulation Scale-18.

[d]GAD-2: Generalized Anxiety Disorder-2 Scale.

[e]PHQ-2: Patient Health Questionnaire-2.

[f]RSES: Rosenberg Self-Esteem Scale.

Discussion

Principal Findings

As part of examining the feasibility of a novel digital treatment, this study assessed sample representativeness. Specifically, the study examined the characteristics of adolescents seeking digital treatment for eating disorders within routine clinical care and explored whether the key components of the novel digital treatment aligned with the characteristics of the adolescents it is designed to support. Although recruitment was not specified as a predefined feasibility criterion, the findings revealed substantial challenges in this area. Given the central role of recruitment in feasibility research, particularly for understanding whether the intended population can be reached, these challenges are addressed first in the discussion to provide important context for interpreting the remaining findings.

Recruitment

The results revealed considerable challenges in enrolling participants. Despite substantial traffic to the online screening portal, only a small proportion of adolescents progressed to study participation, suggesting a gap between initial interest and actual engagement. This pattern may reflect well-established features of eating disorders, such as ambivalence toward treatment and fluctuating motivation, which can reduce readiness to seek or accept help [3,9]. Additional challenges may be related to adolescence as a developmental stage, where factors such as stigma, reliance on caregivers, and competing demands can influence help-seeking behavior [75]. Intervention-specific and contextual factors may also have contributed. Some adolescents may have been hesitant to engage in a digital treatment format or may have preferred traditional face-to-face care [34,37]. At the same time, recruitment via social media appeared to reach individuals who had not previously accessed clinical services, indicating an unmet need for more accessible entry points to care. It should also be noted that recruitment challenges are common in clinical research [76]. In this study, such challenges may have been further exacerbated by practical constraints within clinical settings, including limited time and resources among clinicians. Together, these findings suggest that while digital interventions may lower initial barriers to help-seeking, they do not fully overcome challenges related to participation in studies and treatment.

Characteristics of Adolescents Seeking Digital Treatment for Eating Disorders

Atypical anorexia nervosa was the most frequently assigned diagnosis, which aligns with data from a Norwegian community-based prevalence study [10]. Furthermore, the adolescents' distributions of eating disorder symptoms and psychosocial impairment are consistent with the diagnostic thresholds for inclusion in this study. Moreover, their elevated levels of emotional difficulties and negative self-evaluation are in accordance with other studies examining these mechanisms among adolescents with eating disorders [77-79]. Low

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self-esteem and mood intolerance are particularly pertinent in the adolescent age range [78], and anxiety and depression are the most prevalent comorbid disorders [79]. The adolescents' total burden of symptoms across domains emphasizes the sample's severity. The adolescents reported a high level of internal pretreatment motivation. The strong internal motivation may be linked to the adolescents' severe eating disorder symptoms [9] or to their being more likely to engage in the intervention due to recruitment via a self-selection process [80]. Providing adolescents with a sense of control and agency in treatment decision-making may contribute to improved adherence to therapeutic interventions [37].

The fact that none of the adolescents included in this study were men reflects the well-established gender discrepancies in the field of eating disorders [5]. Stigma associated with the disclosure of mental health issues and cultural perceptions that eating disorders are typically female disorders might influence help-seeking behaviors among adolescent boys [81]. Moreover, although individuals that identify as transgender or nonbinary are at particularly high risk for developing eating disorders [82,83], no participants in this study identified with a gender other than women. The results of this study highlight the presence of underrepresented groups within the adolescent population seeking treatment for eating disorders [17,81,83].

Alignment of Novel Interventions With Adolescents' Characteristics

The distribution of eating disorder symptoms within the sample indicates that the treatment targets core symptoms relevant to the population. In addition, the intervention's focus on functioning is well-matched to adolescents' needs. Moreover, the inclusion of a transdiagnostic sample aligns with the goal of the novel intervention to address the multifaceted and overlapping nature of these conditions. Drawing on perspectives from adolescents with lived experience of an eating disorder, the design of the digital treatment embedded emotional difficulties and negative self-evaluation as key components [27]. The results of this study show that adolescents' high levels of difficulties within these domains support the relevance of the treatment in addressing emotional dysregulation, anxiety, depression, and self-worth. This alignment may indicate that the intervention is designed for the users and contexts in which it will be implemented. Furthermore, adolescents' levels of pretreatment motivation were higher than anticipated when designing the novel intervention. Variability across adolescents highlights that tailored engagement strategies may be an important component for optimizing uptake and adherence to the digital treatment. Although the intervention was developed through a co-design process to reflect the needs of the intended target population, a one-size-fits-all approach may not fully address the heterogeneity among adolescents with eating disorders. Additional flexibility or personalization within the intervention may be needed to better accommodate individual differences and enhance engagement.

Clinical Implications and Future Directions

Half of the adolescents seeking digital treatment had previously received face-to-face treatment for an eating disorder. This emphasizes the relevance of digital interventions to complement or extend traditional care, particularly for individuals who may not have experienced sufficient benefit from prior treatment. Moreover, the adolescents' high level of internal pretreatment motivation may suggest that digital treatment can also serve as a viable alternative to face-to-face approaches for some individuals. Suitable options to traditional eating disorder treatment are urgently needed, not only because of existing treatment challenges but also to address future public health care concerns. A remarkable increase in eating disorders among adolescents since the beginning of the COVID-19 pandemic emphasizes a real challenge for health care providers [4,84,85].

Adolescents with anorexia nervosa and bulimia nervosa were excluded from participating. Given the high prevalence of adolescents who go untreated [11], future steps should be taken to offer the intervention to adolescents with these disorders within routine clinical care. A potential solution involves combining digital treatment with periodic in-person medical evaluations. This would also address the needs of those who prefer face-to-face interventions but who also endorse the advantages of digital interventions (eg, availability in times of need and the ability to address stigma associated with help-seeking) [34]. Additionally, digital platforms offer opportunities to integrate tools for monitoring symptoms that may signal medical risk, thereby enhancing patient safety and clinical responsiveness.

Although emotional difficulties are common in adolescents with eating disorders [77-79], these domains are not a primary focus of first-line eating disorder treatments [17]. In the design of mental health technologies, a shift from a top-down approach to a user-driven process necessitates new models of behavior change that move beyond traditional psychotherapy frameworks [76]. The results from this study are in concordance with other studies that address the importance of targeting emotional difficulties in the treatment of eating disorders [29].

The current findings highlight the need to increase diversity among adolescents participating in eating disorder treatment [17,82,83]. In particular, the absence of male participants and the lack of representation of gender-diverse individuals underscore well-documented disparities in help-seeking and access to care. Future research should prioritize recruitment strategies that actively engage these populations, including the use of culturally sensitive language and appropriate measurement tools [17,82,83].

Limitations

This study has important limitations that need to be addressed. Several aspects of the study design may introduce sampling bias. Recruitment was limited to adolescents eligible for specialist outpatient care within a specific catchment area, which may not reflect the broader geographical population. In addition, this recruitment approach may have constrained the extent to which the sample reflects the broader sociodemographic characteristics and contextual factors considered during the co-design process. The exclusion of those with anorexia nervosa and bulimia nervosa further narrows the sample. In addition, recruitment through self-selection options may favor adolescents who are more motivated, less burdened by barriers to help-seeking, or who already knew that the content would align

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with their preferences. Moreover, the lack of a control or comparison group may introduce sampling bias, as it is unclear whether participants differ systematically from those who did not participate or from those who would have received other treatments. These factors may reduce the representativeness of the sample and limit generalizability. Another limitation is the lack of systematic reporting and evaluation of the co-design process. Even though it is reasonable to consider that user involvement in the design and development process from the start influences the extent to which adolescents' characteristics are embedded in the design, we do not know whether it was the involvement of users at a particular phase or the continuous involvement across all phases of design that offers benefits to design research.

Conclusions

The findings from this study underscore the relevance of digital interventions to complement or extend traditional eating disorder care for adolescents. Furthermore, the findings highlight the importance of enhancing diversity among adolescents participating in digital eating disorder treatments to ensure equitable access and representation. The findings emphasize the importance of designing digital treatments that are sensitive to normative biases and highlight the value of involving a diverse group of adolescents with lived experience of eating disorders in the design and development process from the start. In addition, this study highlights the importance of designing digital treatments that address the multifaceted nature of eating disorders and are tailored to the needs and preferences of a transdiagnostic population. The present findings are important insofar as they may indicate that the key treatment components align with the characteristics of adolescents seeking digital treatment for eating disorders within routine clinical care. Results from the open feasibility trial will show whether adolescents experience the novel digital treatment as acceptable, and credible, and whether the treatment reduces symptoms and increases coping skills.

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Data Availability

Data generated, analyzed, and reported during this study are not publicly available but are available in a slightly shortened, deidentified form from the corresponding author on reasonable request. The protocol may be shared upon request.

Authors' Contributions

Conceptualization: ESN, TN
Formal analysis: GH, TN
Investigation: GH, ESN
Methodology: GH, TN
Project administration: GH, ESN, EMSE, TN
Supervision: IBE, TN
Writing – original draft: GH
Writing – review & editing: ESN, IBE, EMSE, TN

Conflicts of Interest

None declared.

Checklist 1
CONSORT checklist.
[PDF File, 270 KB - pediatrics_v9i1e93431_app1.pdf]

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Abbreviations

ARFID: avoidant or restrictive food intake disorder
CAMHS: Child and Adolescent Mental Health Services
CIA: Clinical Impairment Assessment Questionnaire
CONSORT: Consolidated Standards of Reporting Trials
DERS-18: Difficulties in Emotion Regulation Scale-18
EDA-5: Eating Disorder Assessment for *DSM-5*
EDE-QS: Eating Disorder Examination—Questionnaire Short
GAD-2: Generalized Anxiety Disorder-2 Scale
***ICD-10*:** *International Statistical Classification of Diseases, Tenth Revision*
MINI: Mini-International Neuropsychiatric Interview
PBA: person-based approach
PHQ-2: Patient Health Questionnaire-2
RSES: Rosenberg Self-Esteem Scale

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Original Paper

Effects of an App-Based Intervention on Psychological Well-Being Among Young Individuals not in Employment, Education, or Training With and Those Without Disability: Subgroup Analysis of a Randomized Controlled Trial

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Abstract

Background: The population of young individuals not in employment, education, or training (NEET) is highly diverse, but a common problem appears to be their mental health. NEETs due to illness or disability are of particular concern for social exclusion, but little is known of how young individuals who are NEET with and without disability make use of, and gain from, employment interventions. There is also a scarcity of research on psychological interventions and mental health outcomes among young NEETs. Acceptance and commitment therapy (ACT) has shown promising results in psychological outcomes in young adults.

Objective: This study aimed to expand the knowledge on the effects of an app-based intervention built on ACT on NEETs with and without disabilities.

Methods: A 2-arm randomized controlled trial was conducted in 2021, including 151 young NEETs aged 16-24 years. Participants were recruited mainly via social media platforms and through organizations working with young NEETs. The intervention group (n=77) used an app for psychological well-being with the possibility for digital group meetings for 6 weeks, and the control group (n=74) received film clips once a week. Outcomes were self-assessed through questionnaires. Statistical analyses were made using chi-square, Mann-Whitney *U* test, general linear model, and logistic regression.

Results: No differences in effects on mental health were seen between the intervention and control group, neither overall nor between young NEETs with or without disability. Usage data show that 68.8% (53/77) of the participants in the intervention group downloaded the app, and 24.7% (19/77) completed all 6 modules. Effects on employment and education levels were only seen within the intervention group, where those who had completed one or more modules had a higher likelihood of being active in terms of employment and education compared to those who did not complete modules. No significant effects were seen in employment and education levels in relation to disability status. A high proportion of the participants had a disability, few were in contact with a youth employment center, and there was an overrepresentation of young women in general. Participants with disabilities had lower self-esteem, had less frequently completed high school, had less work experience, and a larger proportion had been in the NEET situation for over a year. A higher dropout were seen among participants in the intervention group and among young men.

Conclusions: No effects of the app-based intervention were seen for psychological well-being between young NEETs with disabilities and those without, but the results showed potential effects on employment and education levels related to engagement in the intervention. NEETs with disabilities are of particular concern and might need additional efforts or other types of interventions than the one investigated in this study. Findings can be considered weak due to the low adherence and high attrition.

Trial Registration: ISRCTN Registry ISRCTN46697028; https://www.isrctn.com/ISRCTN46697028

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KEYWORDS

not in employment, education, or training; NEET; disability; intervention; app-based; psychological health; acceptance and commitment therapy

Introduction

There is a global consensus on the importance of reducing the proportion of young individuals not in employment, education, or training (NEET), as demonstrated in Sustainable Development Goal 8.6 [1]. NEET status per se can be associated with long-term detriments and disadvantages such as economic scarring [2], social exclusion [3], health scarring by impacts on mental health and health behavior [4], and preterm mortality [5]. The population of NEETs is highly diverse, and its composition and characteristics vary between European countries [3]. In the case of Sweden, there is a larger proportion of short-term unemployed NEETs (35.5% vs 25.5%), a substantially higher proportion of NEETs due to illness or disability (16.1% vs 7.1%), and a lower proportion of long-term unemployed NEETs (8.5% vs 23.1%) compared to Europe as a whole [6]. NEETs due to illness or disability (defined as "young people who are not seeking employment or are not available to start a job within two weeks due to illness or disability" including individuals who cannot do paid work due to their illness or disability) are described as of particular concern for social exclusion [3].

Leaving school early or being in the NEET situation is more common among young people with disabilities compared to those without, indicating that the transition from school to work is more challenging for young individuals with disabilities [7]. A recent Organisation for Economic Co-operation and Development (OECD) report states that 8% of 15- to 29-year-olds had a disability in 2019, with a varying prevalence around the world [7]. The incidence is on the rise due to an increasing incidence of chronic depression, particularly in the Nordic countries. This trajectory was further accelerated by the COVID-19 pandemic [8] when mental health support was disrupted, schools closed or shifted to online education, daily routines and social contact were lost, and the labor market became extremely unstable [9]. Work can be a protective factor for mental health if working conditions are adequate [10].

The potential for employment interventions directed toward the NEET population has been demonstrated in a review [11], but the number of conducted trials is few and little is known about effectiveness in relation to, for example, different types of approaches or specific subgroup populations. There is also a scarcity of research on psychological interventions, including mental health outcomes. The review calls for more research on specific aspects of interventions that work and for whom, and highlights that subgroup differences to the detriment of the most disadvantaged groups were shown in some trials in relation to both effects, recruitment, and intervention engagement [11]. The need for intervention studies increasing the understanding of the effects on different subgroups of vocational and mental health support for young people who are NEET is also highlighted in a systematic review and meta-analysis on the mental health of young people who are NEET [12]. A qualitative study on experiences from a program aiming to engage young NEET showed how different elements impacted differently on different individuals [13]. Another study focusing on psychological therapy treatment outcomes of young NEETs showed that young NEETs had worse outcomes in recovery, deterioration, and attrition compared to non-NEET individuals and that the difference between the groups grew in the first few months of the COVID-19 pandemic [14]. There were also differences in outcomes within the NEET group depending on ethnicity and level of deprivation of residential areas [14]. The same study also reports an association between attending more sessions and improved outcomes [14].

Web- and app-based interventions [15] have the potential to reach populations that are normally hard to reach. The evidence around eHealth and smartphone-based psychological interventions is yet to be concluded, but has shown small positive effects on general mental health [15], anxiety and depression [15-17], and acceptance and mindfulness skills [18], and are described as promising tools to make psychotherapy more widely available even though the effects seem to be smaller than face-to-face psychotherapy. For adolescents, the evidence of these kinds of interventions is even scarcer [15]. Web-based acceptance and commitment therapy (ACT) has shown promising results in reducing stress and increasing academic buoyancy among adolescents [19] and improving psychological, emotional, and social well-being, life satisfaction, and self-esteem, and reducing symptoms of stress and depression among university students [20]. ACT aims to increase psychological flexibility, helping individuals regulate difficult thoughts and emotions while engaging in valued actions [16]. These mechanisms may be particularly relevant for NEET youth facing uncertainty, low self-esteem, or avoidance patterns, and could theoretically support both well-being and reengagement in work or education. A meta-analysis on the efficacy of smartphone-based mental health interventions called for more research investigating which aspects of interventions are effective and for whom they are beneficial [21]. Several reviews also underline the difference in effects dependent on the choice of control group, with larger effects when using a waitlist or no treatment control compared to an active control group [15,16,18]. Adherence is another aspect to take into account, where a systematic review and meta-analysis of self-guided online acceptance and commitment therapy interventions reported that 57.6% of all participants completed all modules, with adherence data ranging from 27.5% to 94.7% in the included studies [16]. Another review focusing on web-delivered acceptance and commitment therapy for mental health and well-being reported a mean adherence of 83% in terms of completing post-assessment, ranging from 48% to 100% [17]. Using reminders has been suggested to improve adherence and subsequently the effects of the interventions [15,18].

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Recruitment and attrition are indeed other problems related to intervention studies on the population group NEET. There are numerous reports of the difficulty in reaching NEETs, in particular long-term NEETs and those that are not registered at the public employment services [22]. In Sweden, where this particular study took place, young women in the NEET situation have been particularly difficult to reach with interventions [23]. Social media have shown promise as a possible way to reach hard-to-reach populations [24,25] but have mostly been used for observational or cross-sectional studies and less for clinical or interventional studies [24,25]. In terms of attrition, a recent evidence and gap map of youth employment interventions rated 73.4% of the studies to be of low quality, which was most commonly related to high attrition rates or nonreporting of attrition. Another reason for the low-quality impact evaluations was large differences between intervention and control groups in baseline characteristics [26]. Furthermore, a study on an apprenticeship program directed to young NEETs showed that younger individuals and those with worse relationships with parents were more likely to drop out, underlining the need for different support approaches considering the background of the individuals [27].

In line with the research gaps identified relating to differences in how subgroups of NEETs make use of, and gain effects from, mental health interventions, the study aimed to expand the knowledge on the effects of an app-based intervention built on acceptance and commitment therapy on NEETs with and without disabilities. The following research question was considered: How do the effects (well-being, psychological distress, and employment and education level) of an app-based intervention on psychological well-being on young NEETs in Sweden vary depending on the presence of disability and moderated by background characteristics?

Methods

Study Design

A 2-armed parallel randomized controlled trial (RCT) was conducted between March and October 2021 to assess the feasibility and effectiveness of an app-based intervention built on ACT in comparison to film clips from YouTube dealing with mental health problems. The CONSORT-EHEALTH (Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth) guidelines for reporting RCT [28] were used (Multimedia Appendix 1).

Inclusion and Exclusion Criteria

To be eligible for participation in the study, participants had to be 16-24 years of age, unemployed or not working or studying more than 19 hours per week. The reasons for including individuals who were active up to 19 hours per week were to include semiactive students struggling to get through high school and individuals with insecure employment. They also had to be willing and have the possibility to participate in the full intervention and have a sufficient level of Swedish to take part in the intervention. Participants who received high values on screening for depression, that is, 15 points or more on the Patient Health Questionnaire-9 (PHQ-9), were excluded and provided contact details on where to seek care. The reason for exclusion was that depression was considered to need more treatment than this study intervention could provide. The excluded participants were also offered the chance to be contacted by any of the psychologists involved in the study if they wished to have further support.

Recruitment

The recruitment of participants from all over Sweden was done in two different phases, with the first phase of the recruitment taking place in March and April 2021, with advertisements on Facebook and Instagram. At this stage, municipalities and organizations working with NEETs were contacted and asked for support to reach out by posting on their social media, informing potential participants about the study, or having the study coordinator inform at digital group meetings. The study was also advertised on the Karolinska Institutet website, “Research subjects wanted.” When a participant declared interest in participating in the study at this stage, she or he received an email with a link to a participant information and consent form, followed by a baseline questionnaire. Despite the efforts made to reach out broadly to the target group, recruitment went slowly, which is why a new take on the recruitment strategy had to be made. Phase 2 of the recruitment started in May 2021, when the developer of the app that was tested in the study helped to create a short recruitment video that could be posted on other social media sites such as Snapchat, TikTok, and YouTube. Snapchat became the primary recruitment source. Those who declared interest in this phase were sent a text message where they were asked if the study coordinator could contact them by phone to give them more information about the study or if they preferred to be emailed. All advertisements and information regarding the study contained the logo of Karolinska Institutet.

Randomization

Randomization was performed continuously when 20 new participants had been recruited. This number was twice the number of participants that were required for a full potential group for the digital group meetings in the intervention group (described below). Randomization was performed 1:1 by the study coordinator using the statistical program IBM SPSS by inserting the study ID of the participants and using the command “Random sample of cases,” requesting that exactly 10 out of 20 be selected. The randomization was performed 3 times, and the third randomization was used for all randomization rounds. Due to logistical reasons related to the timing of the group meetings, randomization was sometimes performed before reaching 20 new individuals. In those cases when an uneven number of individuals had been recruited, one additional person was requested to be assigned to the intervention group.

Participants

A total of 590 young individuals declared interest in participating in the study. Of those, 193 individuals consented to participate in the study and filled in the baseline questionnaire. Due to high scores on the screening for depression, 42 individuals were excluded from the study and provided contact details for where to seek care. A total of 151 participants were randomized into either the intervention group (n=77) or the control group (n=74) and started the study.

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The Intervention

The active intervention was a youth program for increased self-compassion, self-care, mindfulness, and value-based behaviors, delivered in the 29k app (29k Foundation) [29]. The 29k app was developed by the nonprofit foundation 29k to make evidence-based tools for mental health available to as many as possible in a user-friendly manner. The youth version used in the study was in Swedish, had been piloted on young people with different backgrounds and experiences, and consisted of 6 modules that were to be used during 6 weeks. The modules included interactive material and exercises on stress, self-compassion, gratitude, relationship skills, recovery, and mindfulness exercises. In the app, additional modules were freely available for the participants to use, but no updates to the app were made, so the content remained the same throughout the trial. Participants randomized to the intervention group received individual, unique links to download the app. Participants were provided with contact details for the research team in case they needed support concerning the use of the app. Participants in the intervention group were invited to participate in weekly digital group meetings led by a trained facilitator. The facilitators did not need to be mental health professionals and got 1.5 hours of training in how to facilitate the groups. The meetings were 45 minutes long. Participation in the digital group meetings was voluntary, and the participants could choose to participate in one or several meetings or decide to use the app program on at least a weekly basis by themselves without participating in the meetings. Reminders were emailed for group meetings, and those reminders were also planned to work as reminders for using the app.

The Control Condition

The control intervention consisted of YouTube film clips where young adults were discussing stress, mental health problems, self-esteem, and the meaning of life (Multimedia Appendix 2). An active control was chosen to reduce expectancy effects and ensure that both groups receive a structured weekly engagement. This design provides a conservative test of intervention-specific effects. Links to the film clips were sent out via email once a week for 6 weeks, and the clips were between 4 and 8 minutes long. The participants were asked to watch the video that was provided in the link and reflect for themselves. A reminder was sent out three days after the link was sent.

Data Collection and Measures

Overview

Data were collected using self-assessed electronically distributed questionnaires at three timepoints: baseline (t1), postintervention (t2), and 6 months after randomization (t3). The secure web platform REDCap (Research Electronic Data Capture; Vanderbilt University) was used for overall project management and for data collection by sending out links to the questionnaires as well as reminders when the questionnaires were not completed. The questionnaire included background questions on age, sex, country of birth, physical or psychological disability or diagnosis, years of schooling, work experience, relationship with parents, trust in different societal institutions, trust in general, and how they found out about the study. The follow-up questionnaires (t2 and t3) also contained 3 free-text questions on whether the study had affected motivation, supported knowing what to do in life, and affected how the participant cares for, or commits to, others or the environment. Furthermore, the following outcome measures were included in the questionnaire.

Self-Esteem

Self-esteem was measured with the Swedish version of the Rosenberg self-esteem scale [30], consisting of 10 items to be answered with a 4-grade scale stretching from “strongly agree” to “strongly disagree.”

Well-Being

The Swedish version of the World Health Organization-Five Well-Being Index (WHO-5) [31] was used to assess well-being among the participants. The WHO-5 has five items to be answered on a 6-grade Likert scale ranging from “all the time” to “at no time.”

Stress

Stress was measured with the Swedish version of the Perceived Stress Scale (PSS-10) [32,33], consisting of 10 items to be answered with a 5-grade Likert scale representing the range from “never” to “very often.”

Anxiety

The Swedish version of the Generalized Anxiety Disorder 7-item scale (GAD-7) [34] was used to assess anxiety among the participants. The instrument consists of seven items to be answered with a 4-grade Likert scale ranging from “not at all” to “nearly every day.”

Depression

Depression was measured using PHQ-9 [35]. The PHQ-9 is used in Swedish health care as a screening instrument for depression and consists of 9 items to be answered with a 4-grade Likert scale representing the range from “not at all” to “nearly every day.”

Career Adaptabilities

Career adaptabilities are individual resources for coping with occupational challenges and tasks. The outcome was measured with a translated version of the Career Adapt-Abilities Scale - Short Form [36]. The scale consists of 12 questions that are to be answered using a 5-point Likert scale ranging from 1=“not a strength” to 5=“greatest strength.”

Employment or Education Status

The outcome was measured by questions on whether the participant was working, in education, or in training (3 different questions). The total time that the participants responded that they were either in employment, education, or training was compiled. A total of 20 hours or more per week was considered “active,” less than 20 hours a week was regarded as “not active.”

For the intervention group, data on app downloads, registration, and completed lessons were collected. Participation in the digital group meetings was noted by the facilitators. Given the design of the study, neither the participants nor the group leaders could be blinded to the intervention conditions. Participants received

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information about the 2 conditions (intervention and control) and to which group they were assigned. Group leaders provided parts of the intervention and feedback on why they were aware of the condition. Researchers had access to the assessments made online.

Data Treatment and Analyses

Sample size was compiled based on a power of .80 and α=.05 for a moderate effect in an analysis of variance with two groups, resulting in a sample of 64 participants in each group [37]. The aim of recruitment was 180 participants to allow for a dropout of about 25%.

Differences in background data of the participants in the intervention and control groups were tested with the chi-square for categorical variables and the Mann-Whitney *U* test for continuous variables due to nonnormality of the variables. The Pearson correlation test was used to assess the correlation between the total score of the Career Adapt-Abilities Scale and completion of modules in the app for the participants in the intervention group.

Composite scores were compiled for the outcomes "well-being" and "psychological distress" using *z*-scores. For well-being, the *z* scores from the instruments WHO-5 and the Rosenberg self-esteem scale were summed into one composite variable. For psychological distress, the *z* scores from the instruments GAD-7, PSS-10, and PHQ-9 were summed. Composite scores were chosen to reduce the number of statistical tests.

A general linear model (GLM) was used to analyze the differences between t1 and t2 for the composite scores of well-being and psychological distress. Analyses were made using both per protocol (PP) and intention to treat (ITT) approach, where missing values in the ITT analysis were replaced with series means of the intervention and control group. The ITT approach assumed data were missing at random at the level of the treatment group. Differences in well-being and psychological distress (t2-t1), respectively, were used as dependent variables in each model. Group, gender, and disability were used as fixed factors in the GLM model. The interaction effect between those variables was included in the tables. Country of birth was not included as a fixed factor since the number of participants born abroad was small. Binary logistic regression was used for the analyses of employment and education status at t3. IBM SPSS (version 28) was used for all analyses.

Ethical Considerations

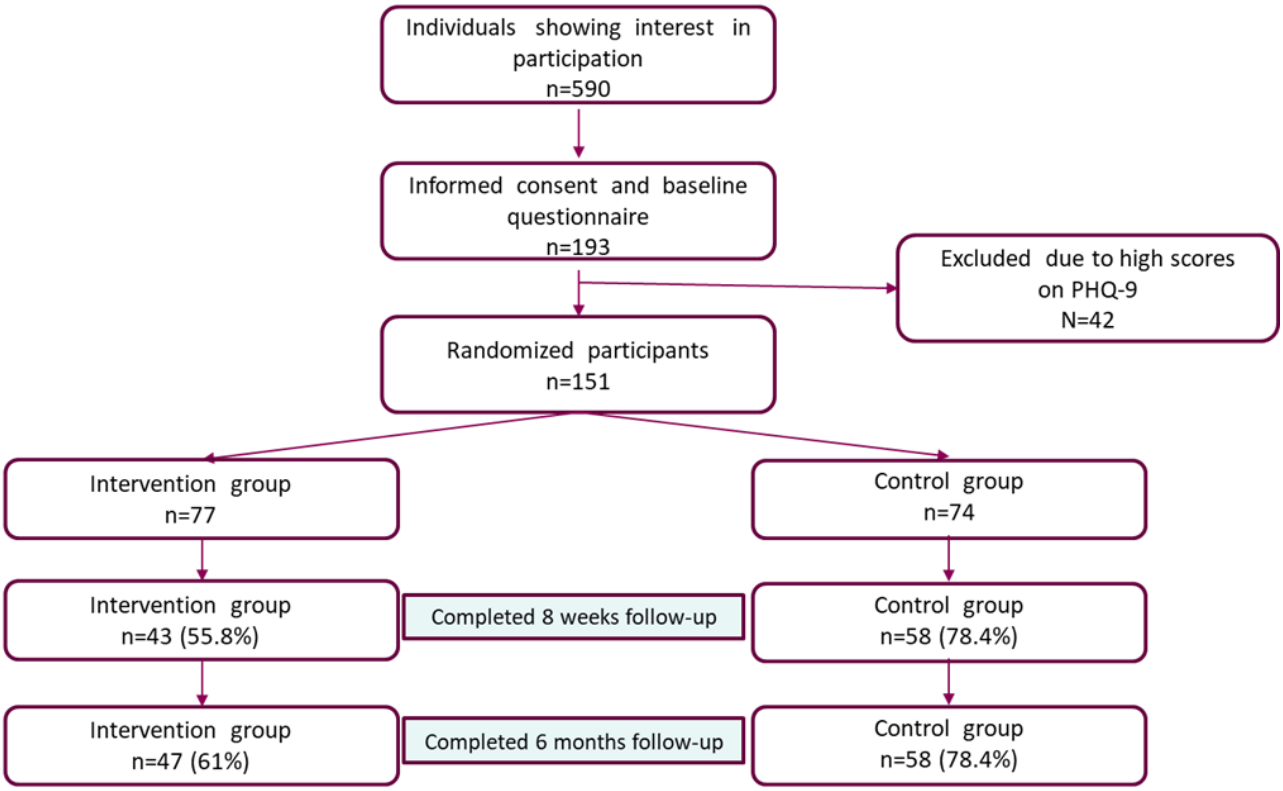
The study was approved by the Swedish Ethical Review Authority (Dnr 2020-03952). All participants were informed about the study and their rights and signed a digital informed consent form before participation. Data collected are stored in secure databases at Karolinska Institutet and presented at the group level to minimize the risk of identifying specific participants. Participants were reimbursed with a gift card of 750 SEK after completing the final questionnaire to cover the time used for the study.

Results

Of the 151 participants who participated in the study (Figure 1), almost three-quarters were young women (Table 1). The mean age of the participants was 20 (SD 2) years, and 9 out of 10 were born in Sweden. Almost half of the participants responded that they had a physical or psychiatric disability or diagnosis (hereafter mentioned as "disability"). More than half of those had several different disabilities, and the most common ones were psychiatric disabilities such as attention deficit hyperactivity disorder (ADHD; n=35), depression (n=25), generalized anxiety (n=20), and autism (n=15). The majority of the participants had passed ninth grade, and about 6 out of 10 had completed high school. Participants came from all parts of Sweden, about half from the middle part, a third from southern Sweden, and the rest from the northern part of Sweden. The largest proportion of participants came from large cities or municipalities nearby, followed by medium-sized towns and nearby municipalities, while 18.5% (28/151) of participants came from small towns or rural municipalities. Slightly more than half of the participants had been outside of employment, education, or training for 3-12 months. Only 21.9% (33/151) were in contact with a youth employment center or other activity directed to NEET youths. No significant differences in terms of background characteristics were found between the intervention and the control group.

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Figure 1. Flowchart of the recruitment and the participants. PHQ-9: Patient Health Questionnaire-9.



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Table 1. Background characteristics of the participants at baseline assessment for the intervention and control groups, and for participants with disabilities and no disability.

	All (N=151), n (%)	Intervention (N=77), n (%)	Control (N=74), n (%)	*P* value[a]	Disability (N=75), n (%)	No disability (N=76), n (%)	*P* value[a]
Gender, n (%)				.26[b]			.28[b]
Women	113 (74.8)	56 (72.7)	57 (77)		60 (80)	53 (69.7)	
Men	33 (21.9)	20 (26)	13 (17.6)		14 (18.7)	19 (25)	
Other or don't know	5 (4.8)	__[c]	__[c]		__[c]	__[c]	
Group				__[d]			.37
Intervention	77 (51)	__[d]	__[d]		41 (54.7)	36 (47.4)	
Control	74 (49)	__[d]	__[d]		34 (45.3)	40 (52.6)	
Age (years), mean (SD)	20.0 (2.0)	20.0 (2.0)	20.0 (2.1)	.98	19.9 (2.3)	20.1 (1.8)	.66
Birth country				.54			.62
Sweden	135 (89.4)	70 (90.9)	65 (87.8)		68 (90.7)	67 (88.2)	
Other than Sweden	16 (10.6)	7 (9.1)	9 (12.2)		7 (9.3)	9 (11.8)	
Disability				.37			__[d]
Yes	75 (49.7)	41 (53.2)	34 (45.9)		__[d]	__[d]	
No	76 (50.3)	36 (46.8)	40 (54.1)		__[d]	__[d]	
Years of education, mean (SD)	11.7 (2.0)	11.9 (1.6)	11.5 (2.4)	.59	11.3 (2.3)	12.1 (1.6)	.08
Graduated ninth grade				.06			.53
Yes	139 (92.1)	74 (96.1)	65 (87.8)		68 (90.7)	71 (93.4)	
No or don't know	12 (7.9)	__[c]	9 (12.2)		7 (9.3)	5 (6.6)	
Completed high school				.77			.01
Yes	88 (58.3)	44 (57.1)	44 (59.5)		36 (48)	52 (68.4)	
No	63 (41.7)	33 (42.9)	30 (40.5)		39 (52)	24 (31.6)	
Part of the country				.46			.34
Southern Sweden	51 (33.8)	29 (37.7)	22 (29.7)		24 (32)	27 (35.5)	
Mid Sweden	78 (51.7)	36 (46.8)	42 (56.8)		37 (49.3)	41 (53.9)	
Northern Sweden	20 (13.2)	11 (14.3)	9 (12.2)		13 (17.3)	7 (9.2)	
Information missing	__[c]	__[c]	__[c]		__[c]	__[c]	
Type of municipality				.95			.15
In or near large cities	66 (43.7)	33 (42.9)	33 (44.6)		28 (37.3)	38 (50)	
In or near medium-sized towns	55 (36.4)	29 (37.7)	26 (35.1)		28 (37.3)	27 (35.5)	
Small towns or rural	28 (18.5)	14 (18.2)	14 (18.9)		18 (24)	10 (13.2)	
Information missing	__[c]	__[c]	__[c]		__[c]	__[c]	
Time in NEET [e] status				.88			.01
0-2 months	34 (22.5)	17 (22.1)	17 (23)		17 (22.7)	17 (22.4)	
3-12 months	82 (54.3)	41 (53.2)	41 (55.4)		33 (44)	49 (64.5)	
13 months or more	29 (19.2)	16 (20.8)	13 (17.6)		21 (28)	8 (10.5)	
Information missing	6 (4)	__[c]	__[c]		__[c]	__[c]	
Contact with the youth employment center or other activity working with NEETs				.64			.88
Yes	33 (21.9)	18 (23.4)	15 (20.3)		16 (21.3)	17 (22.4)	

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	All (N=151), n (%)	Intervention (N=77), n (%)	Control (N=74), n (%)	*P* value[a]	Disability (N=75), n (%)	No disability (N=76), n (%)	*P* value[a]
No	118 (78.1)	59 (76.6)	59 (79.7)		59 (78.7)	59 (77.6)	
Previous work experience				.23			.005
Yes	97 (64.2)	53 (68.8)	44 (59.5)		40 (53.3)	57 (75)	
No	54 (35.8)	24 (31.2)	30 (40.5)		35 (46.7)	19 (25)	

[a]*P* values were calculated by chi-square or Mann-Whitney *U* tests.

[b]Analysis only including women or men categories.

[c]Not displayed as n<5.

[d]Not applicable.

[e]NEET: not in employment, education, or training.

Some statistically significant differences were found in background characteristics between those who reported a disability and those who did not (Table 1). A lower proportion of those with a disability had completed high school and had previous work experience compared to those without disability. Participants with disabilities also had a higher proportion of 13 months or more with NEET status.

There were no significant differences between the intervention and the control group in self-reported health at baseline (Multimedia Appendix 3). The participants had a mean value of 45.7 in the instrument WHO-5, which can be regarded as relatively low considering that values below 52 points indicate further investigation when used in health care [31]. The mean value of the participants on self-esteem, 14.5 points, was on the limits of low and normal self-esteem. About half (74/151, 49.7%) of the participants had values indicating mild anxiety, while 27% (41/151) had values indicating moderate or severe anxiety. The stress levels of the participants were classified as moderate in 74.8% (113/151), and 11.9% (18/151) had values indicating high stress levels. About 57% (86/151) had moderate depressive symptoms, and the remaining participants had either no, minimal, or mild depressive symptoms (those with more severe symptoms had been excluded).

The participants who reported a disability had a significantly lower mean score on self-esteem compared to those without disability (12.0 vs 16.1). No other significant differences were observed (Multimedia Appendix 3).

Table 2 shows that about 30% (46/151) of the participants did not complete the final questionnaire at 6 months and were considered to have dropped out. There was a significantly higher dropout in the intervention group compared to the control group, and among young men compared to young women. There was also a higher proportion of those born outside of Sweden who dropped out, but the difference was not significant. No difference in dropout was found in the other background factors. Looking further into the intervention group, a significantly higher share of the young men dropped out compared to the young women in the intervention group (12/77, 15.6% vs 18/77, 23.4%; χ^2_1=.03). No other significant differences were found in terms of dropout in the intervention group related to age, country of birth, or disability status.

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Table 2. Proportion of participants who did and did not complete the final follow-up questionnaire 6 months post randomization.

	Participants, n	Proportion that completed, n (%)	Proportion that did not complete, n (%)	Chi-square (*df*)
All	151	105 (69.5)	46 (30.5)	
Group				
Intervention	77	47 (61)	30 (39)	.02 (1)
Control	74	58 (78.4)	16 (21.6)	
Gender				.01[a] (1)
Women	113	84 (74.3)	29 (25.7)	
Men	33	16 (48.5)	17 (51.5)	
Other or don't know	5	5 (100)	0 (0)	
Age				.79 (1)
16-19	60	41 (68.3)	19 (31.7)	
20-24	91	64 (70.3)	27 (29.7)	
Country of birth				.09 (1)
Sweden	135	97 (71.9)	38 (28.1)	
Other country	16	8 (50)	8 (50)	
Disability				.68 (1)
Yes	75	51 (68)	24 (32)	
No	76	54 (71.1)	22 (28.9)	
Relationship with mother				.70 (1)
Very good or good	105	72 (68.6)	33 (31.4)	
Ok to very bad or no answer	46	33 (71.7)	13 (28.3)	
Relationship with father				.45 (1)
Very good or good	62	41 (66.1)	21 (33.9)	
Ok to very bad or no answer	89	64 (71.9)	25 (28.1)	
Time outside of studies or employment				.67 (2)
<3 months	34	24 (70.6)	10 (29.4)	
3-12 months	82	55 (67.1)	27 (32.9)	
>12 months	29	22 (75.9)	7 (24.1)	
Recruitment phase				.41 (1)
First phase	33	21 (63.6)	12 (36.4)	
Second phase	118	84 (71.2)	34 (28.8)	

[a]Chi-square analysis only including women and men categories.

Usage data from the app show that about 7 out of 10 participants in the intervention group downloaded and registered in the app (Table 3). Of those that registered, about 87% (46/53) consented to having their usage followed. Slightly more than half of the participants did not complete any modules in the app. About 27% (21/77) of the participants completed 4 or more modules, and the same percentage participated in one or several digital group meetings. There were no significant differences in usage between those with disabilities and those without disabilities. Multimedia Appendix 4 displays some background and health-related characteristics of the participants who completed any modules in the app and those who did not complete any. Among those who did not complete any modules, there was a higher proportion of participants born outside of Sweden, a lower proportion of participants reporting that they trust other people in general, and a higher proportion who were in contact with a youth employment center or other activity toward young NEETs. No significant differences were seen for the other characteristics. A sensitivity analysis examining the correlation between the score on the Career Adapt-Abilities Scale from the participants in the intervention group at the beginning of the study and whether they completed modules or not resulted in a significant negative correlation (Pearson correlation coefficient r=–.31; P=.01). Hence, participants who completed modules tended to score lower on the scale than those that had not completed modules. In terms of time dedicated per week for

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the study, 28.4% (21/74) of the participants in the control group did not answer the question, 33.8% (25/74) answered that they had used 1-15 minutes per week, 24.3% (18/74) had used 16-30 minutes per week and 13.5% (10/74) had used more than 30 minutes per week. In the intervention group, 49.4% (38/77) did not answer, 9.1% (7/77) of the participants answered 1-15 minutes, 11.7% (9/77) had used 16-30 minutes per week, and 29.9% (23/77) had used more than 30 minutes per week for the study.

Table 3. Usage of the app in the intervention group, total, and depending on disability status.

	Intervention (n=77), n (%)	Disability (n=41), n (%)	No disability (n=36), n (%)	Chi-square (*df*)
Registered				.17 (1)
Yes	53 (68.8)	31 (75.6)	22 (61.1)	
No	24 (31.2)	10 (24.4)	14 (38.9)	
Completed modules				.73 (1)
0	43 (55.8)	23 (56.1)	20 (55.6)	
1-3	13 (16.9)	8 (19.5)	5 (13.9)	
4 or more	21 (27.3)	10 (24.4)	11 (30.6)	
Completed all 6 modules				.26 (1)
Yes	19 (24.7)	8 (19.5)	11 (30.6)	
No	58 (75.3)	33 (80.5)	25 (69.4)	
Participation in group meetings				.68 (1)
Yes	21 (27.3)	12 (29.3)	9 (25)	
No	56 (72.7)	29 (70.7)	27 (75)	

Comments in the free-text answers were similar for the participants with and without disabilities in the intervention group. Some comments were raised about using the app, which made them feel less alone, as it was comforting to hear others having similar thoughts and feelings. Other comments were that they appreciated the discussions with the group leaders during the group discussions and the exercises to work on in between. Some participants also described how they valued the exercises provided in the app, such as meditation, and that some exercises had triggered self-reflection and awareness about how they feel. Other participants expressed that they did not perceive that the app had changed their motivation. A few participants wished for a longer duration of the intervention.

The GLM analyses made PP showed no significant differences for improvement of psychological distress or well-being between the intervention and the control group, irrespective of disability status or gender (Table 4). The ITT analysis on change in well-being indicated a tendency (P=.08) where the intervention group had a more positive change in well-being between baseline and directly after the intervention compared to the control group. No interaction effects were observed.

When focusing on the intervention group and their exposure to the intervention using both PP and ITT analysis, there were no significant differences between those who completed one or several modules in the app compared to those who did not complete any (Table 5). Similar results were observed when looking at those who participated in the group meetings (Table 6).

The analyses regarding employment and education level of the participants 6 months after randomization did not yield any significant results when including the full sample, nor when comparing the control group to those in the intervention group that had completed any modules in the app (Table 7).

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Table 4. Change in psychological distress and well-being between baseline and postintervention (per protocol and intention to treat) for the intervention and control group for all participants, depending on disability status and gender.

Variables	Groups		GLM[a] results				
	Intervention, mean (SD)	Control, mean (SD)	Main		Interaction		Partial eta squared
			F test (*df*)	*P* value	*F* test (*df*)	*P* value	
Psychological distress (PP[b])			0.356 (1, 92)	.55	0.097 (1, 83)	.76	0.001
All (n=94)	–0.14 (0.93)	–0.02 (0.92)					
Disability (n=94)			0.771 (1, 90)	.38	—[c]	—	—
Yes	–0.01 (1.05)	0.03 (0.85)					
No	–0.26 (0.79)	–0.06 (0.98)					
Gender (n=91)			0.181 (1, 87)	.67	—	—	—
Women	–0.05 (0.92)	–0.03 (0.93)					
Men	–0.30 (0.84)	0.00 (0.79)					
Psychological distress (ITT[d])			2.081 (1, 149)	.15	0.083 (1, 138)	.77	0.001
All (n=151)	–0.12 (0.98)	0.12 (1.02)					
Disability (n=151)			0.751 (1, 147)	.39	—	—	—
Yes	–0.03 (1.04)	0.17 (0.98)					
No	–0.22 (0.92)	0.08 (1.06)					
Gender (n=146)			0.081 (1, 142)	.78	—	—	—
Women	–0.09 (1.02)	0.11 (1.04)					
Men	–0.08 (0.82)	0.21 (0.99)					
Well-being (PP)			2.183 (1, 95)	.14	1.415 (1, 86)	.24	0.016
All (n=97)	0.20 (0.86)	–0.08 (0.98)					
Disability (n=97)			1.329 (1, 93)	.25	—	—	—
Yes	0.22 (0.98)	–0.36 (1.04)					
No	0.18 (0.73)	0.12 (0.89)					
Gender (n=94)			0.000 (1, 90)	.99	—	—	—
Women	0.18 (0.86)	–0.07 (0.97)					
Men	0.26 (0.99)	–0.16 (1.12)					
Well-being (ITT)			3.038 (1, 149)	.08	0.040 (1, 138)	.84	0.000
All (n=151)	0.14 (0.90)	–0.14 (1.06)					
Disability (n=151)			1.103 (1, 147)	.29	—	—	—
Yes	0.17 (0.94)	–0.36 (1.13)					
No	0.10 (0.86)	0.04 (0.98)					
Gender (n=146)			0.005 (1, 142)	.94	—	—	—
Women	0.13 (0.92)	–0.15 (1.08)					
Men	0.15 (0.89)	–0.20 (1.17)					

[a]GLM: general linear model.

[b]PP: per protocol.

[c]Not available.

[d]ITT: intention to treat.

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Table 5. Change in psychological distress and well-being between baseline and postintervention (per protocol and intention to treat) for those in the intervention group who completed one or more modules and those who did not complete any modules for the whole intervention group, depending on disability status and gender.

Variables	Intervention group		GLM[a] results				
	Completed one or more modules, mean (SD)	Did not complete any module, mean (SD)	Main		Interaction		Partial eta squared
			F test (*df*)	*P* value	*F* test (*df*)	*P* value	
Psychological distress (PP[b])			1.303 (1, 39)	.26	—[c]	—	—
All (n=41)	–0.26 (0.71)	0.08 (1.22)					
Disability (n=41)			0.998 (1, 37)	.32	—	—	—
Yes	–0.28 (0.73)	0.34 (1.33)					
No	–0.25 (0.71)	–0.30 (1.03)					
Gender (n=40)			0.174 (1, 36)	.68	—	—	—
Women	–0.21 (0.65)	0.23 (1.24)					
Men	–0.49 (0.94)	0.17 (0.31)					
Psychological distress (ITT[d])			3.130 (1, 75)	.08	0.225 (1, 68)	.64	0.003
All (n=77)	–0.33 (0.76)	0.06 (1.10)					
Disability (n=77)			0.597 (1, 73)	.44	—	—	—
Yes	–0.30 (0.80)	0.19 (1.16)					
No	–0.37 (0.75)	–0.09 (1.04)					
Gender (n=76)			0.009 (1, 72)	.92	—	—	—
Women	–0.35 (0.67)	0.14 (1.22)					
Men	–0.29 (1.11)	0.03 (0.65)					
Well-being (PP)			0.774 (1, 40)	.38	—[c]	—	—
All (n=42)	0.29 (0.84)	0.04 (0.90)	—				
Disability (n=42)			0.005 (1, 38)	.94	—	—	—
Yes	0.43 (0.88)	–0.09 (1.09)					
No	0.15 (0.81)	0.23 (0.56)					
Gender (n=41)			0.037 (1, 37)	.85	—	—	—
Women	0.24 (0.80)	0.07 (0.99)					
Men	0.50 (1.08)	–0.36 (0.39)					
Well-being (ITT)			2.379 (1, 75)	.13	1.400 (1, 68)	.24	0.020
All (n=77)	0.31 (0.89)	–0.00 (0.90)					
Disability (n=77)			0.162 (1, 73)	.69	—	—	—
Yes	0.40 (0.93)	–0.01 (0.93)					
No	0.21 (0.85)	0.01 (0.88)					
Gender (n=76)			0.118 (1, 72)	.73	—	—	—
Women	0.28 (0.81)	–0.02 (1.00)					
Men	0.43 (1.20)	0.01 (0.67)					

[a]GLM: general linear model.

[b]PP: per protocol.

[c]Interaction could not be computed due to too few participants in some categories.

[d]ITT: intention to treat.

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Table 6. Change in psychological distress and well-being between baseline and postintervention (per protocol and intention to treat) for those in the intervention group who attended or did not attend group meetings for the whole intervention group, and depending on disability status and gender.

Variables	Intervention group		GLM[a] results				
	Attended group meetings, mean (SD)	Did not attend group meetings, mean (SD)	Main		Interaction		Partial eta squared
			F test (*df*)	*P* value	*F* test (*df*)	*P* value	
Psychological distress (PP[b])			0.054 (1, 39)	.82	0.785 (1, 32)	.38	0.024
All (n=41)	–0.09 (1.20)	–0.16 (0.73)					
Disability (n=41)			1.396 (1, 37)	.25	—[c]	—	—
Yes	0.31 (1.44)	–0.21 (0.72)					
No	–0.50 (0.80)	–0.11 (0.78)					
Gender (n=40)			.64 (1, 36)	.43	—	—	—
Women	0.03 (1.23)	–0.10 (0.67)					
Men	–0.64 (1.05)	–0.05 (0.70)					
Psychological distress (ITT[d])			0.001 (1, 75)	.98	0.068 (1, 68)	.79	0.001
All (n=77)	–0.11 (1.28)	–0.12 (0.86)					
Disability (n=77)			3.819 (1, 73)	.06	—	—	—
Yes	0.37 (1.36)	–0.19 (0.84)					
No	–0.75 (0.87)	–0.04 (0.88)					
Gender (n=76)			0.247 (1, 72)	.62	—	—	—
Women	–0.02 (1.32)	–0.13 (0.87)					
Men	–0.47 (1.21)	0.02 (0.72)					
Well-being (PP)			0.225 (1, 40)	.64	0.595 (1, 33)	.45	0.018
All (n=42)	0.28 (0.97)	0.15 (0.80)					
Disability (n=42)			0.0125 (1, 38)	.88	—	—	—
Yes	0.06 (1.11)	0.31 (0.93)					
No	0.50 (0.83)	–0.04 (0.60)					
Gender (n=41)			0.131 (1, 37)	.72	—	—	—
Women	0.18 (0.87)	0.17 (0.87)					
Men	0.69 (1.48)	–0.07 (0.42)					
Well-being (ITT)			0.186 (1, 75)	.67	0.903 (1, 68)	.34	0.013
All (n=77)	0.21 (1.01)	0.11 (0.86)					
Disability (n=77)			0.797 (1, 73)	.38	—	—	—
Yes	–0.12 (1.01)	0.29 (0.90)					
No	0.66 (0.87)	–0.09 (0.79)					
Gender (n=76)			0.297 (1, 72)	.59	—	—	—
Women	0.14 (0.87)	0.12 (0.95)					
Men	0.51 (1.59)	0.06 (0.66)					

[a]GLM: general linear model.

[b]PP: per protocol.

[c]Not available.

[d]ITT: intention to treat.

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Table 7. Logistic regression on being active 20 hours or more per week, 6 months post randomization, comparing control versus intervention group, control group vs those in the intervention group who completed one or more modules, and within the intervention group, depending on completion of modules.

	B (SE)	Odds ratio (95% CI)	*P* value
Control vs intervention group (n=107)			
Crude			
Intervention	0.11 (0.40)	1.12 (0.51-2.42)	.78
Adjusted			
Intervention	0.15 (0.42)	1.17 (0.52-2.63)	.71
Women	0.19 (0.56)	1.21 (0.41-3.62)	.73
Disability	–0.70 (0.42)	0.50 (0.22-1.12)	.09
Control vs those in the intervention group who completed one or more modules (n=86)			
Crude			
Intervention	0.75 (0.51)	2.12 (0.78-5.77)	.14
Adjusted			
Intervention	0.81 (0.53)	2.25 (0.79-6.37)	.13
Women	0.14 (0.64)	1.15 (0.33-4.01)	.82
Disability	–0.83 (0.48)	0.43 (0.17-1.11)	.08
Only including the intervention group (n=49)			
Crude			
Completed	1.39 (0.62)	4.00 (1.19-13.50)	.03
Adjusted			
Completed	1.59 (0.68)	4.89 (1.30-18.38)	.02
Women	0.93 (0.87)	2.54 (0.46-14.02)	.29
Disability	–0.43 (0.67)	0.65 (0.18-2.39)	.52

Discussion

Principal Findings

The study aimed to expand the knowledge on the effects in terms of well-being, psychological distress, and employment and education level of an app-based intervention on NEETs with and without disabilities. The main findings of the study are that no differences were seen overall between the intervention and control groups, irrespective of whether the participants had completed a module in the app or not. No significant differences were found regarding the effect of being active in terms of employment or education, 20 hours or more per week, 6 months post randomization, except within the intervention group, where those who had completed one or several modules in the intervention were more likely to be active compared to those who did not complete any.

The findings could be related to those described in the review of Mawn et al [11], showing varying results from the interventions, and where high-contact interventions seemed to be most effective. Participation in the digital group meetings offered to the intervention group was low in general, and it might be worth considering if other formats would suit the target group better, in particular for participants with a disability. Other studies have presented differences in effects related to, for example, gender, ethnicity, and age [11,14]. Only gender was tested in this study since the material did not allow for examining ethnicity, and the age group was too narrow, but the results on intervention effects did not differ across gender. When reflecting about the effects of the app, it is important to keep in mind that the app is health promotive in the sense that it is developed to enhance the participant's well-being rather than to treat depression or anxiety and the target group excludes those with symptoms of severe depression, all of which are factors that could make it more difficult to detect positive effects of the intervention. Likewise, being a health-promotive app, it was not designed specifically for the purpose of getting young people into employment or education and was not intended as a stand-alone solution to replace traditional employment services but rather as a complement to other services. Indeed, several reviews emphasize the need for multicomponent strategies to cover the complex needs of the diverse population of NEETs [11,38,39]. Digital innovations could be a way to provide scalable and flexible support to young NEETs as an add-on to other activities, both focusing on psychological support and skills acquisition. One example of that is a clinically integrated online platform for young NEETs with mental health difficulties in Australia that showed positive work and study outcomes. The participants appreciated not having to travel and described the online mode as less confronting compared to in-person support, although some would have preferred meeting in-person

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[40]. Other studies have shown promising results from digital interventions such as the use of social media as a platform for skill acquisition [41] and a game-based positive psychology intervention [42] to support and engage young NEETs. A meta-analysis of the effectiveness of gamified interventions for mental health promotion showed positive effects on both mental wellness and psychological symptoms [43]. However, several studies on NEET emphasize the role of a mentor to handle challenges that arise [44,45], in particular for NEETs with mental health challenges or NEETs experiencing other vulnerabilities, where often more intensive strategies are needed [38]. A sustainable contact with a qualified practitioner where the relationship is built on trust and close collaboration with the young NEET and where interventions include psychological support and social skills development are identified as important features for the transition into employment for NEETs with additional vulnerabilities [38]. A Swedish study on workplace-oriented rehabilitation found, on the other hand, a model with personnel-intensive support with a clear and early focus on work to be more effective in getting young NEETs into employment compared to another personnel-intensive support model with a more holistic approach [46]. The diversity of NEETs and the complex flora of needs and interventions provides an additional argument for why digital interventions could be more suitable as a complementary intervention, enhancing other types of contacts and interventions when multicomponent interventions are recommended [38]. Some of the qualitative feedback that came from the participants in the intervention group mentioned how the use of the app made them feel less alone by knowing that others have similar thoughts and feelings. Others mentioned the importance of the discussion with the group leader during the digital group meeting. The feedback shows the potential for digital innovations to provide psychological support in a suitable manner for some participants, appreciating the digital format as a complement to the face-to-face-format although other participants described that the app did not result in any change. Whether this preference could be related to specific disabilities among the participants remains unclear, but participants with and without disabilities brought up similar issues in the free text. The heterogeneity of disabilities among the participants and the fact that the majority of those with disabilities had multiple diagnoses in our study make it difficult to draw any conclusions from the findings on the appropriateness across diverse disabilities. Further studies of a more specific nature in terms of target group and specific diagnoses could increase understanding in this area.

A previous study looking at psychological treatment outcomes found an association between improved outcomes and attending more sessions [14]. In this study, no differences in psychological outcomes were found related to completing modules in the intervention or not. However, there was a higher likelihood of being in employment or engaged in studies 6 months post randomization in this study for those in the intervention group who completed modules in the intervention compared to those who did not. This finding can indicate the importance of further completing the intervention, or at least motivating the participants to give it a try. It is also possible that the results in this study could be related to differences in participant characteristics in the sense that characteristics facilitating completing the intervention, such as, for example, motivation, could also facilitate the process of seeking employment or studies. Motivation was not measured among the participants, but career adaptability has been associated with career motivation [47]. The results from the correlation analysis between career adaptabilities and completion of modules showed a negative correlation, where those with high scores on the career adaptabilities scale tended not complete modules to a higher extent and vice versa, which was a bit surprising. These findings should be interpreted with caution, but a possible explanation could be that the group with high career adaptability had expectations on the app that were not met. Another interpretation is that the app could be a good complement to those with lower career adaptability. The data at hand and the small sample of the intervention group restrict the possibilities to examine the underlying reasons for this further, and it is an area for future research. No significant differences in being active in terms of employment or education, 20 hours or more per week, were found between the intervention and the control groups. Keeping in mind that a meta-analysis of 3 high-intensity interventions directed toward NEETs resulted in a very low increase in employment for the intervention group [11], the intervention studied in this paper is of a lower intensity and, as mentioned previously, was not designed specifically to get people into employment. Additionally, this study had an active control group, which could make it more difficult to detect intervention effects compared to having a waitlist or passive control group, as has been mentioned in previous research [15,16,18,43]. In the same vein, our choice of having the cut-off at 20 hours per week as both inclusion criteria for the study (19 hours or less per week) and as an outcome for being active (20 hours or more per week) could be debated. Similar cutoffs have been used earlier in combination with other measures [48,49], but the diverse flora of outcome measures used in studies focusing on NEETs underline the need to develop standardized outcome measures for reengagement [50]. In Sweden, like in many other countries, poor school results or high absence from school are risk factors for becoming NEET, and insecure employment is common among young individuals [51]. Having a “generous” inclusion criterion that also includes young semiactive individuals embeds for capturing individuals early on in their career in a health-promotive approach. It can also be underlined that the majority of participants in our study were at the extremes in terms of the outcome of being active, three out of four were either active 0 hours or 30 hours or more per week, 6 months post intervention.

Focusing on the participants that were recruited, the larger proportion were young women. This was a bit surprising since the gender division of NEETs in Sweden is relatively equal, with a slightly higher representation of men [6], and women have previously been reported to be difficult to recruit [23]. Young men were also overrepresented among those who dropped out. A scoping review of the use of social media for recruitment to medical research studies did not find a gender difference in the recruited participants [25], and Snapchat, which was the primary recruitment channel during the second recruitment phase when the majority of the participants were recruited, has a relatively equal use over genders [52]. However, a review of digital mental health interventions found that men

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were less likely to complete interventions compared to women and calls for interventions catering to the interests of young men [53]. It is possible that the intervention or the advertisements were more appealing to young women, even though the app and the short recruitment video were designed to appeal to all genders. Gamified interventions have shown promise for promoting mental health across genders, with an even greater potential effect on the reduction in anxiety symptoms in samples with a higher proportion of young men [43]. It is possible that using a gamified type of intervention could have resulted in increased recruitment and attainment of young men.

There was also a substantial proportion of those recruited who had a disability (about half), which is much higher than the general prevalence of 8% stated in an OECD report [7] and higher than the estimated 16% among NEETs in Sweden [6]. This high proportion of participants with a disability could imply that the type of intervention is particularly appealing to those with a disability, even though some adjustments have to be made for it to have an effect. As mentioned above, the heterogeneity of disabilities, as well as the high proportion of participants with multiple disabilities, complicated the interpretation of the findings in relation to disability status. The group of participants with a disability had nevertheless less frequently completed high school, which confirms the previous reports of a higher risk for school dropout among persons with, for example, depression, anxiety, or ADHD [54]. Previous reports of a difficult transition from school to work among individuals with disabilities [7] are also echoed in the findings of this study, where fewer participants with disabilities had previous working experience, and a larger proportion had been in the NEET situation for over a year. Participants with disabilities also had significantly lower self-esteem compared to those without. These findings call for further investigation of how the education system can be adjusted to meet the needs of all children and young people to lay the ground for a successful transition from school to work life. Working toward good health irrespective of disability status should be a priority in a society where all people should be entitled to be included and given possibilities for an engaged and rich life.

Overall, only 1 out of 5 participants had contact with an employment center, and it might be that this type of intervention, in combination with recruitment via social media, facilitates reaching populations that are normally difficult to reach with conventional interventions directed toward NEETs. Self-selection bias is a well-known risk when recruiting based on the fact that participants have volunteered for the study, and it might be that the recruitment strategy also attracted technology savvy participants. Furthermore, the recruiting procedure using both social media and affiliated organizations could also imply selection biases, but most probably of different kinds since the two approaches are likely to reach slightly different target groups. A large proportion of those recruited via social media had not been in contact with employment centers or similar activities, whereas those recruited via affiliated organizations had been informed about the study due to the contact they already had. The use of different approaches for recruiting was chosen to broaden the variety of young NEETs and to increase the possibility of also reaching those who had not been in contact with employment centers. Reaching participants at the beginning of their NEET journey could be a window of opportunity to prevent them from staying in the NEET situation for a long time, since research shows that individuals starting their career as unemployed are more likely to become unemployed later [55].

A major problem in the study was adherence, where slightly more than half of the participants in the intervention group did not complete any module in the app. Among those who did not complete any modules, there was also an overrepresentation of participants born outside of Sweden, a lower proportion of participants reporting that they trust other people in general, and a higher proportion being in contact with youth employment centers. In terms of time dedicated to the study per week, the intervention group had larger proportions on the "extremes" with a large proportions of participants who did not answer, but also a larger proportion of participants who had used more than 30 minutes per week for the study compared to the control group. Just by looking at what was required by the participants from the start, the time for the control arm each week was considerably shorter compared to the intervention arm, with the film clips being 4-8 minutes long. The higher time burden in the intervention arm compared with the control condition likely contributed to lower adherence and should be viewed as a structural feature of the design. Adherence is a problem seen in other similar studies based on smartphone or online interventions [16,56]. To improve adherence to mental health apps, actions such as involving end users in the development and thorough usability testing, as well as including clinician or peer support, have been suggested [56]. The apps that were tested in this study were developed with continuous feedback and input from end-users and underwent usability testing. It also included the digital group meetings that were intended to provide peer support, although these were not used much by the participants and sometimes even seemed to scare some of the participants off. The anonymity of the online context is indeed an appreciated feature that needs to be considered and balanced with the advantage of including social support or interaction with health professionals within an app [53].

High dropout is a common problem in both digital mental health interventions [56] and youth employment interventions [26]. In this study, 3 out of 10 participants did not complete the follow-up questionnaire 6 months post randomization, which is a relatively expected share given the target group, although slightly above the expected 25%. Efforts were made from the start to increase retention by using reminders as well as providing reimbursement for participation in the study, actions that have been suggested to reduce attrition [56]. We also changed the recruitment procedure along the way to have a mixed recruitment procedure involving both online registration, text message, and phone contact, but many participants actually chose to only use the online registration because they did not feel comfortable talking on the phone. Apart from a higher dropout among young men (discussed above), there was a higher dropout among participants in the intervention group. This has been seen in other studies using inactive control group but, to our knowledge, not in studies using active control groups [56],

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such as this particular study. The high drop-out in the intervention group is likely related to the experienced higher demand and the need to dedicate more time to the intervention compared to the control arm. All participants in the intervention group were also invited to participate in digital group meetings that, even though they were described as voluntary, could have put further pressure on the participants. Keeping all that in mind, an app tailored for the target group of young NEETs may contain shorter modules to not appear excessively demanding.

Strengths and Limitations

Among the strengths of the study is the use of an RCT design using an active control group, which lay ground for an investigation of potential additional benefits of the specific app. The downside of having an active control group is that it makes it more difficult to detect effects [15,16,18]. Furthermore, the analyses made with both the PP and ITT approaches to handle missing data in the material due to high dropout resulted in similar results in all analyses. The power of the study was affected by the fact that recruitment had to close before reaching 180 participants due to logistical reasons. In addition, the dropout exceeded the expected 25%, which further lowered the power of the study. The online format also limited the possibilities to further explore the reasons for dropping out. Apart from a high dropout, there were also problems with low adherence to the intervention and low participation in the digital group meetings. About 1 in 10 participants were born outside of Sweden, which is about half the share compared to the Swedish setting, where 1 out of 5 in the age group is born outside of Sweden [57], and the numbers are too small in this sample to allow for assessing the effect of ethnicity which could have provided additional insights of the app's effects. The recruitment strategy with potential participants volunteering to participate limits the generalizability of the findings due to the risk of self-selection bias. Another limitation is related to the lack of blinding in the trial, which could not be done due to the design of the study. Furthermore, the fact that limited qualitative data were collected limits the possibilities of providing explanations of the use and nonuse of the app or for potential reasons for dropping out.

Conclusion

The findings of the study showed no differences in the effects of an app-based intervention for psychological well-being between young NEETs with disabilities and those without, although low adherence and high attrition make the conclusions weak. No effects were, however, seen between those using the app and those receiving film clips. The findings about a higher likelihood of being in employment or education among those who completed modules in the app compared to those who did not call for more research about the potential reasons. The study managed to reach a wide variety of young NEETs, reaching groups that often are hard to reach, such as participants with disabilities and young women. Many were also relatively new to the NEET situation and were not in contact with other activity initiatives, embedding for early interventions. There might be a need to include other social media sources for recruitment and to adjust the app and its content to increase the chances of including and retaining young men, since they were both underrepresented in the study population and overrepresented among those who dropped out. The heterogeneity of disabilities among the participants makes it difficult to conclude the findings, and more studies are needed to assess the appropriateness of digital interventions across diagnoses. NEETs with disabilities are of particular concern and might need additional efforts or other types of interventions than the one investigated in this study.

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Data Availability

The datasets generated and/or analyzed during this study are not publicly available because the informed consent did not include a statement that the data would be made public. However, subsets of the data can be made available from the corresponding author on reasonable request and with permission from the Swedish Ethical Review Authority.

Authors' Contributions

LB, JR, FL, and LL contributed to the conceptualization of the study. LB and LL were in charge of data management and analysis and drafted the manuscript. FL and JR contributed to the conceptualization of the study and to revising the manuscript. LB, JR, FL, and LL took part in revising the manuscript and have approved the final version of the manuscript.

Conflicts of Interest

FL and JR hold positions at Karolinska Institutet and the nonprofit foundation 29k, which developed the app and its content. Neither FL nor JR participated in data analysis, and 29k had no role in study design decisions or interpretation of results.

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Multimedia Appendix 1
CONSORT-eHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 2921 KB - pediatrics_v9i1e71367_app1.pdf]

Multimedia Appendix 2
Film clips to the control group.
[DOCX File , 15 KB - pediatrics_v9i1e71367_app2.docx]

Multimedia Appendix 3
Self reported health of participants at baseline.
[DOCX File , 22 KB - pediatrics_v9i1e71367_app3.docx]

Multimedia Appendix 4
Intervention group characteristics in relation to completion of modules in the app.
[DOCX File , 22 KB - pediatrics_v9i1e71367_app4.docx]

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Abbreviations

ACT: acceptance and commitment therapy
ADHD: attention-deficit/hyperactivity disorder
CONSORT-EHEALTH: Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth
GAD-7: Generalized Anxiety Disorder 7-item scale
GLM: general linear model
ITT: intention to treat
NEET: not in employment, education, or training
OECD: Organisation for Economic Co-operation and Development
PHQ-9: Patient Health Questionnaire-9
PP: per protocol
PSS-10: Perceived Stress Scale with 10 items

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RCT: randomized controlled trial
REDCap: Research Electronic Data Capture
WHO-5: World Health Organization-Five Well-Being Index

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Original Paper

Development and Internal Validation of an Interpretable Machine Learning Model for Identifying Past-Year Nonsuicidal Self-Injury Among Adolescents With Depression: Retrospective Study

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Abstract

Background: Nonsuicidal self-injury (NSSI) is common among adolescents with depressive disorders and is associated with substantial clinical burden. Machine learning may assist in identifying multidimensional patterns associated with NSSI, although its incremental value beyond direct clinical assessment remains uncertain.

Objective: This study compares 7 supervised machine learning model variants for classifying past-year NSSI status among adolescents with depressive disorders and conducts detailed analyses of interpretability, sensitivity, subgroup performance, and clinical utility using a random forest model as the focal exploratory model.

Methods: We retrospectively identified 437 adolescents aged 10-19 years who received inpatient or outpatient psychiatric care at 4 hospitals in Zhejiang Province, China, between January 2021 and December 2023. A total of 410 eligible participants were included, of whom 274 reported NSSI during the preceding year. The primary analysis included 67 assessment-time sociodemographic, physiological, biochemical, and clinical-behavioral features. The sample was divided into a training set (287/410, 70%) and an untouched held-out test set (123/410, 30%) using stratified random sampling. Hyperparameters were optimized using 5-fold cross-validation within the training set. Performance was evaluated using discrimination, classification metrics, calibration, and decision-curve analysis. Random forest model behavior was examined using Gini importance, permutation importance, and Shapley Additive Explanations (SHAP).

Results: The radial basis function support vector machine achieved the highest mean cross-validated area under the receiver operating characteristic curve (AUROC) in the training set (0.720), whereas the random forest showed the highest observed AUROC and area under the precision-recall curve (AUPRC) and the lowest Brier score in the held-out test set. The random forest achieved an AUROC of 0.681 (95% CI 0.583-0.778), an AUPRC of 0.808 (95% CI 0.741-0.874), an accuracy of 0.667 (95% CI 0.585-0.748), a sensitivity of 0.720 (95% CI 0.622-0.817), a specificity of 0.561 (95% CI 0.415-0.707), and a Brier score of 0.212 (95% CI 0.188-0.236). Its calibration slope was 1.013. Pairwise AUROC differences between the random forest and alternative models were not statistically significant after Holm correction (Holm-adjusted *P* values ranged from .17 to .81). The full random forest model did not outperform a suicidal-ideation-only model (AUROC 0.701), whereas excluding suicidal ideation and previous suicide attempt reduced the AUROC to 0.540. A biochemical-only model showed near-chance discrimination (AUROC 0.513). Decision-curve analysis indicated that the random forest provided greater net benefit than the assess-all and assess-none strategies

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across threshold probabilities of approximately 0.51-0.80. Suicidal ideation showed the most consistent importance across Gini, SHAP, and permutation analyses.

Conclusions: The random forest had the highest observed AUROC and AUPRC and the lowest Brier score in the held-out test set among the evaluated algorithms, although the pairwise AUROC differences were not statistically significant after correction for multiple comparisons. Suicidality-related information contributed substantially to model discrimination, whereas routinely collected biochemical variables did not demonstrate clear incremental value. Because this was a retrospective cross-sectional classification study, the findings do not establish prospective risk prediction. External and prospective temporal validation is required before clinical implementation.

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KEYWORDS

nonsuicidal self-injury; depressive disorders; adolescents; machine learning; biopsychosocial approach

Introduction

Depressive disorders are among the most common mental health conditions during adolescence and are associated with substantial impairments in emotional well-being, academic functioning, interpersonal relationships, and daily life [1]. Adolescents with depressive disorders are also particularly vulnerable to nonsuicidal self-injury (NSSI), defined as the deliberate and direct injury of body tissue without suicidal intent [2]. Meta-analytic and epidemiological studies suggest that NSSI affects a substantial proportion of adolescents, with prevalence estimates generally higher in psychiatric and depressive-disorder samples than in community populations [3-6]. Although NSSI is conceptually distinguished from suicidal behavior by the absence of an intention to die, it is associated with greater psychiatric severity, repeated self-harm, suicidal thoughts and behaviors, and increased demand for mental health care [7-9]. Consequently, accurate identification and comprehensive assessment of recent NSSI among adolescents with depressive disorders represent important clinical priorities.

The clinical assessment of NSSI remains challenging because self-injurious behavior is heterogeneous and may vary in frequency, methods, functions, medical severity, and persistence [6,10,11]. Adolescents may also conceal NSSI because of shame, fear of stigma, concerns about confidentiality, or uncertainty about how parents and clinicians will respond [12,13]. Direct inquiry regarding NSSI and suicidal thoughts therefore remains essential. However, multidimensional clinical information may help clinicians identify patterns associated with recent NSSI and determine which patients require a more comprehensive, structured assessment [2,12]. Importantly, models based on concurrently or retrospectively measured variables can classify current or previous NSSI status, but they cannot establish temporal precedence or predict future NSSI onset unless they are evaluated prospectively using longitudinal data [14-18].

NSSI is understood as a complex behavior arising from interactions among psychological distress, behavioral vulnerability, interpersonal experiences, family context, and biological or physiological characteristics [19,20]. Established clinical correlates include younger age, female sex, greater depressive severity, emotional dysregulation, suicidal ideation, previous suicide attempts, and other forms of self-directed or interpersonal aggression [6,9,21,22]. Family-level factors are also particularly relevant during adolescence. Parental psychopathology, family conflict, adverse childhood experiences, limited perceived parental support, maladaptive parenting practices, and difficulties in parent-adolescent communication have all been associated with adolescent NSSI [23-25]. These factors may operate as vulnerabilities, protective resources, or moderators of the relationship between emotional distress and self-injurious behavior.

Physiological and biochemical characteristics have also been explored in relation to depression and self-injurious behavior, including inflammatory markers, thyroid function, metabolic indicators, liver and renal function, and neuroendocrine measures [26,27]. Such routinely collected variables may contain information that is not fully captured by symptom-based assessments and may contribute to nonlinear or interactive model structures [28]. Nevertheless, evidence that individual laboratory markers provide clinically meaningful information beyond established clinical variables remains inconsistent [18]. Laboratory measurements may reflect current depressive severity, medication exposure, nutritional status, physical activity, comorbid conditions, or consequences of recent behavior rather than antecedent mechanisms of NSSI. Accordingly, biochemical variables identified by a cross-sectional model should be regarded as potential model correlates and hypothesis-generating findings rather than independent causal biomarkers [18,19].

Despite the relevance of family context, family-level information is frequently underrepresented in routinely collected electronic medical records. Variables such as family psychiatric history or household residence may be available, whereas standardized assessments of parental mental health, family conflict, parenting practices, perceived support, parent-adolescent communication, and adverse childhood experiences are often absent. This limitation is particularly important in pediatric settings, where parents or caregivers are not only sources of clinical information but also potential partners in safety planning, treatment engagement, and relapse prevention [29]. At the same time, communicating model-derived findings to parents requires careful attention to adolescent autonomy, confidentiality, uncertainty, and the risk of stigmatizing labels [12,30]. Parent-facing information should therefore be accessible, probabilistic, and nondeterministic, and should be communicated within a clinician-mediated assessment rather than through automated alerts or isolated risk scores.

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Machine learning has increasingly been applied to the study of NSSI and related self-harm outcomes using questionnaire data, clinical records, behavioral information, digital phenotyping, neuroimaging, and biological measures [31-34]. Compared with conventional regression approaches, some machine learning algorithms can accommodate complex nonlinear relationships and higher-order interactions [28,35]. Random forests are particularly suitable for modeling heterogeneous clinical data and allow complementary examination through impurity-based importance, permutation importance, and Shapley Additive Explanations (SHAP) [36]. However, algorithmic complexity does not necessarily ensure clinical usefulness. Most published NSSI models have been internally evaluated in cross-sectional or geographically restricted samples, whereas fewer studies have examined future NSSI occurrence using longitudinal designs [17,18,31-33]. Additional limitations include small event-to-feature ratios, inadequate control of information leakage, insufficient reporting of hyperparameter optimization and missing-data procedures, limited assessment of calibration, absence of external validation, and failure to compare complex models with simple clinical screens [30,35].

Model interpretability is particularly important when machine learning is applied in mental health care [30]. SHAP can quantify the contribution of a feature to an individual model output and summarize the magnitude and direction of contributions across a sample [36]. Nevertheless, SHA*P* values explain the predictions of a fitted model rather than the underlying causal process. A high SHAP or Gini ranking does not demonstrate that a feature is independently associated with NSSI, nor does it establish that changing the feature would alter clinical outcomes. Interpretation should therefore be supported by calibration, sensitivity analyses, subgroup performance, comparisons with simpler models, and alternative importance measures such as test-set permutation importance [30,36].

Accordingly, this retrospective multicenter cross-sectional study aimed to compare 7 supervised machine learning model variants for classifying past-year NSSI status among adolescents with depressive disorders using routinely collected sociodemographic, physiological-biochemical, and clinical-behavioral information. We evaluated discrimination, classification performance, calibration, and clinical net benefit in an untouched, held-out test set. As suicidal ideation is both a strong clinical correlate of NSSI and an immediate assessment priority, we examined whether the multidimensional models provided incremental information beyond suicidal ideation and other basic clinical variables. We also evaluated performance after excluding suicidality-related variables and examined sex- and residence-specific performance. The random forest was used as the focal exploratory model for detailed analyses of Gini, permutation importance, and SHAP. Finally, we considered the limited availability of family-context variables and the implications of model-assisted assessment for future parent- and adolescent-involved clinical communication. Given the concurrent and retrospective measurement of the candidate features and outcome, this study was designed to evaluate internal classification rather than prospective prediction of future NSSI.

Methods

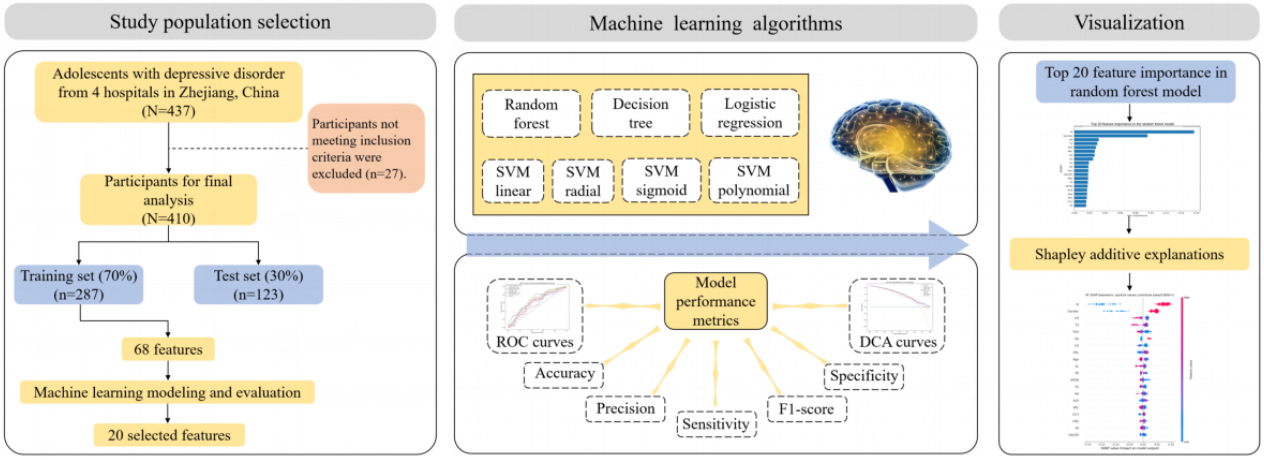
Study Design and Participants

This retrospective multicenter cross-sectional study screened the electronic medical records of adolescents aged 10-19 years with depressive disorders who received inpatient or outpatient psychiatric care at 4 hospitals in Zhejiang Province, China, between January 2021 and December 2023. The study was designed to classify past-year NSSI status rather than to predict the future onset or recurrence of NSSI. Participants were retrospectively identified through systematic screening of electronic medical records and screened for eligibility. The inclusion criteria were as follows: (1) age between 10 and 19 years; (2) a clinical diagnosis of depressive disorder according to the International Classification of Diseases, 10th Revision (ICD-10); and (3) availability of the clinical assessment and laboratory information required for this analysis. The exclusion criteria were as follows: (1) bipolar disorder, schizophrenia-spectrum disorder, or another severe psychiatric disorder; (2) intellectual disability or cognitive impairment that could prevent a reliable clinical assessment; (3) severe or unstable physical illness or a chronic medical condition likely to substantially affect physiological or biochemical measurements; and (4) substance use disorder.

After the initial screening of the electronic medical records, 2 senior psychiatrists independently evaluated participant eligibility. Disagreements were reviewed with a third psychiatrist and resolved through discussion. A total of 437 records were screened, of which 27 were excluded because of severe psychiatric disorders (n=12), intellectual disability or cognitive impairment (n=2), severe or unstable physical illness (n=5), or substance use disorder (n=8). The remaining 410 participants were included in the final analytic sample. The participant-selection and modeling procedures are presented in Figure 1. Missing data within the included dataset were addressed using multiple imputation.

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Figure 1. Study flowchart. AA: amylase; ALP: alkaline phosphatase; APOB: apolipoprotein B; CC3: complement component C3; CK: creatine kinase; CR: creatinine; DCA: decision curve analysis; FA: free fatty acid; FBG: fasting blood glucose; HSCRP: high-sensitivity C-reactive protein; IBIL: indirect bilirubin; PRL: prolactin; PS: previous suicide attempt; RF: random forest; ROC: receiver operating characteristic; SA: suicide attempt; SHAP: Shapley Additive Explanations; SI: self-injury; SL: aspartate aminotransferase-to-alanine aminotransferase ratio; SVM: support vector machine; T3: total triiodothyronine; T4: total thyroxine; TG: triglyceride; TSH: thyroid-stimulating hormone.



Ethics Approval

The Ethics Committee of Kangning Hospital, affiliated with Wenzhou Medical University, approved the study (ethical approval number KNLL-20211011002). The study was performed in strict accordance with the ethical principles of the Declaration of Helsinki (1975).

Data Collection

Outcome Variable

Past-year NSSI status was assessed during clinical interviews conducted independently by 2 senior psychiatrists. Participants were asked, "During the past year, have you intentionally injured yourself without intending to die, for example, by cutting, scratching, burning your skin, or hitting yourself?" Responses were recorded as "yes" or "no," with NSSI coded as 1 and non-NSSI coded as 0. Any disagreement between the 2 psychiatrists was reviewed by a third psychiatrist and resolved by consensus.

The binary outcome represented the presence or absence of broadly defined NSSI during the preceding 12 months. It did not constitute a diagnosis of NSSI disorder or capture NSSI frequency, persistence, methods, medical severity, functions, or associated impairment.

Candidate Features

Overview

Candidate features were identified through expert consultation and a review of the relevant literature. The processed dataset contained 71 candidate feature columns. Three fields that were not consistently defined in the original manuscript or source coding—SS, number of hospitalizations, and creatine kinase muscle-brain isoenzyme—were excluded from the manuscript-matched feature set. Completed length of stay was excluded from the primary model because it was not available at the index assessment and could have been affected by subsequent clinical management. The primary assessment-time model therefore contained 67 candidate features, grouped into sociodemographic and lifestyle features, family and social-context features, physiological and biochemical features, and clinical and behavioral features. The complete feature list is provided in Table S1 in Multimedia Appendix 1.

Sociodemographic and Lifestyle Features

Sociodemographic and lifestyle information was systematically collected during routine psychiatric consultations. The variables included sex, age, education level, BMI (kg/m^2), place of residence, smoking status, drinking status, family psychiatric history, and religious belief.

Family and Social-Context Features

The family and contextual variables available in the routinely collected electronic medical records were family psychiatric history and place of residence. Family psychiatric history indicated whether a psychiatric disorder had been documented among family members. Place of residence was classified according to the urban-rural coding used in the source records and was considered a contextual indicator rather than a direct measure of family functioning.

Standardized assessments of parental psychopathology, family conflict, perceived parental support, parent-adolescent communication, parenting style, and adverse childhood experiences were not systematically collected across the 4 participating hospitals and were therefore unavailable for model development.

Physiological and Biochemical Features

Blood samples were collected from the antecubital vein by trained nursing staff after overnight fasting (≥8 hours) between 7 and 9 AM upon hospital admission, ensuring standardized preanalytical conditions. Blood coagulation function was assessed by measuring D-dimer using a latex-enhanced immunoturbidimetric assay (Sysmex CS-5100). Thyroid function was evaluated by measuring thyroid peroxidase antibodies, thyroid-stimulating hormone (TSH), free

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triiodothyronine, free thyroxine, total triiodothyronine (T3), and total thyroxine (T4) using a chemiluminescence immunoassay (Siemens ADVIA Centaur XP). Liver function was assessed by measuring alanine aminotransferase, aspartate aminotransferase, the aspartate aminotransferase-to-alanine aminotransferase ratio, total protein, albumin, globulin, albumin-to-globulin ratio, alkaline phosphatase, gamma-glutamyl transferase, total bilirubin, total bile acid, direct bilirubin, and indirect bilirubin using automated enzymatic methods (cobas c702; Roche). Serum prealbumin was determined using an immunonephelometric assay (Siemens BN ProSpec), while alpha-L-fucosidase was quantified using a spectrophotometric assay (Hitachi 7600). Markers of glucose and lipid metabolism, including fasting blood glucose, triglycerides, total cholesterol, high-density lipoprotein, low-density lipoprotein, apolipoprotein A, apolipoprotein B, lipoprotein a, and free fatty acids, were assessed using an enzymatic colorimetric assay (cobas c702).

Renal function was evaluated by measuring blood urea nitrogen, creatinine, and uric acid using an enzymatic method (cobas c702). Myocardial and muscle enzyme activities, including creatine kinase, creatine kinase isoenzymes (muscle-brain isoenzyme), and lactate dehydrogenase, were analyzed using an enzymatic assay (cobas c702). Plasma homocysteine levels were measured using an enzymatic cycling assay (cobas c702). Electrolyte balance was assessed by measuring potassium, sodium, chloride, calcium, magnesium, and phosphorus levels using an ion-selective electrode method (cobas c702).

Biochemical markers included serum ferritin, measured using an immunoturbidimetric assay (cobas c702), and cholinesterase, assessed using a butyrylthiocholine substrate method (cobas c702). Inflammatory response was evaluated by measuring high-sensitivity C-reactive protein using a latex-enhanced immunoturbidimetric assay (cobas c702). Complement system activity was assessed by measuring complement component C3 and complement component C4 using an immunonephelometric assay (Siemens BN ProSpec). Lastly, amylase was analyzed using an enzymatic assay (cobas c702), and the prolactin level was determined using a chemiluminescent immunometric assay (Siemens ADVIA Centaur XP).

Clinical and Behavioral Features

Data on length of hospital stay (days), disease course (months), and first episode were obtained from electronic medical records. The depression grade and psychotic symptoms were systematically assessed through structured clinical interviews conducted by trained psychiatrists. The depression grade was classified as mild, moderate, or severe according to ICD-10 criteria based on clinical assessments of symptom intensity, functional impairment, and distress levels. Psychotic symptoms were evaluated based on DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition) diagnostic criteria, with patients systematically assessed for depressive hallucinations and depressive delusions, and symptoms recorded as either present or absent. Suicidal ideation was assessed according to DSM-5 criteria, with patients asked, “In the past month, have you seriously considered ending your life?” Suicide attempt history was assessed using the question, “Have you ever made an actual suicide attempt in your lifetime (eg, overdosing or cutting your wrists with suicidal intent)?” Participants were asked to respond “Yes” or “No.” Aggressive behaviors were documented through both direct clinical observation and structured interviews with caregivers and patients. Verbal aggression was assessed using a single question: “Has the patient recently exhibited hostile, insulting, or aggressive language toward others?” Physical aggression was assessed using the question: “Has the patient exhibited any aggressive physical behavior (eg, hitting, pushing, or fighting) in the past month?” Participants were asked to respond “Yes” or “No.”

Patient and Parent Involvement

Adolescents and parents or caregivers were not involved in the original study design, candidate-feature selection, model development, interpretation of the findings, or preparation of the manuscript. Written informed consent was obtained from participants and their legal guardians as part of the ethical procedures but did not constitute patient or parent involvement in research co-design.

Future prospective implementation studies should involve adolescents, parents or caregivers, and clinicians in determining how model outputs, uncertainty, privacy, and the distinction between NSSI and suicidal intent should be communicated. Any parent-facing use of model-derived information should occur within a clinician-mediated assessment rather than through an automated alert or an isolated risk score.

Statistical Analysis

Descriptive Analysis and Data-Quality Assessment

The revised statistical and machine learning analyses were conducted in Python (Python Foundation) using pandas, NumPy, SciPy, statsmodels, scikit-learn, imbalanced-learn, and SHAP. All statistical tests were 2-sided, and a P value of <.05 was considered statistically significant.

Continuous variables were summarized using medians and IQRs and compared between the NSSI and non-NSSI groups using 2-sided Mann-Whitney U tests. Categorical variables were summarized using counts and percentages. Pearson chi-square tests were used for categorical comparisons, except for 2×2 tables with expected cell counts below 5, for which Fisher exact tests were used. These univariable comparisons were descriptive and were not used to screen or select features for model development.

Automated range checks and category-level audits were conducted before model fitting. Potentially implausible numerical values and unexpected category codes were flagged for verification against the source records. No values were corrected automatically. Any correction was required to be supported by the source record and documented in an auditable correction file before the complete analysis was rerun.

Sample-Size Considerations

All eligible records available during the predefined study period were included; therefore, no prospective sample-size calculation was performed. The primary model contained 67 candidate

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variables and generated 88 model inputs after one-hot encoding. The analytic sample included 274 participants with NSSI and 136 without NSSI, corresponding to 4.09 NSSI cases and 2.03 non-NSSI cases per candidate variable. After one-hot encoding, there were 3.11 NSSI cases and 1.55 non-NSSI cases per model input. These ratios indicated a substantial risk of overfitting and model-selection instability; therefore, the modeling analyses were considered exploratory.

Model Development

The 410 participants were divided by stratified random sampling into a training set (287/410, 70%) and a held-out test set (123/410, 30%), using a random seed of 46. The training set contained 287 participants, including 192 with NSSI and 95 without NSSI. The held-out test set contained 123 participants, including 82 with NSSI and 41 without NSSI. The test set was not used for preprocessing estimation, hyperparameter tuning, resampling, or model fitting. The synthetic minority over-sampling technique was applied to address class imbalance and enhance the representation of the minority class [37].

Categorical features were imputed within the modeling pipeline using the most frequent category and subsequently one-hot encoded. Continuous variables were imputed using the median within the pipeline. Continuous features were standardized for logistic regression and support vector machine models using parameters estimated only from the corresponding training data or cross-validation fold. Continuous features were not standardized for decision tree or random forest models. All preprocessing procedures were incorporated into the model pipelines to prevent information leakage.

Seven prespecified supervised machine learning model variants were evaluated: logistic regression, decision tree, random forest, and support vector machines with linear, radial basis function, polynomial, and sigmoid kernels. Class weights were balanced in the primary analysis to address the unequal frequencies of NSSI and non-NSSI. Synthetic oversampling was not applied before the training-test split or to the held-out test set.

Hyperparameters were optimized using randomized search with stratified 5-fold cross-validation exclusively within the training set. Area under the receiver operating characteristic curve (AUROC) was used as the optimization metric. Up to 30 hyperparameter configurations were sampled for each model; when a search space contained fewer than 30 possible combinations, all possible combinations were evaluated.

The selected random forest configuration used 1500 trees, a maximum tree depth of 15, a minimum of 5 observations required to split an internal node, a minimum of 12 observations per terminal leaf, 44 of the 88 (50%) available model inputs considered at each split, the Gini impurity criterion, bootstrap sampling, and balanced class weights.

The SVM with a radial basis function kernel achieved the highest mean AUROC during training-set cross-validation. After all 7 optimized models were evaluated on the held-out test set, the random forest showed the highest observed test-set AUROC and area under the precision-recall curve (AUPRC) and the lowest observed Brier score. The random forest was therefore designated post hoc as the focal exploratory model for detailed calibration, decision-curve, subgroup, sensitivity, and interpretability analyses. This focal designation did not imply statistically significant superiority over the alternative models.

Model Performance, Calibration, and Formal Comparison

Model discrimination was evaluated in the held-out test set using the area under the receiver operating characteristic curve and the area under the precision-recall curve. At the prespecified probability threshold of 0.50, accuracy, sensitivity, specificity, positive predictive value, negative predictive value, and F_1-score were calculated. NSSI was defined as the positive class.

The 95% CIs for AUROC, AUPRC, accuracy, sensitivity, specificity, positive predictive value, negative predictive value, F_1-score, and Brier score were estimated using 2000 stratified bootstrap resamples of the held-out test set.

Calibration was evaluated using the Brier score, calibration intercept, calibration slope, and calibration plots based on quantile-grouped predicted probabilities. Ideal calibration was represented by a calibration intercept of 0 and a calibration slope of 1.

The random forest was compared with each of the other 6 model variants using paired DeLong tests based on predictions from the same held-out test participants. Holm correction was applied to account for multiple pairwise comparisons. Model rankings based solely on observed test-set AUROCs were not interpreted as evidence of superiority when the adjusted comparisons were not statistically significant.

Clinical utility was assessed through decision curve analysis to quantify the net clinical benefit of model-based decision-making relative to other strategies (eg, treating all or treating none) across a range of threshold probabilities [38]. Feature importance was assessed using mean decrease in Gini impurity, an impurity-based measure commonly used to quantify variable importance in random forest models [39]. Additionally, SHAP was used to enhance model interpretability by quantifying the contribution of individual features to model predictions [36]. The SHAP approach offers both global and individual-level explanations, improving the transparency of the model and facilitating interpretation in clinical applications.

Decision curve analysis was performed over threshold probabilities from 0.01 to 0.80 to quantify net benefit relative to strategies of assessing all participants and assessing no participants. The modeled clinical action was referral for a more comprehensive, structured assessment of NSSI rather than automatic diagnosis, hospitalization, or treatment.

RF-Focused Incremental-Value and Sensitivity Analyses

A series of RF-focused analyses was conducted to examine the incremental contribution of different feature domains and the potential dominance of suicidality-related variables. These analyses included an RF model using suicidal ideation alone; an RF model using suicidal ideation and previous suicide attempt; a basic clinical RF model; a clinical-only RF model; a biochemical-only RF model; an RF model using only the

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available family and contextual variables; a full RF model excluding suicidal ideation and previous suicide attempt; a full RF model excluding sex; a full RF model excluding residence; a full RF model excluding family psychiatric history and residence; and a full RF model including completed length of stay.

Logistic regression models using suicidal ideation alone and suicidal ideation together with previous suicide attempt were additionally fitted as simple clinical benchmarks. For the RF ablation analyses, the RF hyperparameters were fixed at the values selected for the full RF model and were not retuned separately for each reduced feature set.

The full RF model was formally compared with the reduced and benchmark models using paired DeLong tests, with Holm correction for multiple comparisons. These analyses were used to determine whether the multidimensional RF model provided incremental discrimination beyond the direct assessment of suicidal ideation and other basic clinical information.

As a class-imbalance sensitivity analysis, the RF was refitted using the Synthetic Minority Over-Sampling Technique for Nominal and Continuous (SMOTENC). SMOTENC was applied exclusively to the training data, with 5 nearest neighbors, and was never applied to the held-out test set. The RF hyperparameters were fixed at those selected in the primary training-set search.

Subgroup Analyses

RF performance was evaluated separately within the sex and residence subgroups represented in the held-out test set. Within each subgroup, AUROC, AUPRC, accuracy, sensitivity, specificity, positive predictive value, negative predictive value, F_1-score, Brier score, and corresponding bootstrap CIs were calculated when both outcome classes were present.

The subgroup analyses were exploratory and were not used to select separate subgroup-specific models or classification thresholds. Hospital-specific performance and leave-one-hospital-out validation could not be evaluated because the processed analytic dataset did not contain a hospital-site identifier.

RF Model Interpretation

The focal RF model was interpreted using 3 complementary approaches: Gini impurity–based feature importance, test-set permutation importance, and SHAP. Gini importance was aggregated from one-hot-encoded inputs to the corresponding original variables.

Permutation importance was calculated in the held-out test set using AUROC as the scoring measure and 100 repeated permutations per feature. A positive value represented a reduction in test-set AUROC after a feature was permuted, whereas a value near or below 0 indicated a limited or unstable contribution to held-out discrimination.

SHA*P* values were calculated using TreeExplainer and observations from the held-out test set. SHA*P* values were aggregated from encoded inputs to their original variables. Mean absolute SHA*P* values were used to summarize feature importance magnitude. Beeswarm plots were used to display the direction and distribution of feature contributions, with positive SHA*P* values indicating contributions toward the NSSI class. Dependence plots were generated for high-ranking continuous features to examine possible nonlinear and threshold-like patterns.

The agreement between Gini and mean absolute SHAP rankings was assessed using Spearman rank correlation. Gini, SHAP, and permutation importance were compared to identify variables with relatively consistent importance across methods. Model-specific feature importance and SHA*P* values were interpreted as descriptions of fitted-model behavior and not as evidence of independent association, causality, temporal precedence, or treatment targets.

All 67 candidate features remained in the full RF model. The 20 variables displayed in the Gini and SHAP figures represented only the 20 highest-ranked variables for visual clarity and did not constitute a separately selected 20-feature model.

Results

Participant Characteristics

A total of 437 electronic medical records were screened. After application of the eligibility criteria, 27 records were excluded, leaving 410 adolescents with depressive disorders in the final analytic sample. Of these participants, 274 (66.8%) reported NSSI during the preceding 12 months and 136 (33.2%) did not. Stratified random sampling allocated 287 participants to the training set, including 192 with NSSI and 95 without NSSI, and 123 participants to the untouched held-out test set, including 82 with NSSI and 41 without NSSI.

The processed analytic dataset contained no missing values, and all 410 participants were included in the complete-case analysis. The primary assessment-time model contained 67 candidate variables and generated 88 model inputs after one-hot encoding. This corresponded to 4.09 NSSI cases and 2.03 non-NSSI cases per candidate variable, and 3.11 NSSI cases and 1.55 non-NSSI cases per encoded model input.

The median age of the overall sample was 15 (IQR 13-16) years, and 320 of the 410 (78.1%) participants were female. Participants with NSSI were younger than those without NSSI (median 14 years, IQR 13-16 years vs median 15 years, IQR 14-16 years; $P<.001$). The proportion of female participants was also higher in the NSSI group than in the non-NSSI group (232/274, 84.7% vs 88/136, 64.7%; $P<.001$). Education-level distribution differed between the groups ($P=.008$). Smoking was uncommon but was reported by 11 participants in the NSSI group and none in the non-NSSI group (11/274, 4% vs 0/136, 0%; $P=.02$). No statistically significant between-group differences were observed for BMI ($P=.72$), place of residence ($P=.36$), drinking status ($P=.06$), family psychiatric history ($P=.84$), or religious belief ($P=.21$). Other sociodemographic characteristics are presented in Table 1.

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Table 1. Comparison of characteristics of depressed adolescents between the NSSI[a] group and the non-NSSI group (n=410).

Sociodemographic variables	Total sample	NSSI		*P* value
		No (n=136)	Yes (n=274)	
Gender, n (%)				*<.001* [b]
Male	90 (22.0)	48 (53.3)	42 (46.7)	
Female	320 (78.0)	88 (27.5)	232 (72.5)	
Age (years), median (IQR)	15 (13-16)	15 (14-16)	14 (13-16)	*<.001*
Education level, n (%)				*.006*
Primary school or below	27 (6.6)	4 (14.8)	23 (85.2)	
Junior middle school	232 (56.6)	69 (29.7)	163 (70.3)	
Senior high school	151 (36.8)	63 (41.7)	88 (58.3)	
BMI (kg/m^2), median (IQR)	20.37 (18.49-22.85)	20.34 (18.74-22.86)	20.38 (18.41-22.83)	.72
Residence, n (%)				.36
Urban	228 (55.6)	80 (35.1)	148 (64.9)	
Rural	182 (44.4)	56 (30.8)	126 (69.2)	
Smoking, n (%)				*.02*
Yes	11 (2.7)	0 (0.0)	11 (100.0)	
No	399 (97.3)	136 (34.1)	263 (65.9)	
Drinking, n (%)				.06
Yes	7 (1.7)	0 (0.0)	7 (100.0)	
No	403 (98.3)	136 (33.7)	267 (66.3)	
Family psychiatric history, n (%)				.84
Yes	14 (3.4)	5 (35.7)	9 (64.3)	
No	396 (96.6)	131 (33.1)	265 (66.9)	
Religious belief, n (%)				.21
Yes	35 (8.5)	15 (42.9)	20 (57.1)	
No	375 (91.5)	121 (32.3)	254 (67.7)	

[a]NSSI: nonsuicidal self-injury.

[b]Italicized values are statistically significant (*P*<.05).

Physiological and biochemical characteristics are presented in Table 2. Among the continuous physiological and biochemical variables, participants with NSSI had lower creatinine concentrations than those without NSSI (median 59 µmol/L, IQR 52-65 µmol/L vs median 63 µmol/L, IQR 54-72 µmol/L; *P*=.001), lower creatine kinase concentrations (median 64.5 U/L, IQR 51-82 U/L vs median 76 U/L, IQR 55-94.8 U/L; *P*=.005), and lower fructosamine concentrations (median 1.97 mmol/L, IQR 1.86-2.11 mmol/L vs median 2.04 mmol/L, IQR 1.92-2.17 mmol/L; *P*=.009). No other continuous variable showed a statistically significant between-group difference. In particular, high-sensitivity C-reactive protein did not differ significantly between the NSSI and non-NSSI groups (*P*=.19). These univariable comparisons were descriptive and were not used for feature selection or model development.

Clinical and behavioral characteristics according to past-year NSSI status are summarized in Table 3. Suicidal ideation and previous suicide attempt showed different distributions between participants with and without past-year NSSI. Suicidal ideation was reported by 221 of 274 (80.7%) participants with NSSI and 66 of 136 (48.5%) participants without NSSI (*P*<.001). A previous suicide attempt was reported by 88 (32.1%) participants with NSSI and 20 (14.7%) participants without NSSI (*P*<.001). The distribution of psychotic-symptom categories differed between the groups (*P*=.04), whereas depression-severity categories did not (*P*=.52). First-episode status (*P*=.11), illness duration (*P*=.08), verbal aggression (*P*=.26), and physical aggression (*P*=.62) also did not differ significantly between the groups.

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Table 2. Physiological and biochemical characteristics according to past-year NSSI[a] status.

Physiological and biochemical variables	Total sample, median (IQR)	NSSI		*P* value
		No (n=136), median (IQR)	Yes (n=274), median (IQR)	
D-dimer (μg/mL)	0.22 (0.16-0.3)	0.22 (0.16-0.283)	0.22 (0.16-0.31)	.86
Thyroid peroxidase antibody (kU/L)	11 (8.47-16)	11.4 (8.54-16.2)	11 (8.41-15.8)	.51
Thyroid-stimulating hormone (μIU/mL)	1.46 (1.02-2.1)	1.52 (1.04-2.21)	1.43 (1.02-2.08)	.49
Free triiodothyronine (pmol/L)	5.19 (4.67-5.64)	5.21 (4.68-5.63)	5.16 (4.66-5.66)	.96
Free thyroxine (pmol/L)	16.4 (14.7-18.1)	16.6 (14.6-18.8)	16.3 (14.7-17.9)	.19
Total triiodothyronine (nmol/L)	1.83 (1.6-2.06)	1.83 (1.56-2.1)	1.83 (1.61-2.05)	.97
Total thyroxine (nmol/L)	94 (82.4-105)	93.9 (82.1-105)	94.2 (82.8-105)	.82
Alanine aminotransferase (U/L)	9 (7-14)	9 (7-14)	9 (7-14)	.97
Aspartate aminotransferase (U/L)	14 (12-17)	14.5 (12.8-17)	14 (12-17)	.91
Aspartate aminotransferase-to-alanine aminotransferase ratio	1.6 (1.2-1.9)	1.6 (1.2-2)	1.6 (1.12-1.9)	.95
Total protein (g/L)	67.7 (64.7-71.2)	68.5 (64.9-72.2)	67.3 (64.7-70.8)	.16
Albumin (g/L)	44.1 (42.3-46.2)	44.3 (42.6-47)	44 (42.2-45.8)	.12
Globulin (g/L)	23.5 (21.7-25.9)	23.7 (21.9-26.1)	23.5 (21.6-25.7)	.31
Albumin-to-globulin ratio	1.88 (1.7-2.06)	1.89 (1.71-2.03)	1.88 (1.7-2.07)	.93
Prealbumin (mg/L)	231 (205-268)	232 (204-272)	230 (205-263)	.45
Total bilirubin (μmol/L)	7.35 (5.1-11)	8 (5.6-11.9)	7.2 (5-10.5)	.07
Direct bilirubin (μmol/L)	3 (2.23-4.1)	3.2 (2.38-4.33)	2.9 (2.2-3.9)	.08
Indirect bilirubin (μmol/L)	4.35 (2.9-6.67)	4.8 (3.27-7.67)	4.15 (2.8-6.4)	.07
Alkaline phosphatase (U/L)	99 (79-135)	95.5 (78.8-134)	102 (79-136)	.35
Gamma-glutamyl transferase (U/L)	12 (9-16)	12 (10-16)	12 (9-16)	.25
Alpha-L-fucosidase (U/L)	17.2 (14.1-20.6)	17.5 (14.1-21.1)	17.1 (14.2-20)	.56
Fasting blood glucose (mmol/L)	4.71 (4.46-4.95)	4.71 (4.46-4.96)	4.71 (4.46-4.94)	.79
Total bile acid (μmol/L)	3 (1.8-5.17)	3.4 (2-5.9)	2.8 (1.8-4.7)	.06
Fructosamine (mmol/L)	1.98 (1.87-2.13)	2.04 (1.92-2.17)	1.97 (1.86-2.11)	*.009* [b]
Blood urea nitrogen (mmol/L)	3.9 (3.3-4.7)	4 (3.38-4.83)	3.9 (3.2-4.6)	.15
Creatinine (μmol/L)	60 (53-67)	63 (54-72)	59 (52-65)	*.001*
Uric acid (μmol/L)	302 (255-358)	306 (262-374)	302 (253-348)	.23
Triglycerides (mmol/L)	0.96 (0.74-1.27)	0.99 (0.75-1.36)	0.94 (0.725-1.22)	.30
Total cholesterol (mmol/L)	3.93 (3.46-4.39)	3.97 (3.45-4.47)	3.91 (3.47-4.38)	.72
High-density lipoprotein cholesterol (mmol/L)	1.19 (1.06-1.37)	1.17 (1.05-1.36)	1.19 (1.07-1.37)	.48
Low-density lipoprotein cholesterol (mmol/L)	2.3 (1.94-2.73)	2.3 (1.94-2.73)	2.29 (1.94-2.73)	.95
Apolipoprotein A (g/L)	1.28 (1.14-1.47)	1.27 (1.14-1.47)	1.28 (1.14-1.46)	.76
Apolipoprotein B (g/L)	0.73 (0.63-0.87)	0.755 (0.65-0.885)	0.72 (0.62-0.867)	.13
Lipoprotein(a) (mg/L)	85.9 (43.1-244)	74.7 (36-253)	90.2 (46-226)	.37
Creatine kinase (U/L)	66.5 (53-88)	76 (55-94.8)	64.5 (51-82)	*.005*
Lactate dehydrogenase (U/L)	155 (141-171)	158 (143-174)	154 (140-170)	.09
Homocysteine (μmol/L)	10 (8-13)	10 (8-14)	10 (8-13)	.14
Potassium (mmol/L)	4.01 (3.86-4.2)	4.04 (3.87-4.2)	4 (3.86-4.2)	.40
Sodium (mmol/L)	139 (138-141)	139 (138-141)	139 (138-141)	.68

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Physiological and biochemical variables	Total sample, median (IQR)	NSSI		*P* value
		No (n=136), median (IQR)	Yes (n=274), median (IQR)	
Chloride (mmol/L)	104 (103-106)	104 (103-106)	104 (103-105)	.60
Calcium (mmol/L)	2.31 (2.26-2.38)	2.31 (2.26-2.39)	2.31 (2.26-2.38)	.78
Magnesium (mmol/L)	0.87 (0.83-0.92)	0.88 (0.84-0.92)	0.87 (0.83-0.91)	.19
Phosphorus (mmol/L)	1.48 (1.37-1.6)	1.49 (1.37-1.61)	1.48 (1.38-1.59)	.59
Serum iron (μmol/L)	16.3 (11.7-21.2)	16.6 (12.4-21)	16.2 (11.5-21.2)	.46
High-sensitivity C-reactive protein (mg/L)	0.27 (0.16-0.6)	0.32 (0.177-0.535)	0.25 (0.15-0.66)	.19
Complement C3 (g/L)	0.92 (0.82-1.04)	0.92 (0.79-1.04)	0.92 (0.83-1.04)	.57
Complement C4 (g/L)	0.17 (0.14-0.21)	0.17 (0.14-0.21)	0.17 (0.13-0.22)	.74
Amylase (U/L)	61 (49-74)	62 (49-76.5)	61 (49-74)	.45
Prolactin (ng/mL)	25.8 (16.3-39)	23.2 (15.4-37)	26.9 (17.3-39.7)	.11

[a]NSSI: nonsuicidal self-injury.

[b]Italicized values are statistically significant (*P*<.05).

Table 3. Clinical and behavioral characteristics according to past-year NSSI[a] status.

Characteristic	Total sample (N=410)	Non-NSSI (n=136)	NSSI (n=274)	*P* value
Psychotic-symptom category, n (%)				.04
No psychotic symptoms	134 (32.7)	34 (25.0)	100 (36.5)	
Psychotic symptoms present	200 (48.8)	77 (56.6)	123 (44.9)	
Other/uncategorized category	76 (18.5)	25 (18.4)	51 (18.6)	
Depression-grade category, n (%)				.52
Other/uncategorized category	24 (5.9)	6 (4.4)	18 (6.6)	
Mild depression	3 (0.7)	2 (1.5)	1 (0.4)	
Moderate depression	31 (7.6)	10 (7.4)	21 (7.7)	
Severe depression	352 (85.9)	118 (86.8)	234 (85.4)	
Duration of illness (months), median (IQR)	12 (8-24)	12 (6-24)	12 (8.25-24)	.08
First episode, n (%)				.11
No	298 (72.7)	92 (67.6)	206 (75.2)	
Yes	112 (27.3)	44 (32.4)	68 (24.8)	
Suicidal ideation, n (%)				<.001
No	123 (30.0)	70 (51.5)	53 (19.3)	
Yes	287 (70.0)	66 (48.5)	221 (80.7)	
Previous suicide attempt, n (%)				<.001
No	302 (73.7)	116 (85.3)	186 (67.9)	
Yes	108 (26.3)	20 (14.7)	88 (32.1)	
Verbal aggression, n (%)				.26
No	357 (87.1)	122 (89.7)	235 (85.8)	
Yes	53 (12.9)	14 (10.3)	39 (14.2)	
Physical aggression, n (%)				.62
No	392 (95.6)	131 (96.3)	261 (95.3)	
Yes	18 (4.4)	5 (3.7)	13 (4.7)	

[a]NSSI: nonsuicidal self-injury.

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Model Development and Held-Out Test-Set Performance

In training-set cross-validation, the SVM with a radial basis function kernel achieved the highest mean AUROC (mean AUROC 0.720, SD 0.046). This was followed by logistic regression (mean AUROC 0.716, SD 0.049), SVM linear (mean AUROC 0.716, SD 0.025), decision tree (mean AUROC 0.709, SD 0.054), random forest (mean AUROC 0.703, SD 0.050), SVM sigmoid (mean AUROC 0.702, SD 0.062), and SVM polynomial (mean AUROC 0.680, SD 0.037). The relatively small differences in mean AUROC and overlapping cross-validation variability did not indicate clear separation in model performance during development. Detailed cross-validation results and optimized hyperparameters for all evaluated models are provided in Table S1 in Multimedia Appendix 1.

In the untouched held-out test set, the random forest had the highest observed AUROC and AUPRC among the 7 evaluated machine learning models (Table 4). Its AUROC was 0.681 (95% CI 0.583-0.778), and its AUPRC was 0.808 (95% CI 0.741-0.874). At the prespecified probability threshold of 0.50, the random forest had an accuracy of 0.667 (95% CI 0.585-0.748), sensitivity of 0.720 (95% CI 0.622-0.817), specificity of 0.561 (95% CI 0.415-0.707), positive predictive value of 0.766 (95% CI 0.703-0.835), negative predictive value of 0.500 (95% CI 0.395-0.622), and F_1-score of 0.742 (95% CI 0.671-0.810). The corresponding confusion matrix contained 59 true-positive, 23 false-negative, 23 true-negative, and 18 false-positive classifications.

Table 4. Performance of the 7 machine learning models in the untouched held-out test set.[a]

Model	AUROC[b] (95% CI)	AUPRC[c] (95% CI)	Accuracy (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)	PPV[d] (95% CI)	NPV[e] (95% CI)	F_1-score (95% CI)	Brier score (95% CI)
Random forest	0.681 (0.583-0.778)	0.808 (0.741-0.874)	0.667 (0.585-0.748)	0.720 (0.622-0.817)	0.561 (0.415-0.707)	0.766 (0.703-0.835)	0.500 (0.395-0.622)	0.742 (0.671-0.810)	0.212 (0.188-0.236)
Decision tree	0.647 (0.552-0.737)	0.752 (0.696-0.811)	0.642 (0.561-0.724)	0.646 (0.537-0.744)	0.634 (0.488-0.780)	0.779 (0.708-0.852)	0.473 (0.385-0.566)	0.707 (0.621-0.778)	0.237 (0.202-0.276)
Logistic regression	0.620 (0.512-0.726)	0.730 (0.659-0.826)	0.626 (0.537-0.707)	0.659 (0.561-0.756)	0.561 (0.415-0.707)	0.750 (0.677-0.825)	0.451 (0.349-0.553)	0.701 (0.623-0.773)	0.242 (0.211-0.274)
SVM[f]-RBF[g]	0.619 (0.517-0.722)	0.746 (0.672-0.840)	0.650 (0.593-0.707)	0.890 (0.817-0.951)	0.171 (0.073-0.293)	0.682 (0.649-0.720)	0.438 (0.214-0.684)	0.772 (0.729-0.812)	0.219 (0.195-0.245)
SVM sigmoid	0.617 (0.510-0.722)	0.756 (0.683-0.838)	0.610 (0.561-0.659)	0.890 (0.817-0.951)	0.049 (0.000-0.122)	0.652 (0.627-0.675)	0.182 (0.000-0.444)	0.753 (0.713-0.786)	0.218 (0.200-0.237)
SVM linear	0.613 (0.504-0.722)	0.716 (0.651-0.814)	0.667 (0.602-0.732)	0.878 (0.805-0.951)	0.244 (0.122-0.390)	0.699 (0.660-0.743)	0.500 (0.294-0.714)	0.778 (0.731-0.823)	0.223 (0.194-0.252)
SVM polynomial	0.577 (0.465-0.684)	0.715 (0.646-0.811)	0.659 (0.602-0.715)	0.902 (0.829-0.963)	0.171 (0.073-0.293)	0.685 (0.652-0.721)	0.467 (0.222-0.714)	0.779 (0.738-0.817)	0.224 (0.202-0.247)

[a]All metrics were evaluated in the same held-out test set (n=123) at a probability threshold of 0.50, except AUROC, AUPRC, and Brier score, which are threshold-independent. CIs were obtained from 2000 stratified bootstrap resamples.

[b]AUROC: area under the receiver operating characteristic curve.

[c]AUPRC: area under the precision-recall curve.

[d]PPV: positive predictive value.

[e]NPV: negative predictive value.

[f]SVM: support vector machine.

[g]RBF: radial basis function kernel.

The decision tree showed the second-highest observed test-set AUROC at 0.647, followed by logistic regression (0.620), support vector machine with a radial basis function kernel (SVM-RBF; 0.619), SVM sigmoid (0.617), SVM linear (0.613), and SVM polynomial (0.577). Several SVM variants had higher sensitivity but lower specificity at the 0.50 threshold. Sensitivity ranged from 0.878 to 0.902 among the 4 SVM models, whereas specificity ranged from 0.049 to 0.244. In comparison, the random forest had a sensitivity of 0.720 and specificity of 0.561 at the same threshold.

Although the random forest showed numerically higher test-set AUROCs than the alternative models, none of the 6 pairwise comparisons remained statistically significant after Holm correction (Holm-adjusted P values ranged from .17 to .81). The largest observed difference was between the random forest and SVM polynomial (AUROC difference 0.104, 95% CI

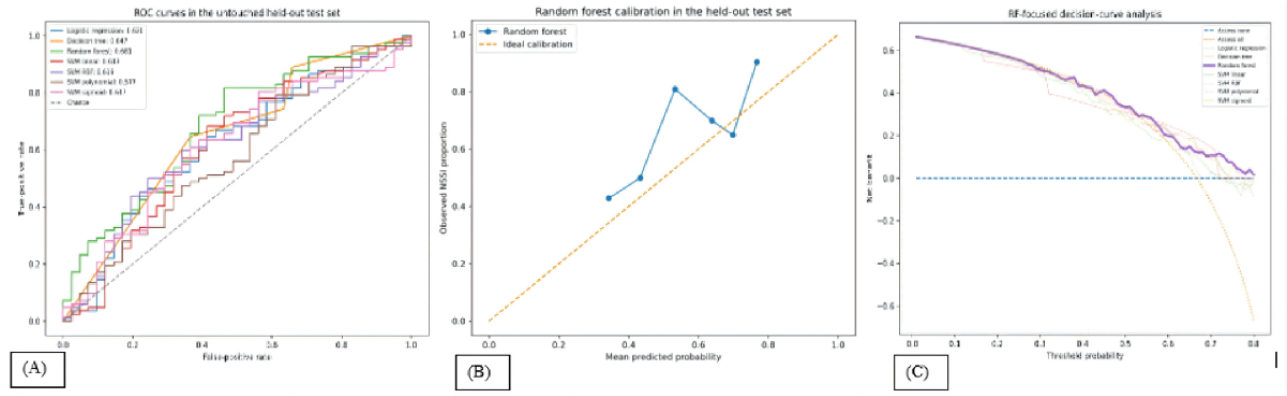
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0.011-0.197; unadjusted *P*=.03; Holm-adjusted *P*=.17). The difference between the random forest and the SVM-RBF model, which achieved the highest cross-validation AUROC during model development, was 0.062 (95% CI –0.027 to 0.152; unadjusted *P*=.17; Holm-adjusted *P*=.81). Therefore, the random forest was selected as the focal exploratory model for subsequent interpretation based on its overall held-out test-set performance and suitability for nonlinear interpretation; these comparisons did not demonstrate statistical superiority. Full pairwise AUROC comparisons between the random forest and alternative models are presented in Table S2 in Multimedia Appendix 1.

Calibration and Decision-Curve Analysis

Calibration performance of the random forest model is summarized in Table 4 and illustrated in Figure 2B. The model achieved a Brier score of 0.212 (95% CI 0.188-0.236), with a calibration intercept of 0.457 and a calibration slope of 1.013. The calibration slope was close to the ideal value of 1, indicating that the spread of predicted probabilities was generally consistent with the observed outcomes. However, the positive calibration intercept suggested that the model tended to underestimate the overall observed probability of past-year NSSI. Across the 6 calibration groups, mean predicted probabilities ranged from 0.343 to 0.767, whereas the corresponding observed NSSI proportions ranged from 0.429 to 0.905.

Figure 2. Performance evaluation and clinical utility analysis of the machine learning models. (A) Receiver operating characteristic (ROC) curves for the 7 model variants in the untouched held-out test set. (B) Calibration plot for the focal random forest model. (C) Decision curve analysis, with the random forest model highlighted. The modeled clinical action was referral for a comprehensive, structured nonsuicidal self-injury (NSSI) assessment rather than automatic diagnosis or treatment. RBF: radial basis function kernel; SVM: support vector machine.



Decision-curve analysis of the random forest model is shown in Figure 2C. The random forest demonstrated greater net benefit than both the assess-all and assess-none strategies across the main continuous threshold-probability range of approximately 0.51-0.80. At the prespecified threshold probability of 0.50, the net benefit of the random forest was approximately equivalent to that of the assess-all strategy. Compared with the other evaluated models, the random forest had the highest model-specific net benefit only within selected threshold intervals rather than across the entire probability range. These intervals included 0.01-0.10, 0.12-0.26, 0.34, 0.37-0.38, 0.45-0.46, 0.50-0.52, 0.56, 0.72-0.73, 0.76-0.77, and 0.79-0.80. Overall, the random forest had the highest model-specific net benefit at 40 of 80 (50%) evaluated threshold probabilities, indicating potential usefulness for identifying adolescents who may benefit from further structured NSSI assessment rather than serving as a standalone diagnostic tool.

RF Incremental-Value and Sensitivity Analyses

Incremental-value and sensitivity analyses of the focal random forest model are summarized in Table 5. The suicidal-ideation-only logistic regression benchmark achieved an AUROC of 0.701 (95% CI 0.616-0.780), which was numerically higher than the AUROC of 0.681 for the full multidimensional random forest model. However, the difference between the full random forest and the suicidal-ideation-only benchmark was not statistically significant (AUROC difference –0.020, 95% CI –0.079 to 0.038). A benchmark model including both suicidal ideation and previous suicide attempt achieved an AUROC of 0.697 (95% CI 0.594-0.790).

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Table 5. Incremental-value and sensitivity analyses of the focal random forest model.

Analysis	AUROC[a] (95% CI)	AUPRC[b]	Accuracy	Sensitivity	Specificity	Brier score
SI[c]-only logistic benchmark	0.701 (0.616-0.780)	0.774	0.732	0.793	0.610	0.228
SI + previous-attempt logistic benchmark	0.697 (0.594-0.790)	0.770	0.732	0.793	0.610	0.226
RF[d]: basic clinical model	0.676 (0.559-0.778)	0.773	0.642	0.646	0.634	0.228
RF: clinical variables only	0.682 (0.573-0.781)	0.788	0.642	0.659	0.610	0.224
RF: full multidimensional model	0.681 (0.581-0.778)	0.808	0.667	0.720	0.561	0.212
RF: without SI and SA[e]	0.540 (0.429-0.655)	0.717	0.659	0.829	0.317	0.233
RF: biochemical variables only	0.513 (0.409-0.622)	0.685	0.618	0.793	0.268	0.238
RF: family/context variables only	0.488 (0.396-0.579)	0.661	0.455	0.390	0.585	0.253
RF: without sex	0.692 (0.597-0.785)	0.825	0.667	0.720	0.561	0.213
RF: without residence	0.678 (0.582-0.776)	0.808	0.667	0.732	0.537	0.214
RF: without FH[f] and residence	0.676 (0.570-0.774)	0.806	0.659	0.707	0.561	0.213
RF: including length of stay	0.677 (0.570-0.776)	0.805	0.675	0.732	0.561	0.214
RF: training-only SMOTENC[g] sensitivity	0.697 (0.593-0.798)	0.805	0.675	0.707	0.610	0.212

[a]AUROC: area under the receiver operating characteristic curve.

[b]AUPRC: area under the precision-recall curve.

[c]SI: suicidal ideation.

[d]RF: random forest.

[e]SA: suicide attempt.

[f]FH: family psychiatric history.

[g]SMOTENC: Synthetic Minority Over-Sampling Technique for Nominal and Continuous.

Removing suicidality-related variables reduced model discrimination. The random forest without suicidal ideation and previous suicide attempt achieved an AUROC of 0.540 (95% CI 0.429-0.655), compared with 0.681 for the full model (AUROC difference 0.141, 95% CI 0.045-0.237; Holm-adjusted *P*=.048). This finding indicated that suicidality-related variables contributed substantially to the full model's discrimination of concurrent NSSI status in this sample, while also highlighting the close conceptual relationship between NSSI and suicidality-related clinical features.

Domain-specific sensitivity analyses showed that the clinical-only random forest achieved an AUROC of 0.682 (95% CI 0.573-0.781), which was comparable with that of the full multidimensional model (AUROC difference –0.001). The basic clinical random forest achieved an AUROC of 0.676 (95% CI 0.559-0.778). By contrast, the biochemical-only model achieved an AUROC of 0.513 (95% CI 0.409-0.622), and the available family/context-only model achieved an AUROC of 0.488 (95% CI 0.396-0.579). The full random forest model showed higher discrimination than the biochemical-only and available family/context-only models after Holm correction (adjusted *P*=.048 and .03, respectively). These findings did not demonstrate measurable incremental discrimination from adding the available biochemical variables to the clinical features.

Sensitivity analyses addressing potential demographic and contextual influences showed minimal changes in model performance. Excluding sex resulted in an AUROC of 0.692, excluding residence resulted in an AUROC of 0.678, and excluding both family psychiatric history and residence resulted in an AUROC of 0.676. Adding completed length of stay also did not improve discrimination (AUROC 0.677). These results indicated that excluding sex, residence, available family-context variables, or completed length of stay had limited effects on model discrimination in our sample.

In the class-imbalance sensitivity analysis, SMOTENC was applied exclusively within the training data. The resulting random forest achieved an AUROC of 0.697 (95% CI 0.593-0.798), an AUPRC of 0.805 (95% CI 0.735-0.879), an accuracy of 0.675, sensitivity of 0.707, specificity of 0.610, and Brier score of 0.212. The calibration slope was 0.959. These results were broadly consistent with those of the primary class-weighted random forest model, indicating that the observed model performance was not substantially altered by the approach used to address class imbalance. The AUROC distributions of these incremental-value and ablation analyses, with bootstrap CIs, are additionally presented in Figure S1 in Multimedia Appendix 1.

Sex- and Residence-Specific Performance

Exploratory subgroup analyses according to sex and residence are summarized in Table S3 in Multimedia Appendix 1. Among male participants in the held-out test set (n=26; 15 with NSSI and 11 without NSSI), the random forest had an AUROC of 0.776 (95% CI 0.576-0.945). At the 0.50 threshold, sensitivity was 0.267 and specificity was 1.000. Among female participants (n=97; 67 with NSSI and 30 without NSSI), the AUROC was 0.665 (95% CI 0.548-0.777), sensitivity was 0.821, and

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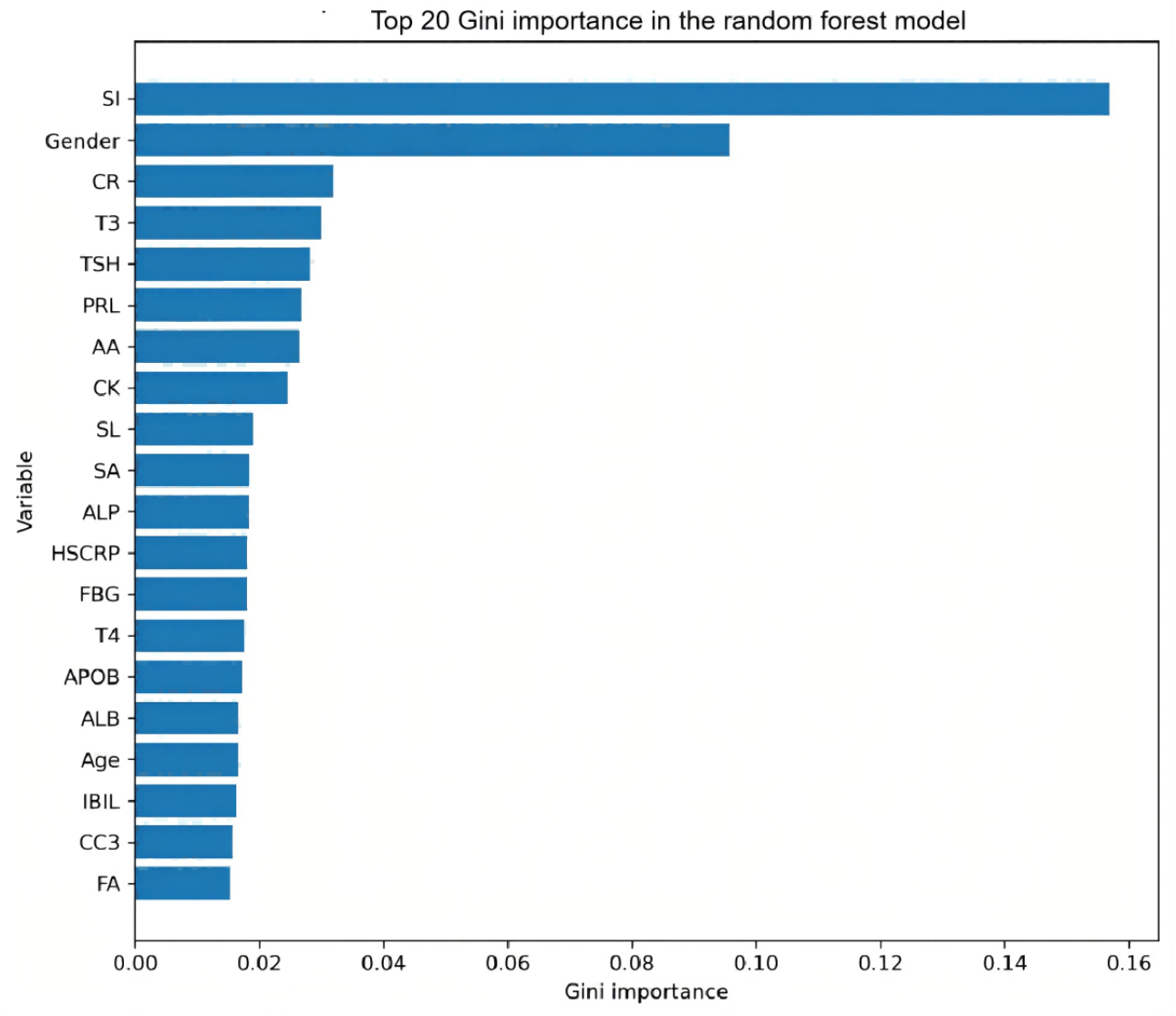
specificity was 0.400. The wide CI among male participants and the markedly different sensitivity-specificity profiles indicated substantial uncertainty in the subgroup-specific performance estimates.

Among participants coded as urban residents in the held-out test set (n=74; 50 with NSSI and 24 without NSSI), the random forest had an AUROC of 0.718 (95% CI 0.587-0.835), sensitivity of 0.660, and specificity of 0.667. Among participants coded as rural residents (n=49; 32 with NSSI and 17 without NSSI), the AUROC was 0.619 (95% CI 0.445-0.778), sensitivity was 0.813, and specificity was 0.412. The CIs overlapped, and removal of residence from the full model resulted in minimal change in overall AUROC. Hospital-specific performance and leave-one-hospital-out validation could not be evaluated because the processed analytic dataset did not contain a hospital-site identifier.

Random Forest Model Interpretation

According to Gini impurity–based importance, the 5 highest-ranked variables in the focal random forest model were suicidal ideation, sex, creatinine, T3, and TSH. Their corresponding Gini importance values were 0.157, 0.096, 0.032, 0.030, and 0.028, respectively. Previous suicide attempt ranked 10th, high-sensitivity C-reactive protein ranked 12th, and age ranked 17th among the 67 candidate variables. All candidate variables remained included in the fitted random forest model; Figure 3 displays the 20 highest-ranked variables according to Gini importance for visual clarity. Gini importance reflects the contribution of each variable to impurity reduction within the fitted tree ensemble and should not be interpreted as evidence of a causal relationship.

Figure 3. The 20 highest-ranked variables according to Gini importance in the focal random forest model. The fitted random forest included all 67 candidate variables; only the 20 highest-ranked variables are shown for visual clarity. AA: amylase; ALB: albumin; ALP: alkaline phosphatase; APOB: apolipoprotein B; CC3: complement component C3; CK: creatine kinase; CR: creatinine; FA: free fatty acid; FBG: fasting blood glucose; HSCRP: high-sensitivity C-reactive protein; IBIL: indirect bilirubin; PRL: prolactin; SA: suicide attempt; SI: self-injury; SL: aspartate aminotransferase-to-alanine aminotransferase ratio; T3: total triiodothyronine; T4: total thyroxine; TSH: thyroid-stimulating hormone.



Mean absolute SHAP values showed a broadly similar ranking pattern. Suicidal ideation, sex, creatinine, T3, and TSH were again among the 5 highest-ranked variables, followed by previous suicide attempt, creatine kinase, prolactin, age, and

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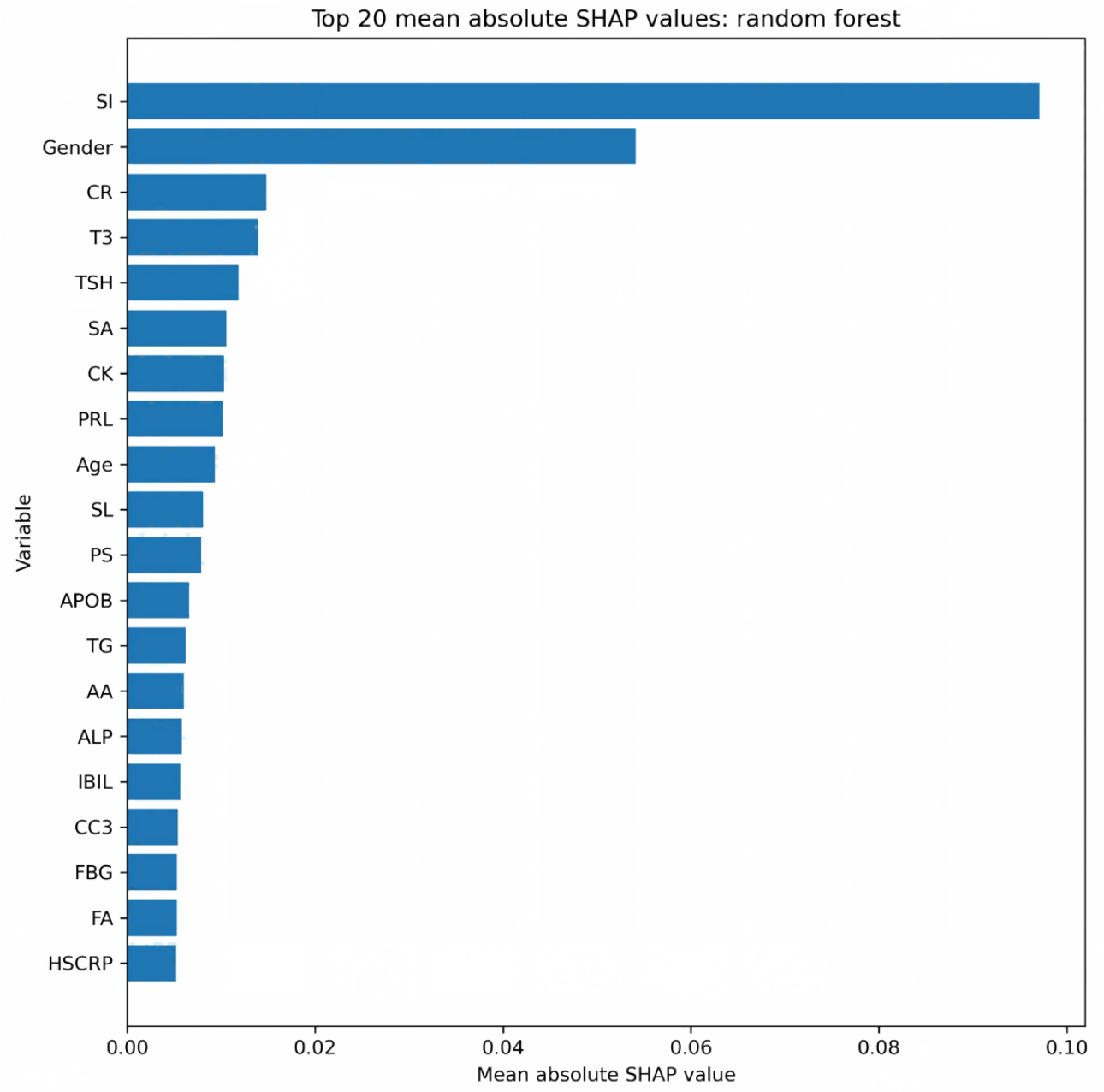
the aspartate aminotransferase-to-alanine aminotransferase ratio. The Gini importance and mean absolute SHAP rankings were strongly correlated (Spearman ρ=0.917, *P*<.001), showing substantial agreement between the 2 model-specific importance measures. A detailed comparison of variable rankings across Gini importance, SHA*P* values, and permutation importance is provided in Table S4 in Multimedia Appendix 1. However, differences in individual rankings were observed, reflecting that Gini importance and SHA*P* values capture different aspects of variable contribution within tree-based models.

Test-set permutation importance provided a more conservative assessment of feature contribution on unseen data. Permuting suicidal ideation resulted in the largest reduction in test-set AUROC (mean decrease 0.134), which was substantially greater than the reductions associated with amylase (mean decrease 0.014), age (mean decrease 0.006), previous suicide attempt (mean decrease 0.005), free thyroxine (mean decrease 0.004), and creatine kinase (mean decrease 0.004). Although sex, T3, and TSH ranked highly according to Gini importance and SHA*P* values, their mean permutation importance values were negative (–0.002, –0.011, and –0.003, respectively; Figure 4). High-sensitivity C-reactive protein ranked 12th according to Gini importance and 20th according to SHA*P* values but also showed negative permutation importance. These findings indicated that suicidal ideation showed the most consistent model-specific contribution across the interpretation approaches, whereas the apparent contribution of several physiological variables varied depending on the interpretation method.

The SHAP beeswarm plot further characterized the direction and distribution of variable contributions within the fitted random forest model (Figure 5). The presence of suicidal ideation generally showed positive SHA*P* values, indicating a shift in model output toward classification as NSSI=1. Female sex also tended to contribute positively toward the NSSI class. In the continuous-feature dependence analyses, feature values were inversely correlated with SHAP contributions for creatinine (Spearman ρ=–0.909), T3 (Spearman ρ=–0.758), TSH (Spearman ρ=–0.901), age (Spearman ρ=–0.896), and creatine kinase (Spearman ρ=–0.692), whereas prolactin values showed a positive correlation with SHAP contributions (Spearman ρ=0.767). Within the fitted model, lower creatinine, T3, TSH, age, and creatine kinase values tended to shift predictions toward NSSI classification, whereas higher prolactin values tended to shift predictions toward NSSI classification. The creatine kinase pattern was interpreted cautiously because its distribution in the held-out test set was heterogeneous (range 24-3935 U/L). These SHAP-based patterns describe fitted-model behavior and should not be interpreted as causal or prospective effects.

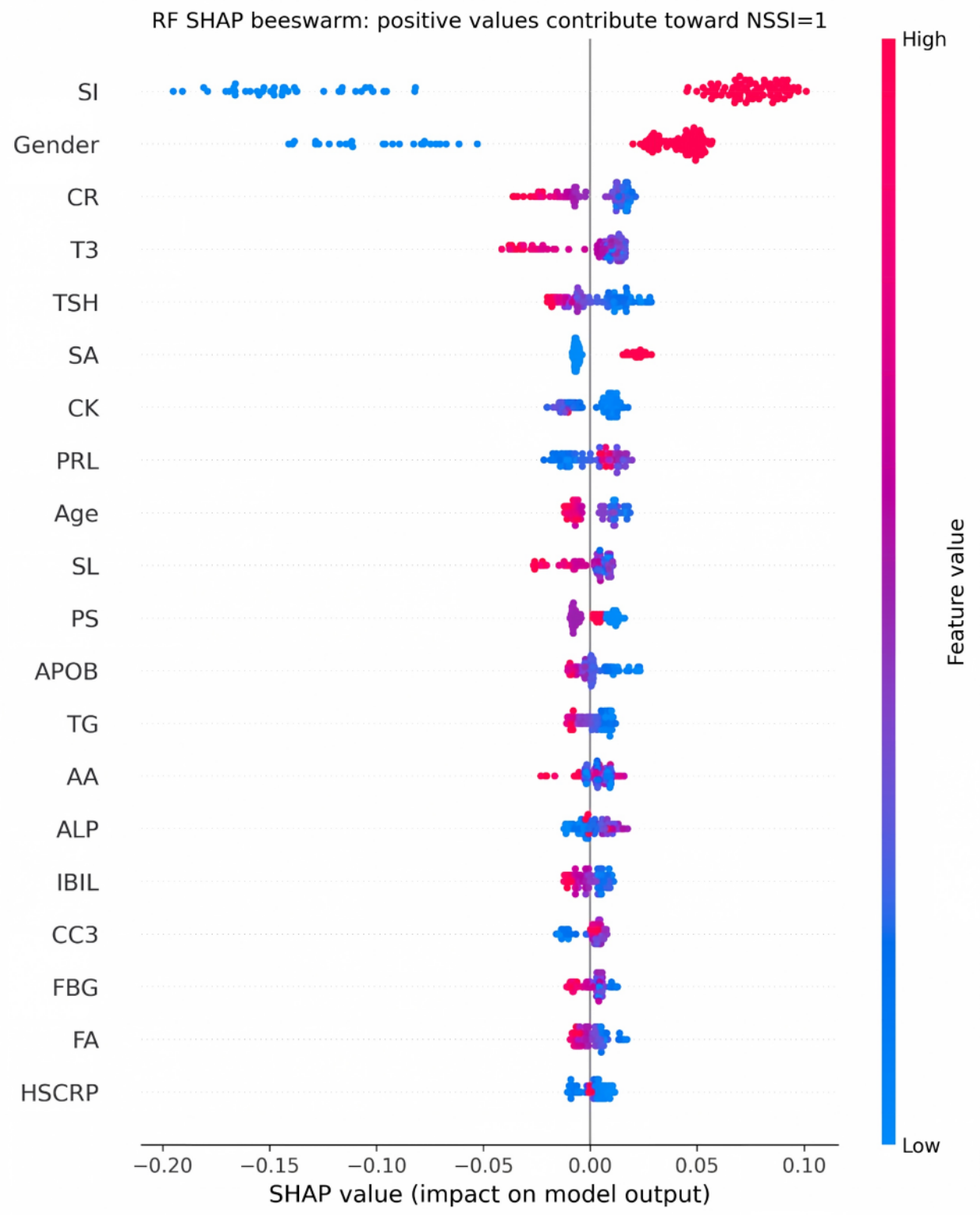
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Figure 4. Mean absolute Shapley Additive Explanations (SHAP) values for the 20 highest-ranked variables in the focal random forest model. Mean absolute SHAP values quantify the magnitude of each variable's contribution to the model output but do not indicate the direction of the association. AA: amylase; ALP: alkaline phosphatase; APOB: apolipoprotein B; CC3: complement component C3; CK: creatine kinase; CR: creatinine; FA: free fatty acid; FBG: fasting blood glucose; HSCRP: high-sensitivity C-reactive protein; IBIL: indirect bilirubin; PRL: prolactin; PS: previous suicide attempt; SA: suicide attempt; SI: self-injury; SL: aspartate aminotransferase-to-alanine aminotransferase ratio; T3: total triiodothyronine; T4: total thyroxine; TG: triglyceride; TSH: thyroid-stimulating hormone.



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Figure 5. Shapley Additive Explanations (SHAP) beeswarm plot for the 20 highest-ranked variables in the focal random forest model. Positive SHAP values indicate contributions toward classification as nonsuicidal self-injury (NSSI)=1. Red points represent higher feature values, and blue points represent lower feature values. SHAP values describe the fitted model output and should not be interpreted as causal effects. AA: amylase; ALP: alkaline phosphatase; APOB: apolipoprotein B; CC3: complement component C3; CK: creatine kinase; CR: creatinine; FA: free fatty acid; FBG: fasting blood glucose; HSCRP: high-sensitivity C-reactive protein; IBIL: indirect bilirubin; PRL: prolactin; PS: previous suicide attempt; SA: suicide attempt; SI: self-injury; SL: aspartate aminotransferase-to-alanine aminotransferase ratio; T3: total triiodothyronine; TG: triglyceride; TSH: thyroid-stimulating hormone.



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Discussion

Principal Findings

In this study, we evaluated 7 supervised machine learning models for classifying past-year NSSI status among adolescents with depressive disorders using multidimensional clinical, behavioral, and biochemical variables. The support vector machine with a radial basis function kernel achieved the highest mean AUROC during training-set cross-validation, whereas the random forest had the highest observed AUROC and AUPRC and the lowest Brier score in the untouched held-out test set among the evaluated models. However, the random forest did not demonstrate statistically significant superiority over alternative algorithms after correction for multiple comparisons. The discrepancy between training-set and held-out test-set rankings suggests that algorithm rankings may be unstable in relatively small clinical datasets.

Previous applications of machine learning to suicidal and self-injurious outcomes have demonstrated the potential of these approaches for classification and prediction [40]. However, systematic reviews have also identified methodological limitations, including inconsistent reporting and a lack of validation in external samples [41]. Recent longitudinal work has applied machine learning to identify clinical predictors of persistent NSSI trajectories among adolescents [37], while other NSSI-focused studies have reported favorable internal classification performance using machine learning algorithms [42]. Nevertheless, independent validation remains essential before such models can be considered for clinical implementation. Transparent reporting of model development and validation is important for evaluating the reliability and reproducibility of clinical prediction research [43], while careful assessment of risk of bias and applicability is required to identify potential methodological limitations [44]. The most consistent contributor to discrimination in the focal random forest model was suicidal ideation. The suicidal-ideation-only logistic regression benchmark achieved discrimination comparable to that of the random forest, whereas removal of suicidal ideation and previous suicide attempt substantially reduced random forest performance. These findings indicate that direct suicidality-related information accounted for a considerable proportion of the model's classification ability in this sample. Longitudinal evidence has shown that adolescents engaging in NSSI or nonsuicidal self-harm are at increased risk of subsequent suicide attempts [45]. Prospective evidence further suggests that the co-occurrence of NSSI and suicidal ideation may identify adolescents at particularly elevated risk of subsequent suicide attempts [46]. Nevertheless, NSSI is conceptually distinguished from suicidal behavior by the absence of suicidal intent [47]. NSSI may serve multiple psychological and interpersonal functions, including regulation of negative affect and other intrapersonal or interpersonal functions [48]. Real-time monitoring studies further demonstrate substantial between-person and within-person variability in the functions of NSSI over time [49]. Person-centered analyses likewise support substantial heterogeneity in NSSI presentations and behavioral patterns [50].

Therefore, the prominent contribution of suicidal ideation in our model should not be interpreted as indicating that NSSI can be reduced to suicidality-related variables. Rather, our findings reinforce the importance of directly assessing suicidal ideation and previous suicidal behavior while maintaining a separate and comprehensive assessment of NSSI characteristics. In clinical practice, models incorporating suicidality-related information could potentially help organize complex patient information and identify adolescents who may warrant more comprehensive assessment, but they should complement rather than replace clinical judgment.

By contrast, biochemical variables did not demonstrate clear incremental discrimination beyond the available clinical information. Although creatinine, T3, TSH, creatine kinase, and prolactin appeared among the higher-ranked variables according to Gini importance or SHA*P* values, their contributions were less consistent in permutation-based analyses. Previous research has identified differences in inflammatory and immune-related biomarkers between adolescents with depression and healthy controls, although findings remain heterogeneous [51]. Peripheral biological correlates have also been investigated in relation to suicidality among children and adolescents, but their clinical utility remains uncertain [52]. More specifically, emerging research has suggested a possible role of inflammatory processes in adolescent depression accompanied by NSSI [53]. Neuroendocrine mechanisms may also be relevant, with studies reporting associations between NSSI and variations in testosterone and cortisol levels [54]. Alterations in the hypothalamic-pituitary-thyroid axis have similarly been reported among adolescents with major depressive disorder and NSSI [55]. However, these findings remain insufficient to establish clinically reliable biomarkers. In this study, high-sensitivity C-reactive protein did not differ significantly between participants with and without NSSI despite appearing among the higher-ranked variables in some model-interpretation analyses. This discrepancy illustrates an important limitation of interpreting variable importance in complex machine learning models: a variable that contributes to model discrimination does not necessarily represent an independent biological mechanism or causal risk factor [56]. Explainability methods may provide information about model behavior, but they should not be assumed to ensure trustworthy patient-level decision support or to substitute for rigorous model validation [57]. Tree-based algorithms can capture nonlinear relationships, interactions, and conditional dependencies that may not be apparent in conventional univariable comparisons. Accordingly, the physiological variables identified in this study should be interpreted as contributors to fitted-model behavior rather than as established biomarkers or causal determinants of NSSI.

The random forest demonstrated acceptable calibration characteristics and potential clinical usefulness within selected threshold ranges in decision-curve analysis. However, these findings do not justify automated diagnosis, treatment selection, hospitalization decisions, or direct risk labeling of adolescents. Evaluation of clinical prediction models should extend beyond discrimination alone and include calibration, validation, and assessment of potential clinical usefulness [58]. Decision-curve analysis provides a framework for estimating net clinical benefit

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across different threshold probabilities [59]. Nevertheless, favorable decision-curve results cannot substitute for prospective evaluation of whether use of a model actually improves clinical outcomes. Similarly, although explainability methods can provide information about how a model generates its predictions, such explanations should not be assumed to ensure trustworthy patient-level decision support or to substitute for rigorous model validation [57]. Translation of AI from retrospective model development into clinical practice therefore requires staged and rigorous evaluation of real-world performance and clinical utility [60]. Trustworthy implementation also requires attention to robustness, fairness, transparency, usability, and potential unintended harms throughout the model life cycle [61]. Importantly, meaningful clinician oversight should remain central when AI is used to support decisions in complex and high-stakes psychiatric settings [62].

Another important consideration is the limited representation of family and broader social-contextual factors in the present model. Family dynamics have been consistently associated with self-harm and suicidality among children and adolescents [63]. Peer relationships, including interpersonal difficulties and social experiences, may also contribute meaningfully to the development and maintenance of self-harm thoughts and behaviors [64]. As the available dataset contained relatively limited information regarding family functioning, peer relationships, interpersonal stressors, social support, and adverse experiences, the model may not have fully captured important developmental and interpersonal pathways associated with NSSI. Future models may therefore benefit from incorporating more comprehensive psychosocial assessments alongside clinical and biological information. Standardized measures of family functioning, peer relationships, emotion regulation, adverse experiences, and social support could help determine whether these variables provide meaningful incremental value beyond readily available clinical indicators. In addition, clinical evaluation of AI systems should consider whether the information provided by a model is understandable, actionable, and compatible with real-world clinical workflows [60]. Broader frameworks for trustworthy health care AI also emphasize the importance of human-centered development and stakeholder involvement when models are intended for clinical use [61]. Involving adolescents, caregivers, and clinicians in future model development and evaluation may therefore improve the clinical relevance and acceptability of prediction tools.

Overall, our findings suggest that machine learning can integrate multidimensional clinical information to assist in identifying adolescents with depressive disorders who report past-year NSSI. However, the substantial contribution of suicidal ideation and previous suicidal behavior indicates that much of the model's discriminatory ability was derived from established clinical indicators rather than from biochemical information. The comparable discrimination achieved by the suicidal-ideation-only benchmark further suggests that the incremental value of a more complex multidimensional model should be interpreted cautiously. Nevertheless, machine learning may provide a means of integrating heterogeneous information and capturing complex patterns that may not be readily identified using conventional approaches. Rather than replacing standard clinical assessment, interpretable machine learning may be most appropriately positioned as an adjunctive tool for organizing multidimensional information, identifying patterns that warrant further evaluation, and supporting comprehensive clinician-led assessment.

Limitations

Several limitations warrant consideration. First, the sample size was relatively small and drawn from psychiatric clinical settings in Zhejiang Province, which may limit the generalizability of the findings. Second, the cross-sectional design precludes causal inferences; therefore, future longitudinal studies involving larger and more diverse populations are needed to externally validate and refine these models and to evaluate their prospective performance. Lastly, incorporating self-reported psychosocial data, such as family dynamics and peer relationships, alongside clinician-assessed information could provide a more comprehensive representation of the psychosocial factors relevant to NSSI.

Implication

This study provides clinical and research implications for understanding the clinical characteristics associated with NSSI among adolescents with depressive disorders. By integrating demographic, physiological, biochemical, and behavioral variables, this study demonstrates the potential of combining multidimensional information to characterize clinical profiles associated with NSSI. The interpretable machine learning approach may assist in identifying adolescents with past-year NSSI and provide information to support comprehensive assessment. Importantly, the model should be considered a decision-support tool rather than a replacement for clinical judgment. Future studies incorporating larger samples, longitudinal designs, external validation, and richer psychosocial information are warranted to further evaluate the robustness, generalizability, and clinical applicability of such models. These findings may contribute to the development of more individualized assessment strategies and support the identification of adolescents who may benefit from comprehensive evaluation and targeted clinical support.

Conclusions

This study demonstrates the potential utility of integrating multidimensional clinical, behavioral, and biochemical data with interpretable machine learning approaches to classify past-year NSSI status among adolescents with depressive disorders. The findings suggest that machine learning models integrating heterogeneous information may provide complementary support for comprehensive clinical assessment. However, further validation in larger and independent cohorts, particularly using longitudinal designs, is required before clinical implementation. Ultimately, interpretable machine learning models may serve as useful adjuncts to clinician-led assessment and may contribute to improving the identification and evaluation of adolescents with NSSI.

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Data Availability

The data that support the findings of this study are available from the corresponding author (KZ) upon reasonable request. However, due to ethical and privacy restrictions, the data are not publicly accessible.

Authors' Contributions

Conceptualization: GZ
Data curation: GL, CY, ND, WT
Formal analysis: GL, CY
Investigation: WC, ND, WT
Methodology: GZ
Project administration: KZ, XY
Resources: KZ, XY
Supervision: GZ
Validation: ML, XM
Visualization: ML, XM
Writing – original draft: GL, CY
Writing – review & editing: GZ, WC
All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Additional analysis.
[DOCX File , 207 KB - pediatrics_v9i1e95340_app1.docx]

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Abbreviations

AUPRC: area under the precision-recall curve
AUROC: area under the receiver operating characteristic curve
DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
ICD-10: International Classification of Diseases, 10th Revision
NSSI: nonsuicidal self-injury
RF: random forest
SHAP: Shapley Additive Explanations
SMOTENC: Synthetic Minority Over-Sampling Technique for Nominal and Continuous
SVM-RBF: support vector machine with a radial basis function kernel
T3: total triiodothyronine
T4: total thyroxine
TSH: thyroid-stimulating hormone

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Development of a Virtual Transition Program for Adolescents and Young Adults With Type 1 Diabetes: Three-Stage User-Centered Design Study

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Abstract

Background: Adolescents and young adults (AYAs) with type 1 diabetes (T1D) face a heightened risk of care gaps and preventable complications during the transition from pediatric to adult care. AYAs from low-income families are more likely to experience poor outcomes. Care guidelines for T1D now recommend a transition program beginning several years prior to anticipated independence. However, existing transition programs often require substantial resources, limiting their scalability and accessibility.

Objective: We used a human-centered design approach to develop and refine a low-cost, virtual intervention to support T1D transitions among publicly insured AYAs.

Methods: Guided by the "3I" model (inspiration, ideation, implementation) of IDEO, we conducted semistructured interviews with 26 providers and staff across 4 University of California medical centers to identify challenges and opportunities for improving transition care. We then completed customer discovery interviews with 36 adopters and influencers, including AYAs, endocrinologists, and diabetes educators, to identify priorities and needs and create value propositions. The resulting intervention was tested with 3 cohorts (n=25) of publicly insured AYAs aged 17 to 21 years receiving pediatric diabetes care at an academic medical center. The intervention consisted of two 75-minute virtual group sessions led by a diabetes educator and peer mentors with lived experience. Feasibility, acceptability, and appropriateness were assessed via validated surveys and qualitative interviews.

Results: Core functions of the intervention included education and discussion on "adulting with diabetes" and navigating the health care system, interactive creation of a transition plan, mentors sharing their experiences with diabetes, open discussion among peers, opportunities to ask questions, and provision of resources based on individual needs. Facilitators and mentors reported high feasibility (mean 4.25, SD 0.52) and appropriateness (mean 4.43, SD 0.53). Qualitative interviews highlighted peer support and lived-experience mentorship as core drivers of engagement. Attendance was highest among participants enrolled closer to session dates. Participant feedback informed ongoing adaptations to content and delivery across cohorts, including timing of the intervention, use of the chat function, multiple text reminders before intervention sessions, and specific topics of interest.

Conclusions: This human-centered virtual transition intervention addressed priorities identified by AYAs, peer mentors, and clinicians, including peer support, judgment-free discussion, and self-advocacy. While engagement and attendance varied across cohorts, findings support further refinement and evaluation of the intervention in diverse settings.

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KEYWORDS

type 1 diabetes; adolescents; human-centered design; transition to adult care; peer support

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Introduction

Type 1 diabetes (T1D) is a serious medical condition that affects more than 300,000 children and adolescents in the United States [1]. T1D poses a significant burden on patients and families in terms of health-related quality of life, missed school days, missed work days, and health care costs [2-4]. Previous research suggests that increased independence and a desire for autonomy during adolescence and young adulthood may lead to reduced adherence to medications and other self-care strategies, as well as lapses in communication with health care providers [5-9]. The transition from adolescence to young adulthood has been identified as a particularly vulnerable stage for lapses in care; up to one-third of patients with T1D fail to complete an initial visit with an adult endocrinology provider within 12 months after their final pediatric endocrinology visit [10,11]. For patients with T1D, the transition phase is associated with high rates of hospitalization due to diabetic ketoacidosis (DKA), a life-threatening complication that can be prevented with appropriate management [9,12]. Patients from low-income families are the most vulnerable to these lapses in care and subsequent hospitalizations; intervening in the transition period is therefore essential to prevent the widening of disparities into adulthood [12,13].

Current guidelines from the American Diabetes Association suggest that the transition process from pediatric to adult specialty diabetes care should begin at least 1 to 2 years prior to the actual transfer of care to allow for a gradual increase in adolescents' self-management responsibilities and continuous education on navigating the logistical aspects of adult health care [14]. Previous T1D transition programs have demonstrated success in improving continuity of care and reducing hospitalizations using full-time transition coordinators, case management, designated young adult clinics, delaying transition until age 25 or 26 years, and shared medical appointments for adolescents and young adults (AYAs) [15-19]. However, more recent studies highlight ongoing gaps in transition preparation, including unmet psychosocial needs and variability in both transition readiness and the effectiveness of existing interventions [20-22]. In addition, transition interventions have not been systematically implemented, even at large academic medical centers, due to limited resources. We sought to design a low-resource, sustainable T1D transition intervention that could be easily implemented and scaled with existing resources within pediatric diabetes clinics. Here, we describe the human-centered design (HCD) process based on the "3I" framework of IDEO used to develop and test the transition intervention, as well as the key components we identified as essential to transition programs for AYAs with T1D.

Methods

HCD and Intervention Development Process

We used an HCD approach based on the "3I" model of IDEO, which includes 3 phases: inspiration, ideation, and implementation [23,24]. Across the 3 phases, we engaged distinct participant groups and data collection approaches, including provider and staff interviews (phase 1), stakeholder customer discovery interviews (phase 2), and intervention delivery with surveys and qualitative interviews among AYAs and mentors (phase 3). We incorporated the principles of HCD throughout, including engaging stakeholders early and throughout the design process, understanding the needs of patients, clinicians, and staff involved in diabetes care, and taking a systems approach to design [25,26]. We enhanced standard HCD steps with rigorous qualitative and customer discovery methods [27], adapted for implementation science [28], to aid in a rigorous, adopter-centered assessment of the "jobs, pains, and gains" that would be addressed by the transition intervention. Collectively, this iterative process followed best practices for designing for dissemination and sustainability and ensuring strong fit-to-context [29].

Phase 1: Inspiration

In the first phase of the project, we gathered perceptions and ideas from providers and staff involved in delivering specialty diabetes care across 4 University of California medical centers. An open-ended question about transitions from pediatric to adult care was added to a semistructured interview guide for an existing qualitative study examining telehealth use for specialty diabetes care. This study used purposive and snowball sampling to identify adult and pediatric endocrinologists, nurses, and staff involved in specialty diabetes care. Interviews lasted 1 hour, were conducted on Zoom, and were recorded and transcribed. We conducted thematic analysis using line-by-line coding in Dedoose (Sociocultural Research Consultants, LLC) [30], as fully described elsewhere [31]. Responses to the transition question were coded and analyzed separately using qualitative content analysis. The research team organized and discussed the main findings for this question.

Phase 2: Ideation

The second design phase was customer discovery, a process widely used across industries to identify intervention adopters' and influencers' "jobs, pains, and gains" and to develop value propositions tailored to different types of stakeholders (ie, adopters and influencers) involved in the clinical transition workflow [32-34]. Our process, adapted for implementation science, focused on understanding (1) adopters' and influencers' perspectives on the most important jobs to be done regarding transitions for patients with T1D, (2) the "pains" (ie, current challenges in supporting transition) and "gains" (ie, opportunities for improved experience or impact) for each group, and (3) how each group defines success [27,28,35]. We first developed a value proposition hypothesis, then conducted customer discovery to validate this hypothesis, and finally established a final value proposition statement. Value proposition statements articulate how the proposed intervention will relieve pains and create gains while carrying out the jobs to be done. Four groups of adopters and influencers were included in customer discovery: (1) people with T1D who had experienced the transition from pediatric to adult care in the past 10 years, (2) pediatric endocrinologists, (3) adult endocrinologists, and (4) diabetes educators. We recruited participants through a snowball sampling strategy, beginning with the participants from the phase 1 qualitative study. Customer discovery interviews were conducted over the

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telephone and lasted between 15 and 30 minutes; the interview guide was informed by standard customer discovery questions [27]. Questions for people with diabetes included the following: (1) Can you tell me about your experience transitioning from pediatric to adult care? (2) What types of things were you most concerned about? (3) What were the main challenges and how did you deal with them? (4) Is there anything that could have made the transition easier? (5) What would an ideal transition intervention look like? (6) How would you define a successful transition? Questions for providers and staff included the following: (1) What is your role in transitions of care for patients with T1D? (2) Can you walk me through a typical transition? (3) How do you feel your health system/department/division/clinic is doing at transitions? (4) What resources are offered? (5) How do you think transitions could be improved? (6) How important do you think transitions are (for you, your colleagues, your patients, and leadership)? (7) What motivates you to want to improve transitions? Responses were captured in notes during interviews and were summarized immediately afterward.

Phase 3: Implementation

Participants

To refine the intervention components identified in phases 1 and 2, we tested our intervention with 3 cohorts of 6 to 10 AYAs. Participants were eligible for the study if they were (1) currently receiving pediatric endocrinology care at UC Davis, (2) between the ages of 17 and 21 at the time of enrollment, (3) planning to transition to adult endocrinology care at UC Davis, (4) insured under Medicaid or California Children's Services (CCS) insurance, which we used as a proxy for low-income status, and (5) able to participate in English-language video sessions. Participants were recruited by a trained clinical research coordinator both during in-person visits and through messages sent via the electronic health record (EHR). The clinical research coordinator confirmed the eligibility criteria and obtained informed consent as described below.

Intervention and Adaptations

The first of our 3 cohorts received three 75-minute group virtual sessions led by a diabetes nurse educator and supported by 2 "T1D mentors," adults aged 23 to 35 with T1D who had previously transitioned to adult endocrinology care. Initial content included modules on the following: (1) navigating the health care system, (2) "adulting" with diabetes (eg, alcohol, pregnancy, social interactions, and explaining diabetes to others), and (3) developing a transition plan. Sessions were conducted synchronously via Zoom and included a combination of facilitator-led discussion, mentor storytelling, and interactive activities. At the end of each session, we asked for feedback from participants on the intervention components, discussion topics, and meeting format. Feedback was tracked and discussed with the research team to make subsequent adaptations to sessions. Two subsequent cohorts of AYAs received the adapted intervention.

Qualitative Interviews

Following the completion of each cohort, we invited all participants and T1D mentors to participate in a qualitative interview about their experiences with the intervention. Interviews were completed via Zoom or phone, lasted approximately 30 minutes, followed a semistructured interview guide, and were audio-recorded and transcribed. Deidentified transcripts were coded line-by-line by 2 independent coders. Coders met regularly to review codes and resolve discrepancies through discussion. Final themes were discussed, categorized, and refined by the research team. Findings from interviews from the first 2 cohorts were also incorporated into intervention adaptations.

Survey Measures

All participants completed a baseline survey on demographics, employment, educational status, and time since T1D diagnosis. After completing the intervention, facilitators and T1D mentors completed 2 short validated surveys that measure perceived intervention appropriateness and feasibility on a 5-point Likert scale: the intervention appropriateness measure and the feasibility of intervention measure [36]. Participants were also asked to complete a third validated measure, the acceptability of intervention measure. Surveys were analyzed using means and SDs.

Ethical Considerations

This study was reviewed and approved by the UC Davis Institutional Review Board (approval number 1982341). Interview participants for phases 1 and 2 provided verbal consent. AYA participants in phase 3 provided written informed consent if aged 18 years or older and written assent along with written informed consent from the parent or guardian if younger. Participants who turned 18 during the study were reconsented.

Results

Phase 1: Inspiration

Qualitative study participants included 5 pediatric endocrinologists, 7 adult endocrinologists, 4 diabetes educators, 2 diabetes pharmacists, and 8 staff members involved in specialty diabetes care. We identified 3 main findings related to transitions from pediatric to adult care for persons with T1D: (1) There is a perception among all types of clinicians and staff that transitions to adult care need improvement; (2) Levels of support for transitions vary widely depending on the patient's distance from the health system; and (3) Components that may be helpful for a transition program include navigating the health care system independently (eg, insurance, appointments, pharmacy, and device companies) and a transition plan available to all members of the care team (pediatric and adult) in the EHR.

Phase 2: Ideation

We completed customer discovery interviews with 36 participants, including 16 people with diabetes, 8 pediatric endocrinologists, 6 adult endocrinologists, and 6 diabetes educators. Adults with diabetes who had previously transitioned emphasized that, during that period of their lives, their primary concern was not health outcomes per se but succeeding in broader developmental milestones, such as starting college, entering the workforce, or living independently. They described the transition as most effective when it supported their ability

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to manage diabetes in a way that enabled these life goals, rather than focusing narrowly on avoiding adverse health events like DKA or hospitalization. When reflecting on what would have helped them most during the transition, participants consistently identified 3 essential components: access to peer support, a space to ask questions without judgment, and the development of strong self-advocacy skills. Table 1 summarizes the motivating gains, pains, and value proposition statements for each adopter or influencer group.

Table . Motivating "pains and gains" and value propositions by adopter or influencer group.

Group	Motivating "gains"	Current "pains"	Value proposition statement
AYA[a] with T1D[b]	More independence and confidence as they move into a new phase of life (eg, entering the workforce, attending college, living independently).	Not knowing others with T1D diabetes ("no one to talk to about it"), anxiety about navigating the health system, anxiety about asking for accommodations.	For adolescents and young adults with T1D, this intervention provides all of the information they need to transition to adult care in one place along with a supportive, judgment-free environment where they can learn from diabetes experts and peers, they can call on for help in the years to come, allowing them to focus on living their life instead of on their diabetes.
Pediatric endocrinologists	Greater ability to provide resources to ensure a smooth transition to adult care.	Emotional pain seeing patients not successfully transition, discomfort around continued insulin prescriptions after leaving pediatrics.	For pediatric endocrinologists who want to ensure the patients they have cared for for so long end up thriving after transition, this intervention provides them with an easy way to increase that likelihood and feel good about the resources being provided to their AYA patients.
Adult endocrinologists	Greater confidence that AYAs are arriving to adult care with more education and connection to resources.	High no-show rates for AYAs, which contribute to inefficient use of physician and staff time and may lead to poor outcomes for patients.	For adult endocrinologists who want to avoid poor clinical outcomes and reduce no-shows for new AYA patients, this intervention provides an easy way to help these patients transition to their care and gives them the opportunity to take advantage of the wealth of knowledge gathered on these patients over the years by their pediatric colleagues.
Diabetes educators	Having a more convenient resource available for all AYAs.	Limited time to provide individualized education and transition resources to every patient.	For diabetes educators that want to provide as much support as possible to all of their AYA patients, this intervention allows them to do this in a convenient way that will give them the opportunity to participate as much as they would like but won't place a mandatory burden on their time.

[a]AYA: adolescents and young adult.

[b]T1D: type 1 diabetes.

Across interviews with pediatric endocrinologists, adult endocrinologists, and diabetes educators, several key themes emerged about the transition from pediatric to adult diabetes care. Pediatric endocrinologists saw their primary role as initiating transition conversations and referring patients to adult care, often with support from diabetes educators. Many described significant emotional distress when patients failed to transition successfully, especially when long-term patients experienced poor outcomes. They also expressed discomfort about continuing to refill insulin prescriptions for patients who should have moved on, and they described time and resource limitations as ongoing challenges. Adult endocrinologists focused more on ensuring that young adults received the care and tools they needed to manage diabetes in adulthood. While they reported less emotional strain, given they typically meet patients after the transition, they highlighted high no-show rates and limited background information as key pain points. Diabetes educators emphasized their role in providing resources and answering questions about what to expect in adult care but noted that strict oversight of how they use their time limited their ability to support transitions more fully. They were enthusiastic about anything that could reduce the burden of 1:1 education and help more patients. Customer discovery significantly influenced the intervention design, including prompting the addition of "T1D mentors," adults who have transitioned in the past 10 years, to share their experiences and strategies, and having a specific focus on advocating for oneself (eg, explaining diabetes to others, asking for accommodations, etc). These

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features created the "gains" sought by participants in terms of connecting with other people with T1D and improving confidence, and addressed the "pains" of anxiety around self-advocacy.

Phase 3: Implementation

We identified 73 eligible patients at the beginning of the study. Of these, 25 were enrolled through in-clinic recruitment and EHR messaging. Seven eligible participants declined, citing that they were either not interested in research (n=4), had a work conflict (n=1), were concerned about the time commitment (n=1), or did not feel comfortable participating in English (n=1). The remaining 41 did not respond to StudyPages (Yuzu Labs PBC) messages and were not seen in the clinic during the recruitment window. Table 2 shows the demographic and health characteristics of participants for phase 3 testing. The group was diverse, with 48% (12/25) female participants, 40% (10/25) of Hispanic or Latino ethnicity, and a variety of self-identified races. The median age of participants was 18 (IQR 18-19), and median number of years living with diabetes was 6 (IQR 4-12.5). Self-reported employment status varied, with 44% (11/25) enrolled as students (including 3/25, 12% with part-time jobs), 12% (3/25) working part-time, 4% (1/25) working full-time, and 20% (5/25) unemployed and not in school.

Table . Characteristics of participants in phase 3 user testing.

Characteristics	Values (N=25)
Sex, n (%)	
Male	13 (52)
Female	12 (48)
Race, n (%)	
White	9 (36)
Black	6 (24)
Asian	3 (12)
Native Hawaiian or Pacific Islander	1 (4)
Other	6 (24)
Ethnicity, n (%)	
Hispanic or Latino	10 (40)
Not Hispanic or Latino	15 (60)
Employment, n (%)	
Student only	8 (32)
Student also employed part-time	3 (12)
Part-time job	3 (12)
Full-time job	1 (4)
Unemployed	5 (20)
Missing	5 (20)
Age, median (IQR)	18 (18-19)
Years living with type 1 diabetes, median (IQR)	6 (4-12.5)

The intervention for the first cohort consisted of three 75-minute sessions scheduled monthly. In the first cohort, 7 out of 9 participants enrolled attended the first session, but only 3 participants attended the subsequent 2 sessions, and only 2 participants completed all 3 sessions. We subsequently adapted the intervention to 2 sessions delivered over consecutive weeks in response to feedback from cohort 1 participants. In the second cohort, 5 out of 8 participants enrolled attended session 1, and 4 also attended session 2. In the third cohort, only 2 out of 8 participants enrolled attended the first session, and only 1 attended both sessions. Attendance appeared to be influenced in part by the timing of the sessions relative to enrollment, with lower participation observed when there was a longer delay between enrollment and the session start.

After the completion of cohort 1, we also increased the use of the chat function in subsequent sessions, as many participants were uncomfortable speaking on video but actively participated in the chat when asked to do so. We also adapted the transition plan component of the intervention; rather than asking participants to fill out and share their transition plans, participants preferred to watch one of the T1D mentors fill out the transition plan template and discuss the rationale behind their choices. Table 3 shows the resulting core components and adaptive forms of the intervention.

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Table . Core functions of the transition intervention, refined over 3 stages of human-centered design.

Core functions of transition intervention	Components
Education and discussion on "adulting with diabetes" facilitated by a certified diabetes educator	• Asking for accommodations at work or school • Advocating for oneself • Talking about diabetes with others • Understanding the relationships between diabetes and alcohol, drugs, sleep, stress, pregnancy, and driving • Managing diabetes while away from home • Being prepared for emergencies
Education and discussion on navigating the health care system as an independent adult with T1D[a]	• Making appointments • Asking diabetes-related questions and finding information • Filling prescriptions • Implications of insurance changes • Communicating with device companies • Obtaining additional supplies and replacement devices • Expectations for adult care
Interactive creation of a detailed transition plan	• Provide fillable online template • Talk through examples as a group
"T1D mentors" sharing experiences with T1D	• Between 2 and 4 T1D mentors during each session provide stories and differing perspectives about how they navigated the transition to adult care
Open discussion between peers with T1D	• Provide time between topics and at the end of sessions for open discussion
Opportunities to ask any questions about T1D management to peers, T1D mentors, and facilitators	• Encouragement to discuss • T1D mentors facilitate discussion and questions
Assess individual needs and provide additional resources as needed	• Facilitator and T1D mentors provide links to informational resources based on group discussion or questions • Participants were encouraged to use chat during session or to email afterwards with questions

[a]T1D: type 1 diabetes.

We completed a total of 15 qualitative interviews (9 participants, 5 T1D mentors, and 1 facilitator) during phase 3. Table 4 summarizes qualitative findings and provides illustrative quotes. Participants described the intervention as helpful, prompting them to think about aspects of managing their care they had not previously considered, and improving their confidence that they would transition successfully to adult care. The 2 components highlighted by participants as being most valuable were the T1D mentors and peer support. Many participants had not previously spoken with other people with T1D and appreciated the open discussions about challenges others had encountered and how they overcame them. These findings suggest that the core needs identified during customer discovery, particularly peer support, judgment-free discussion, and self-advocacy, were reflected in participants' experiences of the intervention. T1D mentors and facilitators also perceived the intervention to be valuable. Mentors and participants had different perspectives on session participation. While mentors were concerned that some participants were not engaged in the sessions, participants themselves noted that, although they may have had their cameras turned off or not spoken often, they were nonetheless engaged and learned from the discussions between the peer mentors and other participants. Qualitative interviews also provided insights into the intervention timing, ideal number of participants, and perspectives on topics and exercises.

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Table . Key findings from qualitative interviews with adolescent and young adult (AYA) participants and type 1 diabetes (T1D) mentors and facilitators.

Finding	Illustrative quote	Implications for transition intervention
AYAs found interaction with peers with T1D to be supportive and encouraging; peer support may mitigate some of the barriers to transitioning successfully (eg, feeling discouraged or lonely).	"I think hearing from other people my age and what they deal with really helped me realize I'm not alone. We've all got to deal with it, and we are still trying to accomplish everything even though we have diabetes." [AYA participant]	Highlight this aspect of the intervention in recruitment and during sessions. Encourage further peer-to-peer support to reduce isolation and foster motivation.
AYAs found the discussion with T1D mentors, who shared their experiences managing T1D, how they overcame challenges, and strategies they use to manage health, social situations, and logistics, to be extremely valuable.	"At first, I was kind of scared because I didn't know how I was going to do everything on my own. But now I feel like I am better. I see other people who have done this and I kind of think to myself, if they can do it, I can too." [AYA participant]	Incorporate structured opportunities for mentors to share experiences and strategies (eg, structured questions, preparation in advance of sessions).
Personal stories from the T1D mentors can help make AYA participants feel more comfortable in the group setting.	"Yeah, I definitely felt comfortable because the fact that everybody had the same thing as I do and especially people sharing, like, how [one mentor] talked about how her mom was kind of micromanaging and really on her about her numbers and all that. I can relate to that. It made me kind of come forward and speak about my own experiences." [AYA participant]	Include mentor storytelling to normalize challenges and encourage peer discussion.
Navigating the health care system, including insurance, device companies, and pharmacies, will present challenges for many AYAs. Discussing prior to independence or transition may be helpful.	"Just knowing where to get your stuff, like prescription and stuff, knowing where your closest pharmacy is. I didn't even think about that because I'm going to be in charge and stuff like that now too. I might be doing things with friends and stuff, and this is all kind of going to be different." [AYA participant]	Ensure that practical content on health care navigation is covered.
The transition intervention may increase self-efficacy regarding transition.	"I've been nervous about transitioning to an adult endocrinologist. And I found it very helpful that it gave me the peace of mind that it would be easy to transition." [AYA participant]	Emphasize skill-building and reassurance to boost confidence in managing transition.
Some participants may be uncomfortable being on camera but want to participate in the discussion.	"Personally, I didn't turn on my camera because I feel like I can still stay engaged without it on. And it makes me more awkward, I guess." [AYA participant]	Allow flexible participation modes (eg, camera optional) to support comfort and engagement.
Icebreakers at the beginning of the session were helpful for improving comfort and engagement.	"I liked how they asked little questions, like what is your favorite low blood sugar snack…it gave me a feeling of like we all are dealing with the same thing and made it more comfortable to open up." [AYA participant]	Incorporate icebreakers consistently to build connection and lower barriers to participation.
Participants found that a variety of different media and activities (eg, a mix of icebreaker questions, presentation by the facilitator, structured questions, and unstructured discussion time) were helpful for staying engaged.	"I thought the slide show was great…because the information was really helpful and stuff that we need to know about. And then you could also ask questions about other things if you wanted to." [AYA participant]	Use diverse formats to maintain engagement and accommodate different learning styles.
T1D mentors were enthusiastic about sharing their experiences to help young people with T1D.	"I enjoyed it so much that I would love to do something like that again…so I think it would interest a lot of others like me to do it because it's not often that you get an opportunity to be a mentor to somebody who is experiencing something you've already experienced." [T1D Mentor]	Build sustainability by recruiting and supporting mentors who find value in contributing.

Seven facilitators and mentors (100% response rate) completed the intervention appropriateness measure and feasibility of intervention measure surveys. They rated the intervention as having good feasibility (mean 4.25, SD 0.52) and appropriateness (mean 4.43, SD 0.53). Of the 14 AYAs who participated in the sessions, only 3 completed the acceptability of intervention measure survey. These 3 participants rated the intervention as having high acceptability (mean 4.67, SD 0.29).

Discussion

This study describes the development and iterative refinement of a human-centered virtual transition intervention designed to support AYAs with T1D during the transition from pediatric to adult care. The intervention was intentionally designed to align with existing clinic workflows and resources while addressing priorities identified by AYAs, peer mentors, and clinicians.

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Stakeholder input was gathered at every stage, including from patients, peer mentors, pediatric and adult providers, and educators. Across phases, we identified peer support, judgment-free education, and the development of self-advocacy skills as essential components of an effective transition program. Through iterative fit-to-context validation and refinement, we arrived at a virtual, mentor-supported intervention focused on practical concerns such as navigating insurance, managing diabetes in educational or work settings, and advocating for accommodations. While these components were consistently identified as valuable by participants, this did not necessarily translate into sustained participation, underscoring the distinction between intervention content and participant engagement.

Consistent with previous studies, participants described the transition as a time of vulnerability, not only because of elevated risk for adverse health events but also due to major life changes such as moving out, starting college, or entering the workforce [37-39]. While DKA and hospitalizations are often used as clinical indicators of a failed transition, participants in this study defined success differently. For them, successful transition meant maintaining diabetes care in ways that supported broader developmental goals. These findings highlight the importance of aligning intervention content with the real-world priorities of young adults rather than focusing solely on clinical end points [40].

Our intervention shared several elements with prior programs, including peer mentorship and a focus on building self-management skills [16,17,41-43]. However, unlike many existing models that depend on intensive resources, such as full-time coordinators or dedicated young adult clinics [44], this intervention was designed for use in settings with limited capacity. The structure of 2 virtual sessions, led by a diabetes educator and supported by trained mentors, may offer a practical approach for clinics with limited resources to support transition care. This is especially relevant for clinics serving large numbers of publicly insured patients or those with limited infrastructure to support transition care. However, efficiency is dependent on participant engagement, and low attendance may limit cost-effectiveness and scalability in practice. Prior educational and transition-focused interventions for AYAs with T1D have similarly reported mixed findings regarding engagement and retention, with some programs demonstrating strong participation and others encountering substantial challenges with sustained involvement [16,45-47]. Difficulty engaging AYAs and families in structured diabetes education has also been identified as an important implementation barrier, even in larger, well-resourced programs [48].

We also identified several important findings related to implementation. We observed lower attendance in the third cohort, which may be partially explained by the longer delay between enrollment and the start of the sessions. More broadly, engagement and retention were variable across cohorts, reflecting common challenges in delivering interventions during the transition stage. Future programs may benefit from enrolling participants closer to the intervention start date or developing strategies to maintain engagement during waiting periods. In addition, small adaptations, such as increased use of the chat function and a shift toward observational learning, were well received by participants. These changes reflect the value of responsiveness to participant preferences and highlight how flexible delivery can enhance engagement. Future adaptations may explore shorter or more flexible session formats to better align with participant preferences and competing demands.

A key strength of this study is its focus on publicly insured AYAs, a group often underrepresented in transition research and at increased risk for poor transition outcomes. AYAs from low-income households may face additional barriers, such as limited access to technology, competing work responsibilities, or less involvement from parents or caregivers. These factors can affect both participation in and the success of structured transition programs. Future research should explore how to further reduce these barriers. Potential strategies include integrating content into clinical workflows, using mobile-first platforms, or offering incentives for completion. This study has several limitations. First, the phase 3 testing was conducted at a single academic medical center in Northern California, which may limit generalizability. While some features of the intervention may support adaptation in other underserved settings (eg, the virtual format, limited number of sessions, and use of existing clinic personnel), implementation and engagement may differ in settings with fewer institutional resources, different staffing models, rural populations, or more limited access to reliable technology. Second, the phase 3 testing experienced notable attrition across sessions, with declining attendance over time. Interpretation of feasibility, appropriateness, and acceptability findings is therefore limited by low participant survey response rates and variable attendance. In addition, a substantial proportion of eligible participants were not reached or did not respond to recruitment, underscoring the challenge of engaging AYAs during the transition stage. These individuals may represent those at highest risk for care gaps, suggesting a need for alternative outreach and engagement strategies. Finally, the study focused on user testing and did not assess clinical outcomes, such as appointment attendance or hospitalization rates. Future work should evaluate the impact of this intervention on health outcomes and explore adaptation for other populations, including those in rural areas or non–English-speaking groups.

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Data Availability

The data generated during this pilot study are not publicly available due to their sensitive nature and the potential risk of participant identification. Participants did not provide consent for sharing qualitative data beyond the research team, and permission to share deidentified data was not obtained as part of the informed consent process. As a result, the data cannot be shared or made available upon request.

Authors' Contributions

SCH conceptualized and designed all study phases, recruited participants, collected and analyzed data, and drafted and edited the manuscript. PSR conceptualized and designed phase 3 of the study, provided continuous oversight of study activities, and contributed to drafting and editing the manuscript. SL recruited patients, collected data for phase 3 of the study, and contributed to drafting and editing the manuscript. ECH conceptualized and designed phase 3 of the study, facilitated study sessions, assisted with the recruitment for all 3 study phases, and contributed to drafting and editing the manuscript. AR conceptualized and designed phase 3 of the study, facilitated study sessions, assisted with the recruitment for all 3 study phases, and contributed to drafting and editing the manuscript. BMK conceptualized phase 2 of the study, provided feedback on the interpretation of phase 2 results, and contributed to drafting and editing the manuscript. EHM conceptualized phase 2 of the study, provided feedback on the interpretation of phase 2 results, and contributed to drafting and editing the manuscript. JLR conceptualized the study phases, analyzed phase 1 data, provided feedback on the interpretation of results for all phases, and contributed to drafting and editing the manuscript.

MS collected and analyzed data for phase 1 of the study, assisted with the interpretation of results, and contributed to drafting and editing the manuscript. AL facilitated phase 3 sessions, analyzed qualitative data for phase 3, and contributed to drafting and editing the manuscript. DP conceptualized phase 3 of the study, assisted with the recruitment for all study phases, and contributed to drafting and editing the manuscript. SSC conceptualized and designed all study phases, recruited participants, assisted with the interpretation of data, and drafted and edited the manuscript.

Conflicts of Interest

EHM has served as a consultant on issues of drug safety to Eli Lilly, i2o, Reata Pharmaceuticals, and Syneos Health, as well as to the Class Plaintiffs of the Xyrem (Sodium Oxybate) Antitrust Litigation, including United Healthcare Services, Inc, Humana Inc, Molina Healthcare, Inc, and Health Care Service Corporation, Inc, and has received compensation for these services. The terms of this arrangement have been reviewed and approved by Loyola University Chicago in accordance with its policy on objectivity in research.

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Abbreviations

AYA: adolescents and young adults
CCS: California Children's Services
DKA: diabetic ketoacidosis
EHR: electronic health record
HCD: human-centered design
T1D: type 1 diabetes

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Amplifying the Voices of Parents From Underserved Communities in Digital Health for Children With Medical Complexity: Interview Study Among Parents

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Abstract

Background: Children with medical complexity experience multiple chronic conditions that demand intensive, ongoing, and highly coordinated care, often placing a burden on their parents, who serve as primary caregivers. Digital health offers a promising solution for enhancing care coordination, monitoring, and communication. However, its effectiveness depends on it being developed as a user-centered solution that incorporates feedback from parents, who are the primary decision-makers and advocates in their children's health care. By prioritizing the voices of parents, especially those from underserved communities, during the design and implementation of digital health solutions, these tools can more effectively meet their unique needs. This ensures that digital health solutions are effective in real-world caregiving scenarios.

Objective: This qualitative study explored the experiences of family caregivers of children with medical complexity, with a focus on parents from underserved communities, shedding light on the challenges they face and opportunities for future digital health innovations. Underserved communities in this study are defined as families experiencing structural barriers to accessing specialized care for children with medical complexity, often necessitating additional support from nonprofit or community-based organizations.

Methods: We conducted semistructured interviews with 19 parents of children with medical complexity from underserved communities. All interviews were conducted over Zoom and were audio recorded. We conducted an inductive, reflexive thematic analysis using an iterative codebook to support analytic transparency.

Results: The children in this study had a variety of chronic conditions, each experiencing at least 3 chronic, long-lasting medical conditions. An inductive thematic analysis revealed two broader key themes: (1) virtual care and (2) consumer mobile health (mHealth) apps. The "virtual care" theme focused on the use of remote health care services and communication with health care providers, highlighting parents' challenges and needs for enhancing virtual care. The "consumer mHealth apps" theme identified needs and challenges in the care management of children with medical complexity that could be addressed through consumer mHealth apps.

Conclusions: This study highlights several insights into the digital health needs of children with medical complexity and their family caregivers. Parents identified a clear and urgent need for telehealth features tailored to better support the unique needs of care for children with medical complexity. Despite the growing adoption of consumer mHealth apps, caregivers reported ongoing challenges, underscoring the necessity for user-centered solutions that are specifically designed with their needs in mind. Future research and development should focus on integrating user feedback to continuously refine and enhance digital health solutions. By addressing these gaps, technology can better empower caregivers and improve the overall health care experience for families of children with medical complexity. Ultimately, this study provides valuable guidance for future digital health innovations to support parents of children with medical complexity from underserved communities.

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KEYWORDS

children with medical complexity; pediatric care; digital health; mobile health; mHealth; design; care coordination; underserved populations

Introduction

Children with medical complexity are individuals with multiple chronic conditions—either congenital or acquired—that often involve significant cognitive and/or physical impairments [1,2]. These children typically face functional limitations; rely on life-sustaining medical technologies; and require ongoing, intensive care across multiple body systems [3]. For instance,

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a child with medical complexity might have a genetic syndrome, a congenital heart defect, cerebral palsy, swallowing difficulties, and a urologic condition [4]. Meeting the needs of children with medical complexity requires highly coordinated, specialized care delivered by a multidisciplinary team of health care professionals [5] along with continuous, collaborative engagement between families and health care providers [6]. Although there is no clear definition of children with medical complexity, they are affected by chronic, often very severe conditions for their entire life, which represents a significant cost for the health care system due to their need for continuous assistance [7]. In our study, we defined "children with medical complexity" as individuals aged 21 years or younger who have at least 3 chronic medical conditions [7].

Parents of children with medical complexity are often the foremost experts on their children's needs. They shoulder responsibility for both routine and intensive medical care, frequently under unpredictable and high-stakes conditions with few—if any—alternatives to their demanding role [8]. This unpredictability stems from the child's fragile and often unstable health status [9]. Parents of children with medical complexity perform tasks typically performed by licensed professionals, such as managing life-sustaining technologies, administering medications, and providing complex daily care [10]. As a result, the family caregivers of children with medical complexity report significantly poorer well-being than the general US adult population, including elevated levels of anxiety and impaired sleep health [11].

User-centered digital health solution design incorporating end user input increases the likelihood that digital health solutions will be seen as useful, making it essential to understand patients' and parents' access to and interest in such interventions during technology development [12]. Digital health solutions may play an essential role in improving mental and physical health outcomes [13]. The development of digital health technologies represents a rapidly growing area, offering global health care systems opportunities to enhance care and accessibility [14].

This research aimed to elevate the voices of parents of children with medical complexity by exploring their experiences with current digital health tools and gathering their insights into future innovations. As constant caregivers, advocates, and decision-makers, these parents play a central role in managing their children's complex health care needs and navigating fragmented care systems. By examining how existing technologies support—or fail to support—families of children with medical complexity, this study aimed to identify how digital health can improve care delivery for children with medical complexity and empower families in underserved communities in their caregiving roles. Ultimately, the goal was to identify needs in terms of current digital health solutions and offer actionable recommendations to develop tools that more effectively address the caregiving challenges faced by families of children with medical complexity in underserved communities.

Methods

Ethical Considerations

This qualitative study used semistructured interviews to collect data following ethics approval (2023‐006) from the institutional review board of Stevens Institute of Technology. The interview questions focused on identifying challenges and needs in digital health for the care of children with medical complexity (Multimedia Appendix 1). Participation in the study was entirely voluntary, and participants were informed that the data would be reported anonymously. Data access was strictly limited to the study researchers. Each participant was given a US $30 Amazon gift card for completing the interview. We structured our methodology in alignment with the COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist to ensure transparency [15]. The study team received verbal consent from all participants.

Semistructured Interviews

This qualitative study explored parents' perspectives on how digital health technology supports them in providing care for children with medical complexity, and this study also has potential to shape the path for future enhanced digital health solutions designed for primary caregivers of children with medical complexity. Participants were recruited through the Statewide Parent Advocacy Network (SPAN) based in New Jersey [16]. SPAN is a community organization for children with special needs and children with medical complexity. It was founded by parents of children with special needs in 1987 to provide support to the families of these children and of children with medical complexity [16]. The staff has supported more than 500 families of children with medical complexity in New Jersey for many years, especially those from underserved communities. We designed a brochure and worked with SPAN members to distribute it to families of children with medical complexity from underserved communities who lacked access to medical services. Participants were family members identified as the primary caregivers for children with medical complexity; most were the children's parents. We conducted semistructured interviews with primary family caregivers of children with medical complexity from underserved communities between October 2023 and March 2024. In this study, "underserved communities" refers to families who face structural and access-related barriers to specialized care for children with medical complexity, including provider shortages, geographic constraints, fragmented health systems, and challenges navigating services [17]. These barriers are often substantial enough that families rely on nonprofit or community-based organizations (SPAN) for additional support, care coordination, and resource access beyond what is available through the formal health care system. We also used snowball sampling techniques by asking for referrals from the participants. We used the theoretical data saturation approach to determine the final sample size [18]. Data saturation occurs when further interviews do not yield new themes or reveal new subthemes within the existing themes [19,20]. All interviews were conducted over Zoom (Zoom Video Communications) and were audio recorded.

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Data Analysis

An inductive, reflexive thematic analysis was conducted, with a codebook developed iteratively during analysis to support analytic transparency rather than to impose a priori coding structures. We used a constant comparative approach to collect and analyze data simultaneously. Transcripts were analyzed using inductive thematic analysis. The inductive approach focuses on identifying themes as they emerge from the data to understand the needs of children with medical complexity regarding technology preferences and challenges [21]. Inductive thematic analysis ensures that the themes are representative of participant responses and not shaped by a predefined hypothesis [22]. We used a line-by-line coding method [23]. The first author (FE) coded the data and created a codebook, which was then reviewed, refined, and validated by the second author (OA). We identified themes by comparing situations, suggestions, and experiences from the same and different individuals and gradually refined the coding schema [24]. The coding was performed using Microsoft Excel, which included both inductive analysis and participant demographics.

Results

This study included interviews with 19 family caregivers of children with medical complexity, focusing on parents of children with medical complexity from underserved communities; each interview lasted approximately 45 minutes.

Demographics

Participant demographics were documented to describe the sample. Table 1 presents a summary of the demographic characteristics of the participating caregivers and their children with medical complexity.

Most participants (15/19, 78.9%) were from New Jersey. However, through snowball sampling, in which existing participants referred others to the study, additional caregivers from California, Alaska, Colorado, and New York were included (4/19, 21.1%). Most (12/19, 63.2%) were African American, with others identifying as Hispanic (3/19, 15.8%) or White (4/19, 21.1%) individuals. Most caregivers were aged between 30 and 49 years. The study included 52.6% (10/19) female and 47.4% (9/19) male participants. All caregivers had 1 child with medical complexity except for one caregiver who had twins with medical complexity. The educational backgrounds of the participants included 10.5% (2/19) with master's degrees, 73.7% (14/19) with bachelor's degrees, and 15.8% (3/19) who had completed high school. Finally, most of the children (15/19, 78.9%) were boys. The largest age group was 12 to 14 years.

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Table . Demographic information of the participants.

Participant ID	Age group (y)	Gender	Educational level	Race or ethnicity	State	Relationship to the child	Children with medical complexity, n	Child age (y)	Child gender
P1	40 - 49	Male	High school	Black or African American	New Jersey	Father	1	12 - 14	Boy
P2	30 - 39	Female	Bachelor's degree	Black or African American	New Jersey	Mother	1	15 - 18	Boy
P3	30 - 39	Male	Bachelor's degree	Black or African American	New Jersey	Father	1	12 - 14	Boy
P4	30 - 39	Male	Bachelor's degree	Black or African American	Alaska	Father	1	12 - 14	Boy
P5	40 - 49	Female	Bachelor's degree	Black or African American	New Jersey	Mother	1	15 - 18	Girl
P6	40 - 49	Male	Bachelor's degree	Black or African American	New Jersey	Father	1	6 - 11	Boy
P7	40 - 49	Male	Bachelor's degree	Black or African American	New Jersey	Father	1	12 - 14	Girl
P8	30 - 39	Male	Bachelor's degree	Black or African American	New Jersey	Uncle	1	6 - 11	Boy
P9	30 - 39	Male	Master's degree	Black or African American	Colorado	Father	1	6 - 11	Boy
P10	40 - 49	Male	Bachelor's degree	Black or African American	New Jersey	Father	1	12 - 14	Boy
P11	30 - 39	Male	Bachelor's degree	Black or African American	New York	Father	1	12 - 14	Boy
P12	≥50	Female	Master's degree	White	New Jersey	Mother	1	6 - 11	Boy
P13	40 - 49	Female	Bachelor's degree	Black or African American	California	Mother	1	12 - 14	Boy
P14	40 - 49	Female	Bachelor's degree	White	New Jersey	Mother	2; twins	12 - 14	Boy and girl
P15	40 - 49	Female	Bachelor's degree	Hispanic or Latino	New Jersey	Mother	1	19 - 21	Boy
P16	18 - 29	Female	High school	Hispanic or Latino	New Jersey	Mother	1	0 - 5	Boy
P17	30 - 39	Female	Bachelor's degree	White	New Jersey	Mother	1	15 - 18	Boy
P18	18 - 29	Female	High school	Hispanic or Latino	New Jersey	Mother	1	6 - 11	Girl
P19	≥50	Female	Bachelor's degree	White	New Jersey	Mother	1	15 - 18	Girl

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Qualitative Analysis

An inductive thematic analysis of the qualitative data revealed 2 primary themes related to current experiences with technology in the care for children with medical complexity and unmet needs that could be addressed through digital solutions. These themes were (1) virtual care and (2) consumer mobile health (mHealth) apps.

Virtual Care

The first theme, "virtual care," refers to any interaction between patients and health care providers occurring remotely, using technology with the aim of facilitating or maximizing the quality and effectiveness of patient care [25]. This theme encompasses subthemes based on parents' experiences with using virtual care for their children with medical complexity, highlighting both the challenges they encountered and their needs for improving the virtual care process. Table 2 includes the subthemes, their definitions, and supporting quotes.

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Table . Subthemes, definitions, and supporting quotes for the theme of virtual care.

Subtheme	Definition	Quotes
Information and mental overload related to the parental role as mediator	Refers to the overwhelming amount of information and emotional strain while passing on information to health care providers during telehealth sessions	• "During the pandemic, it was overwhelming. We had to understand the whole process of how and what my child was going through, because it was at this point that we had to communicate with the doctors more remotely, and we had to pass out information to the service providers." [P6] • "It was just me trying to give all the information to the healthcare provider during the telehealth session, and somehow I kind of felt uncomfortable because I do not know, but I had to do it." [P5] • "You can look at the child, but things are subjective. There are these types of things. How swollen are they? My child's stomach is hard and painful. How hard is it? There is no clear answer for that. So how do we make sure that the physicians are getting a clear picture of what is happening with the child physically, based on what you see and measure." [P19]
User-friendly vocabulary	Refers to the need to clearly explain and simplify the medical language so that health information is easy to understand for parents of all levels of medical knowledge	• "There are some terminologies I came across that I did not understand. So maybe providing resources where you can actually understand some of the symptoms or what your child is going through. This can be very helpful. We have to carry out personal research. But these are some things that could be included in telehealth services. And it will actually reduce the stress." [P6]
Support for nonverbal children with medical complexity	Refers to the need to engage, comfort, and support nonverbal children with medical complexity during health care appointments by providing various communication methods based on their abilities and preferences	• "My experience is that providers should know how to communicate with a patient with autism who is nonverbal, or how to understand whether they would like to be touched or whether they have struggles waiting like having survey questions to ask the parent before you begin the telehealth session. It really helps to do those prescreening questions." [P5] • "Some service providers actually do not know how to treat kids who have a hearing impairment, because I know it might be like very tense talking to someone, and the person is finding it hard to hear you." [P7] • "The doctor asked some questions and stuff like that. But facing the screen and answering questions is a bit stressful for my child, and my child can get upset, or just leave the virtual meeting." [P2]
Child-friendly virtual waiting room	Refers to the need for a digital tool designed to engage, comfort, and entertain children with medical complexity while they wait for their health care appointments	• "In terms of the virtual aspects, like sitting, viewing a laptop, and having an appointment, waiting for the doctor. It is kind of intense and stressful for the child." [P6]

Consumer mHealth Apps

The theme "consumer mHealth apps" represents the needs and challenges of parents of children with medical complexity that can be addressed through consumer-focused mHealth features to support their caregiving experience. It explores the features and tools that parents of children with medical complexity need to be developed to manage their caregiving responsibilities effectively. Table 3 presents the subthemes, their definitions, and supporting quotes.

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Table . Subthemes, definitions, and quotes for the theme of consumer mobile health apps.

Subtheme	Definition	Quotes
Digital health notebook	Refers to the need for organizing, tracking, and managing health information in an accessible format	• "I write all symptoms down. But it is always kind of hard for me, because, like, in the process of rushing to take my kid to the doctor. Sometimes, I forget to carry the book with me, so I drive back to the house to bring it." [P10] • "I think we need a milestone tracker of where they should be, or where they could be at that age. I think, if it follows them through their milestone and through their ages as they grow and develop, it could be helpful." [P16]
Medication administration	Refers to the challenges of managing medications for children with medical complexity due to having multiple medications and doses that change frequently	• "Change in medication is a big thing, because giving the child certain things at certain times of the day. And suddenly things have changed. So now you have to be able to make sure you are giving it the right time. And there are no other medications that could potentially have a negative effect on the child due to cross interactions." [P4]
Health technology synchronization	Refers to the need for integrating digital tools and systems related to the care for children with medical complexity to enhance connectivity and user experience	• "I think for us, the safety issue is being able to access medical teams that are all on the same page, who can interact, even if they are in different facilities, can communicate with each other effectively." [P19]
Supporting decision-making	Refers to supporting children with medical complexity in their transition to adult care, enabling them to make informed and confident choices in various situations	• "What they really should be learning at the earliest stages is supported decision-making and self-direction supports. Because I was not told. My kids are 12, and I really was not aware of supported decision-making and self-direction until my kids were 9, and I should have been doing this when they were 3." [P14]

Discussion

Principal Findings

Caring for children with medical complexity involves navigating an extensive network of health care providers—primary care clinicians, specialists, and nurses—across multiple settings, including the home, school, clinics, and hospitals. This fragmentation increases the risk of care gaps over time [26-28]. Prior studies have shown that parents of children with medical complexity face multiple barriers to communication and information accessibility, including difficulties scheduling appointments; coordinating among health care providers; and obtaining clear, actionable health information [29-32]. Many are also tasked with administering complex medication regimens without formal training or having children with medical complexity–specific tools to ensure accuracy [33]. These challenges are even more pronounced for families in underserved communities.

Underserved populations who lack access to proper health care infrastructure are rapidly increasing their adoption of digital health tools to address gaps in care by overcoming barriers such as language and geography [34,35]. A previous study shows that further research is needed to evaluate the effectiveness of mHealth and virtual care and their impact on health care delivery in underserved communities [36]. In addition, digital health tools for the care for children with medical complexity should be shaped by the voices and experiences of families on the front lines of care to build systems that work for children with medical complexity [37]. A unique aspect of this study is its focus on children with medical complexity in underserved communities as a first step, revealing how caregiving challenges intersect with the realities of digital health use with the goal of advancing user-centered digital health solutions for parents of children with medical complexity.

Telehealth has been suggested as a possible way to address health care disparities among underserved urban populations who are often unable to access health care in a timely manner due to low physician-to-population ratios and limited specialty care [38]. Accordingly, telehealth is viewed as a strategy for improving access to care for rural and underserved populations by connecting them with primary care providers, specialists, and mental health services [39]. While virtual care offers a promising avenue for overcoming geographic and resource-related barriers [40], our findings demonstrate that it can also shift significant responsibility onto caregivers. Parents

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described the mental and emotional overload of acting as the primary information conduit between child and health care provider, particularly during remote visits.

Therefore, health literacy is essential for parents of children with medical complexity to make informed decisions and manage their children's specialized care needs [41,42]. Low parental health literacy has been associated with limited health knowledge and poorer child health outcomes [43,44]. Consistent with this, our participants emphasized that integrating user-friendly vocabulary and parent-centered resources within telehealth platforms can reduce the cognitive burden on parents by enabling them to interpret information immediately while communicating with health care providers via telehealth and actively participate in their children's care.

While parental understanding supports a child's care, providers also need to adopt strategies that allow them to communicate effectively with nonverbal children with medical complexity during telehealth appointments. A previous study reported that medical providers' communication strategies often failed to address the needs of nonverbal children with medical complexity, and that strategies such as warmly greeting patients and introducing themselves were sometimes skipped based on the false assumption that these patients could not engage in meaningful communication, which in turn diminished trust between patients and medical providers [45]. This supports our findings that telehealth tools need to be designed as child friendly and support nonverbal children with medical complexity to facilitate communication between patients and health care providers. These considerations were identified as critical for developing an inclusive telehealth tool and are often overlooked in current platforms.

In addition, mHealth is a type of digital health that refers to the use of mobile technologies to deliver health services. It is particularly valuable for improving health outcomes in patients with chronic conditions [12]. Families of children with medical complexity commonly struggle to accurately recall symptoms, clinical events, or over-the-counter medication use, highlighting the need for mHealth tools to document health events outside clinical settings [46]. Regarding caregiver needs, our participants sought mHealth solutions to reduce daily burden and empower decision-making. They envisioned tools consolidating digital health notebooks and medication management. These findings align with those of previous research on the potential of mHealth to empower patients through personalized, timely support [47,48] and integrate digital tools across home, health care, and school systems [49-52]. The desire for synchronized health technology highlights a critical gap in current systems as caregivers of children with medical complexity must repeatedly communicate the same information across providers, increasing workload and the risk of errors.

In addition to supporting day-to-day care, participants emphasized the need for digital technologies that facilitate decision-making for children with medical complexity as they transition to adult care. Few studies have examined the effectiveness of digital health interventions to assist adolescents and young adults with chronic conditions in facilitating self-management and transitioning to adult care [53,54]. There is an interest in using mHealth tools to facilitate the transition to adult care, but early co-design with users and collaboration with health care providers are needed to address varying preferences and needs [53].

Figure 1 summarizes the key challenges that parents of children with medical complexity face—managing complex needs, accessing specialized resources, and coping with emotional and physical burdens—that emerged from our findings. We also developed and listed targeted solutions and recommendations for researchers, health care providers, and software engineers to develop effective, user-friendly systems that better support families.

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Figure 1. Challenges, solutions, and recommendations for enhancing care for children with medical complexity through technological and supportive interventions.



As part of the user-centered design approach, we developed key digital health functionalities to address participants' needs and bridge gaps in the care for children with medical complexity (Table 4). Effective mHealth tools begin with a user-centered design approach that engages end users throughout development to ensure functionality, usability, and relevance [55-57]. Guided by this principle, we assessed the needs of parents of children with medical complexity and translated them into recommended mHealth platforms, including a description of their functionalities to inform the development of actionable software solutions. Technology developers must also ensure compliance with HIPAA (Health Insurance Portability and Accountability Act) alongside robust security, reliability, and usability in collaboration with health care leaders and policymakers [58-60]. In addition, expanding access to digital health tools in underserved communities requires investment in telehealth infrastructure, mobile-friendly screening tools, and community outreach programs that educate caregivers on how to use these technologies effectively [61].

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Table . Technological solutions to support caregivers in underserved communities.

Subtheme	Recommendation	Description
Information and mental overload related to the parental role as mediator	Centralized child-specific care app	• A personalized platform tailored to each child's unique needs, providing a database of treatments, technologies, and resources for mobility, speech, and feeding; contact information for specialists and facilities; and video tutorials and step-by-step guides on managing medical devices, administering medications, and responding to emergencies at home
Medication administration	Medication and device management tool	• An app with features providing barcode scanning for medications; automated reminders for dosage and allergy tracking; integration with medical devices to monitor use and performance; medication interaction checker (the app cross-references medications and alerts parents if there are potential interactions or adverse effects); and notifications to reorder critical medical supplies, with direct links to pharmacies or online retailers
Support for nonverbal children with medical complexity, child-friendly virtual waiting room, and information and mental overload related to the parental role as mediator	Virtual assistant and follow-up tracker	• A virtual assistant app that sets follow-up reminders after treatment; logs symptoms automatically during video consultations; provides summaries of past interactions with physicians; analyzes logged symptoms over time and provides reports, highlighting patterns or triggers for review with health care providers; automatically translates medical terminology into simple, parent-friendly language during telehealth interactions; integrates a pre–telehealth visit form to identify the child's communication preferences, including visual aids, text-based prompts, captioning, or other alternative input methods, to support nonverbal children during telehealth visits; and provides an interactive virtual waiting room with games and calming visuals to reduce children's stress while waiting for appointments
Information and mental overload related to the parental role as mediator	Medical team coordination tool	• A shared platform for health care providers that links professionals from different facilities; offers real-time updates on the child's medical condition; allows caregivers to monitor progress remotely; provides shared medical records and care plans; allows for easy access to specialists in cases of emergency; features a one-tap emergency alert button that notifies all members of the health care team and shares the latest health data; and includes a comprehensive profile that can be shared with new health care providers, including past treatments, medications, and allergies
Supporting decision-making and information and mental overload related to the parental role as mediator	Enhanced appointment and scheduling system	• A system for booking appointments that integrates with personal reminders and health care databases • Parental controls to allow older children to schedule appointments independently • Ability to set appointments and notifications in the caregiver's preferred language to accommodate diverse backgrounds

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Subtheme	Recommendation	Description
Information and mental overload related to the parental role as mediator	Stress relief features for parents	• A caregiver-focused app with emotional support resources such as online counseling; guided journaling to reduce the mental load of caregiving; sleep and stress management techniques; and quick, step-by-step instructions for handling medical emergencies, with links to emergency contacts or services
Health technology synchronization	Smart integration with existing technology	• Compatibility with devices such as Alexa or Google Assistant for reminders and notifications • A mobile-friendly design that integrates seamlessly with smart home ecosystems • Hands-free voice commands to log symptoms, check schedules, or receive reminders • A shared care dashboard that syncs updates across caregivers and medical teams

Strengths and Limitations

To our knowledge, this is the first study to examine the needs and challenges related to digital health technology among parents of children with medical complexity in underserved communities. A key strength of this study is the inclusion of a relatively large sample of caregivers from underserved communities, a group that is frequently underrepresented in qualitative research on children with medical complexity. Although participants were recruited from underserved communities, the relatively high educational attainment among caregivers in our sample may limit the generalizability of the findings to caregivers with lower levels of education. Another limitation of this study is its reliance on Zoom interviews, which may have excluded participants with limited access to technology or who were uncomfortable with digital platforms. This could result in a sample that does not fully capture the experiences of parents who might prefer face-to-face communication.

Conclusions

Our study reinforces that parents in underserved communities are not resistant to digital health; rather, they are eager for solutions that are trustworthy, accessible, and tailored to the care of children with medical complexity. By addressing the intersecting barriers of medical complexity and systemic inequity, health care systems and technology developers can design digital tools that meaningfully enhance care coordination, reduce caregiver burden, and improve health outcomes. Future work should focus on co-design approaches with families of children with medical complexity, evaluation of tailored interventions, and longitudinal research to examine impacts on care transitions and health care use.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview guide.
[DOCX File, 19 KB - pediatrics_v9i1e82317_app1.docx]

Checklist 1
COREQ checklist.
[DOCX File, 23 KB - pediatrics_v9i1e82317_app2.docx]

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Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Research
HIPAA: Health Insurance Portability and Accountability Act
mHealth: mobile health
SPAN: Statewide Parent Advocacy Network

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Leveraging Immersive Virtual Reality to Prevent Child Injuries in the Home: Proof-of-Concept Study

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Abstract

Background: Injury is the leading cause of death among US children, with over 2700 deaths due to unintentional injuries among children aged <6 years in 2023. Many of these deaths occur in the home and involve addressable safety hazards. Evidence-based parenting programs (EBPPs), in which parents work with a provider to learn parenting skills, offer an infrastructure for disseminating home safety content. However, few programs have structured modules on home safety, with most home safety education coming from printed materials or websites. Immersive virtual reality (IVR) allows participants to engage in activities in a simulated, risk-free environment. IVR's technological affordances create a training environment that supports experiential learning and helps learners internalize and transfer knowledge more effectively to real-world situations.

Objective: This study aimed to (1) design an IVR home safety program for parents of children aged <6 years in line with our conceptual model, (2) obtain feedback from parents and EBPP providers on the initial design, and (3) test an initial prototype of the program with parents.

Methods: The prototype was developed using human-centered design principles. The team first identified key components for program content using existing research and theory. Qualitative data were then collected from EBPP provider interviews (n=5) and focus groups with parents (n=7) regarding implementation constraints, program content, barriers/facilitators for engagement, and feedback on the use of IVR. Thematic analysis was used to identify themes from the qualitative data. The initial prototype was then pilot tested with parents of children aged <6 years (n=5).

Results: The IVR program addresses knowledge and skill enhancement in three key areas: (1) home safety hazard identification, (2) hazard removal/mitigation, and (3) parental supervision. Using surveillance data, we identified leading causes of unintentional injuries in the home environment among US children aged <6 years, including sleep-related deaths, firearm injuries, and drowning. Hazards and corresponding tasks in the IVR program were developed for these leading causes. Findings from interviews with providers indicate that they are open to the use of IVR in EBPPs and envision uses for both group and individual settings. They expressed concerns about the cost of incorporating IVR into their usual programs. Parents were interested in IVR, especially if presented in brief sessions. They also noted a desire for the virtual environment to look realistic and "lived in."

Conclusions: Currently, home safety information is delivered in a didactic or pamphlet-driven format in most EBPPs, which is not ideal for behavior change. This IVR home safety program will provide unique benefits in training, including (1) real-world simulations, (2) hands-on learning, (3) a risk-free environment, and (4) IVR scenario-based assessment. This study provides support for the use of IVR in engaging parents in home safety education and presents considerations for future research.

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KEYWORDS

injury prevention; child health; immersive virtual reality; parent behavior; parenting programs; unintentional injury; child safety

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Introduction

Background on Child Injury

Injury is a major public health issue faced by children in the United States. In 2023, over 3500 children aged 0-5 years died due to injury, amounting to 226,385 years of potential life lost. In addition to fatal injuries in this age group, there were almost 2 million nonfatal injuries that required an emergency department visit [1]. Over 3 quarters of fatalities (77.3%) among children aged 0‐5 years in 2023 were due to unintentional injuries, and these injuries predominantly occur in the home environment [2-4]. Common types of unintentional home injuries associated with the leading causes of death among young children include drowning, suffocation, poisoning, burns and scalds, falls and tip-over incidents, and firearm injuries [1].

Child Home Injury Prevention

Parents and other primary caregivers (referred to in this paper simply as “parents”) are key to the prevention of home injuries among young children. Fundamental elements of injury prevention include parents’ ability to identify safety hazards, adequately address hazards, and provide proper supervision. Parents’ knowledge of home safety is associated with reductions in observed home safety hazards [5]. Additionally, children whose parents adopt unsafe behaviors in terms of failing to address hazards and provide adequate supervision are more likely to sustain injuries [6]. Supervision is an especially important element of child injury prevention. Research has found this to be a stronger contributor to child injury prevention than simply identifying and addressing hazards [7,8]. One study noted that parents’ proximity “beyond reach” was associated with serious injuries in young children [8].

Efforts exist to educate parents on home safety in order to prevent child injury. For instance, parents may receive written and/or verbal patient education from their pediatrician at child well visits [9]. There are also organizations such as Safe Kids Worldwide [10] that connect parents with safety devices through their local health department and provide home safety and child injury prevention information online and on social media. Additionally, each year over 280,000 families participate in evidence-based parenting programs (EBPPs), which involve parents meeting with a trained program provider in an individual or group setting to learn parenting skills [11]. These programs typically focus on parent-child interaction skills for parents of young children, and many incorporate home safety in some way. However, home safety information delivered through EBPPs is primarily didactic, involving written materials and/or videos with home safety and child injury prevention information, with home safety devices provided in some instances [12]. A notable exception is SafeCare, which includes a dedicated home safety module with opportunities for home assessment by the provider, parent practice, and feedback [13].

Digital Health and Child Injury Prevention

Digital health tools have been used as a way to engage parents and enhance learning on home injury prevention. To date, this has primarily involved screen-based applications or games. A serious game developed to teach home safety skills was found to be feasible and acceptable among teenage mothers, and their reaction time was faster when they had the opportunity to play the game multiple times [14,15]. This game involved hazard identification in a screen-based virtual home environment and required mothers to maintain focus as distractions such as alarms were deployed periodically in the game [14]. Other serious games and screen-based programs have been deemed feasible and acceptable by parents learning home safety skills [16-18].

Immersive virtual reality (IVR) engages parents and enhances learning beyond what is possible through screen-based interactions. IVR incorporates immersion, embodiment, sense of presence, and interactivity, which have been positively associated with user engagement and learning outcomes [19,20]. Furthermore, IVR has been found to be effective in increasing procedural knowledge [21]. This is especially applicable to home safety education for parents, as much of the knowledge involves understanding the skills necessary and the steps required to create a safer environment. Using IVR, parents can practice skills in a virtual home environment, receiving feedback in real time. Rehearsing skills in a safe, controlled environment allows parents to refine their responses to improve the likelihood of success in the physical world during real-life scenarios.

Study Aims

The goals of this study included (1) designing an IVR home safety program for parents of children aged 0‐5 years intended for dissemination through EBPPs, (2) developing a prototype of the program, and (3) testing the feasibility and usability of the program with parents.

Methods

Overview

The IVR program was developed using principles of human-centered design in a discover, design/build, and test framework [22]. In Phase 1, we conducted preliminary work to identify key content areas and obtained feedback from parents on the initial design. We then developed the prototype and tested it in Phase 2. Each phase is described in more detail below. All data collection from study participants took place between November 2024 and May 2025.

Ethical Considerations

This study was approved by the Kennesaw State University Institutional Review Board (IRB-FY24-579).

Discover and Design: Phase 1

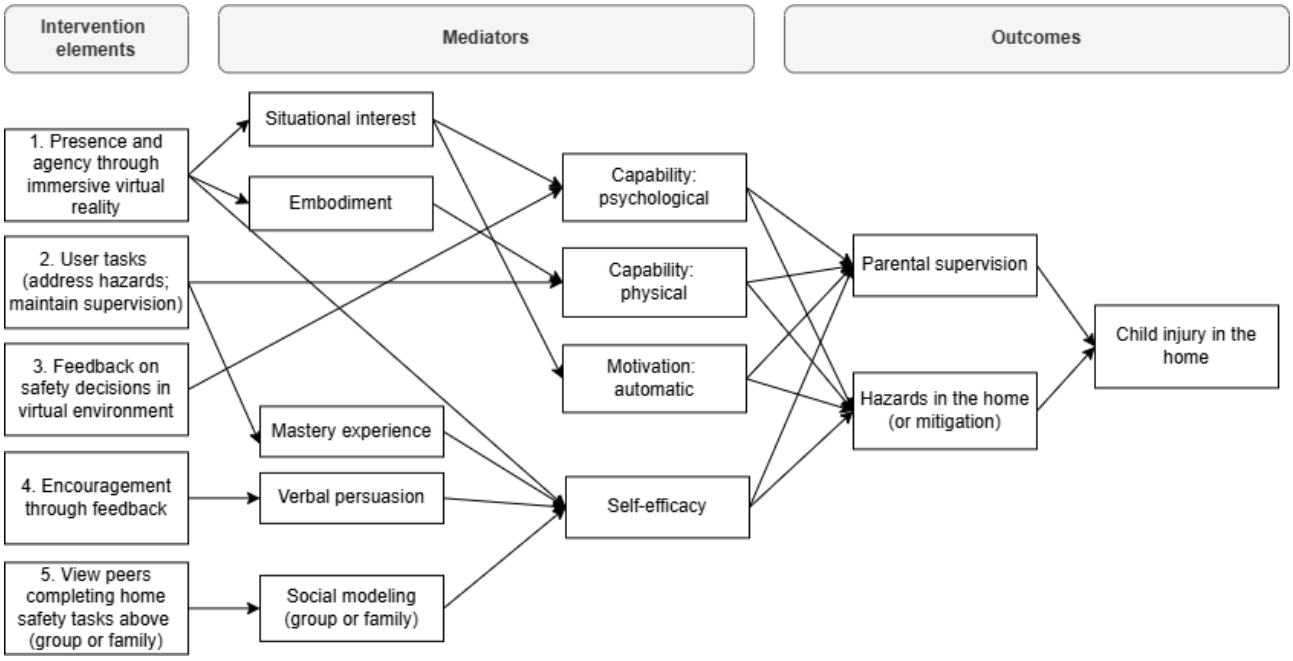
Overview

We first developed a conceptual model for the IVR home safety program (see Figure 1). It is important to note that the goal in this study was not to test this model but to provide a theoretical foundation for the program. The model integrates components of the behavior change wheel [23] and the cognitive affective model of immersive learning (CAMIL) [24]. The behavior change wheel is centered around a framework that states that capability, opportunity, and motivation lead to behavior (the COM-B system) [23]. Our model incorporates elements of capability and motivation, as this best reflects our

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individual-level intervention. CAMIL is a theoretical model for understanding the mechanisms by which education and training through IVR are related to learning outcomes [24].

Figure 1. Conceptual model of ParentSHIELD-VR. Mediators are constructs from the behavior change wheel and the cognitive affective model of immersive learning.



The intervention elements are proposed to ultimately lead to the outcomes of interest (ie, parental supervision and home safety hazards and child injury) through several mediators. Figure 1 depicts these relationships. We will now describe how we propose that each intervention element is related to proximal and distal mediators and, ultimately, to the outcomes of interest. We will describe the proposed paths for each intervention element (numbered in Figure 1). First, the model posits that the sense of presence and agency afforded through IVR (Element 1) leads to increased situational interest, embodiment, and self-efficacy. These proximal mediators lead to effects on distal mediators. Specifically, increased situational interest subsequently leads to increased psychological capability (ie, knowledge) [25] and motivation [26-28]. Embodiment leads to increases in physical capability (ie, skills) [21], which has favorable impacts on the outcomes of interest. Next, the model posits that the user tasks in the program (Element 2, ie, identifying and addressing hazards; maintaining proper supervision in the midst of distractions) favorably impact outcomes through increased physical capability (ie, skills) [23]. Feedback provided to users after they address safety hazards in the virtual environment includes facts or additional context around each hazard (Element 3), and this impacts outcomes through increased psychological capability. Similarly, encouraging statements within the feedback (Element 4) affect home safety outcomes through increased self-efficacy [29]. The program is intended for use both in EBPPs that meet with families individually and those that meet in a group setting. Parents meeting in a group setting could watch other parents engaging with the program through the “cast to screen” feature (Element 5). This feature could also be used for EBPP participants who meet as a family with their provider (eg, one parent watching the other parent or caregiver engaging with the program). These situations would offer an opportunity for social modeling, which would impact self-efficacy [29]. Further details on the conceptual model for the program can be found in Figure 1.

As part of Phase 1, we also identified tasks for inclusion in the program. Our team reviewed the literature and publicly available data sources to identify key content areas. We decided to focus the program’s content areas on leading causes of death related to home injury among children aged 0 - 5 years. As such, we used data from the Centers for Disease Control and Prevention to identify the leading causes of injury in this age group [1] and considered those that occur in a home environment. The initial set of user tasks designed by the research team related to these leading causes as well as hazards of increasing concern (eg, vaping devices), as identified in recent peer-reviewed literature [30]. We included tasks related to the following hazard categories: poisons, burn/scalds, sharp objects, tip-over/crush, falls, firearms, strangulation, suffocation, and drowning.

Provider Interviews

After creating the user tasks and the initial program design in a rough prototype, we conducted qualitative interviews with EBPP providers and focus groups with parents. Specifically, we sought to recruit 5 EBPP providers based on available seed funding resources (ie, funding and timeline). While we would have preferred a sample size of 6 - 12, based on recommendations for qualitative interviews [31], we decided to maximize the number of parent voices included in the project while obtaining as much feedback as possible from providers. Inclusion criteria were providers who were currently delivering an EBPP, had been doing so for at least 1 year, and had the technology necessary to participate in a virtual interview through video conferencing software. Administrators from local social service agencies that deliver EBPPs were contacted via email

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with a description of the study opportunity and a recruitment flyer. They were asked to distribute the opportunity to their providers. Interested providers were instructed to contact the principal investigator (PI; MCO) via email to confirm eligibility. Once eligibility was confirmed, the provider scheduled a virtual qualitative interview with the PI. Each interview took approximately 60 minutes, and providers received a US $35 gift card as compensation.

Qualitative interviews were conducted using an interview protocol developed by the research team. The interview began with the consent process, followed by questions about the provider's current experiences delivering home safety information to parents (eg, current content provided, areas of interest to families, parents' receptivity to safety education) and their current use of technology in program delivery. We then presented the provider with a description of the overall program concept, user tasks, and screenshots of the rough prototype. We also shared the proposed name of the program: parent safe home immersive education and learning development–VR (ParentSHIELD-VR). Following this presentation, the provider was given an opportunity to share feedback verbally. We then conducted a Roses, Thorns, and Buds activity [32] in which providers were given a link to a shared Google Sheet where they listed aspects of the program that they liked, things they did not like, and things they would change. Providers were given 5 - 10 minutes to provide feedback in this way and then were given the opportunity to expand on any written feedback. Finally, providers were asked questions related to resource constraints (ie, time and cost).

The virtual qualitative interviews were recorded and transcribed using features available through Microsoft Teams. Transcriptions were deidentified, and recordings were subsequently deleted. Google Sheets files from the Roses, Thorns, and Buds activity were also saved using a unique identification number for each participant. Following all interviews, data from transcriptions and Google Sheets were analyzed using descriptive qualitative analysis [33,34]. This approach was selected over a thematic qualitative analysis, as the questions focused primarily on program content and design and often requested discrete answers (eg, ways of incorporating home safety content and time spent on the program). Essentially, the questions elicited primarily surface-level responses, and the resulting data are better aligned to descriptive analysis rather than thematic analysis, in which underlying themes are identified [34]. The research team (ie, PI, co-investigators, and research assistants) developed a codebook based on the interview protocol, with codes reflecting each topic area. For instance, there was a code for home safety content in EBPP and subcodes for content provided and not provided. Similarly, there was a code for response to IVR use in EBPP and subcodes for positive, neutral, or negative sentiment. The interview transcripts were then coded by the PI using ATLAS.ti (ATLAS.ti Scientific Software Development GmbH). Through the descriptive analytic approach, similar ideas or responses were identified. Responses from the Roses, Thorns, and Buds activity were organized into common responses using Microsoft Excel. These findings were then shared with the research team and agreed upon before finalizing the results.

Parent Focus Groups

We sought to recruit 10 parents for focus groups to inform the program, with a goal of 5 parents per focus group. The target sample size was based on considerations for ideal focus group size, funding constraints, and study timeline. While we ideally would have included 12 parents across 2 focus groups [35], as with provider interviews, we sought to maximize the number of participants per focus group within our available resources, getting as close as possible to the sample size recommendations. Initially, the inclusion criteria for parents were as follows: at least one child aged 0-5 years, ability to read and speak English, access to the technology necessary to participate in a meeting using web-based conferencing software, and current or previous participation in an EBPP. We attempted to recruit parents through the EBPP providers who participated in qualitative interviews. However, after 2 months of attempts, we were unable to recruit any parents through EBPP providers and their agencies. We revised our inclusion criteria such that the criteria related to participation in an EBPP were eliminated. Using the new inclusion criteria, we recruited parents through an advertisement on the authors' university's Children and Family Programs website and weekly email communication.

Study procedures for parent focus groups closely mirrored those of provider interviews. Interested parents contacted the PI to confirm eligibility and sign up for a virtual focus group. Each focus group lasted approximately 60 minutes. Participants received a US $35 gift card as compensation. The focus group protocol was developed by the research team and was structured similarly to that of the EBPP providers' interviews, with questions adapted for the parent experience (eg, asking about experiences learning about home safety instead of delivering home safety information). The goal of the initial questions regarding sources of information on home safety and interests was to better understand the context in which parents approached the topic of home safety; our primary interest was around the questions asking for feedback on the use of IVR and about ParentSHIELD-VR. Each focus group had 3 - 4 participants. Analysis of qualitative data was conducted in the same manner as the provider interview data described above.

Build: IVR Program Development

Storyboards were developed to provide the initial structure of the virtual environment and the room layout of a virtual apartment. Hazard identification and supervision tasks were also outlined and added to specific scenarios. For example, in a kitchen room, hazards may include scattered knives on a tabletop, a misplaced pot with boiling water on a stove with the handle sticking out, and rotten fruits. Based on detailed scenarios with hazard identification and supervision tasks and room layout descriptions, the development team created a fully immersive virtual environment (VE) using the game engine "Unity." The VE consisted of a living room, kitchen, 2 bedrooms (parent and child), and a bathroom. Interactivity with virtual objects in the VE and supporting virtual hand-based 3D user interfaces (3DUI) were also added to the experience to simulate the real-world interactive experiences. Many of the interactions used Earnest Robot's Auto Hand–VR interaction package, which enhanced the experience with automatic hand posing. The IVR experience

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was intended for use with the Meta Quest 3 mixed reality (MR) headset and controllers, a midtier VR system available on the market with a large user population. The full experience included a tutorial session, which taught participants how to travel in the virtual home and interact with virtual objects, followed by the training session. Users were tasked with identifying and resolving hazards in the VE. Within the training session, players received feedback via 3DUI upon attempting to address each hazard. See Figure 2 for screenshots of the VE. In the top panel of Figure 2 is an example of a firearm hazard in the primary bedroom. The middle panel depicts the kitchen in ParentSHIELD-VR. Participants can see the number of hazards that need to be resolved. Two hazards can be seen in Figure 2: a pot of boiling water and a knife (on the counter next to the stove) within reach. The bottom panel depicts an example of a supervision scenario in ParentSHIELD-VR. When the parent places the baby in the bathtub, they are presented with a situation in which the older child calls for them in another room. The parent is asked to select a response to this scenario.

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Figure 2. Screenshots from parent safe home immersive education and learning development–virtual reality (ParentSHIELD-VR).



Test: Phase 2

Study Design and Procedures

Following prototype development, we sought to conduct prototype testing with 10 parents of children aged 0 - 5 years, based on recommendations of 5 - 10 individuals for usability testing [36,37]. Parents were recruited through flyers at local community organizations (eg, local libraries and social service agencies) and the authors' university weekly email communications. Interested parents contacted the PI to confirm eligibility and schedule a research assessment at the university. At the research assessment, participants first completed a survey (pretest), then went through ParentSHIELD-VR, and finally completed a second survey (posttest). Measures in the pretest and posttest are described in more detail below. While we use the terms "pretest" and "posttest," the study aims primarily focused on feasibility and usability data, which were collected at posttest. Secondarily, we aimed to collect data on the research

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process and to pilot measures related to home safety and child injury to be used in a future large-scale trial. When participants tested ParentSHIELD-VR, members of the research team were present to orient them to the headset, answer questions, and remain present for the session. Each research assessment took approximately 90 minutes, and participants were compensated with a US $99 gift card.

Measures

The pretest was administered using Qualtrics (Qualtrics International Inc) and included sociodemographic information, injury history, and a safety hazards knowledge assessment. Data from the latter 2 categories were collected as part of piloting measures in preparation for future studies examining injury outcomes. Sociodemographic items captured data on parents' age, race, ethnicity, household income, and child's age. Two items asked about child injury history in the past 3 months. First, parents were asked about the frequency of injuries that were treated at home: "In the past 3 months, how many accidental or unintentional injuries did your child have that you treated at home (eg, with an ice pack, bandages, etc)? This could be from a fall, scrape, burn, or any other injury that occurred and that you cared for at your home but did not require a visit to the doctor, hospital, or urgent care." Then they were asked about the frequency of injuries that required treatment by a medical provider: "In the past 3 months, how many accidental or unintentional injuries did your child have that occurred at your home and required you to take them to seek care from a medical provider (eg, at the hospital, urgent care, or doctor's office)?" Finally, participants' knowledge of home safety hazards was assessed through a task in a physically simulated home environment in the authors' university simulation center. A simulation space typically used for nursing home health simulations was transformed into a home with a young child and their family. Nine safety hazards were placed in the room by the research team. Participants were given 10 minutes to walk through the physical space and list the hazards in the Qualtrics survey.

The posttest included items on the research process, program usability, feedback on the program, and a safety hazards knowledge assessment. Specifically, items in the research process related to recruitment source, motivation to participate, and satisfaction with compensation. Program usability was assessed with the User Experience Questionnaire (UEQ) [38], a 26-item measure asking participants to rate the program using a 7-point Likert scale with bipolar anchors representing various elements of usability and experience. For instance, one item asks respondents to rate the program in terms of how annoying (1) or enjoyable (7) it is. Several items (3, 4, 5, 12, 23, 24, and 25) were reverse-coded such that 7 indicated the favorable side of the scale. However, note that some UEQ items do not necessarily have one favorable side (eg, fast to slow), and the open-ended items provided participants the opportunity to expand on the aspects of the program that they favored. Participants were given the Roses, Thorns, and Buds activity that was used in Phase 1, but it was completed via open-ended items in the Qualtrics survey. Finally, participants returned to the physical home simulation space and were given 10 minutes to assess the space for hazards.

Analytic Plan

Quantitative data (ie, sociodemographic information, the UEQ, and research process items) were summarized using descriptive statistics. Given the small sample size, UEQ items are presented as frequencies by category and range. As in Phase 1, qualitative data were analyzed using descriptive analysis. Data from the safety hazards knowledge assessment were examined in terms of the feasibility of using the physical simulation space to assess parents' home safety knowledge rather than to assess knowledge itself. That is, we sought to determine whether assessing parents' knowledge in this way was practical and to identify any barriers to collecting data in this way.

Results

Phase 1

EBPP Providers

Five EBPP providers (4 women and 1 man) were recruited for qualitative interviews. They represented 4 different EBPPs. Four of the 5 providers (80%) delivered programs that focused on parent-child interaction but incorporated home safety information; one provider delivered a program that had a dedicated home safety module along with parent-child interaction and other content. All providers incorporated home safety information in some way. The 4 providers who delivered an EBPP that did not have a dedicated home safety module all said that their approach to incorporating the content involved discussion of written information or videos, with some agencies providing parents with home safety devices. For example, one provider stated, "Yes, we do have some handouts, and then we give them to the parents...." Another provider said, "...we have a video we review. We provide a book that we review...as well as their worksheets and that kind of stuff in the book." The one provider delivering the EBPP with a dedicated home safety module said she typically begins with that module if the family has been referred to the program based on allegations of safety concerns. When asked about home safety topics of interest to families, providers, interestingly, initially provided responses related to a range of safety topics, not necessarily related to in-home safety. For instance, 2 providers discussed families' interest in learning how to avoid violence from strangers, one mentioned the importance of emotional safety, and one cited parents' concerns about children's physical health after a recent environmental crisis that occurred in their community in which toxins were released in the air. When prompted specifically about home safety topics that parents would benefit from, providers noted safe sleep, car seats, and "child proofing" (eg, cabinet locks and outlet covers). Four of the 5 providers in the sample reported limited use of technology for program delivery.

> *I have a computer to enter my [hours spent with families], but I don't use it when I go to do my home visits. I just take papers.* [Provider C]

Some used their mobile phones or the parents' phones to share videos during sessions (eg, "I take my phones and show them videos...."). While 2 providers reported that their EBPP had an app, they reported inconsistent use.

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> *I mean, the app is only used with some people, honestly, if they want to see those handouts [digitally] or if they don't want me to physically give them a copy, but we don't use a lot of technology.* [Provider B]

All providers had an overall positive response to the idea of using IVR in EBPP sessions and thought it would be engaging to parents (eg, "I think that'll be great," "...it's another great way to present the program and have parents explore," "...it could be really powerful to do"). Questions and concerns about the use of IVR related to logistics (eg, who brings the headset and would Wi-Fi be required) and cost.

> *The families that we serve do not have a lot of access to things, so a lot of things may not have Wi-Fi. I have families that use only Text Now numbers, so they're not even able to receive phone calls or see videos like that.* [Provider E]

This provider also noted that some parents may be "more receptive to it [IVR] than others just because of age." Regarding ParentSHIELD-VR, providers also had an overall positive reception to the concept and name. One provider noted that the name may cause some parents to think of a popular movie franchise, but they did not think that was a negative thing. Providers suggested more realism in terms of the graphics (ie, higher-quality graphics) and the look of the VE. Of note, the rough prototype used to develop screenshots shared in Phase 1 featured a home setting with a bright, clean look, new appliances, and few imperfections. Providers suggested that there should be typical imperfections, such as piles of laundry, to make the house appear like a realistic family home and therefore more relatable to the average family they serve, with one provider especially emphasizing this issue.

> *My only worry would be like making it more real-ish for our parents because none of our parents has a clean—you know...they have more than just a knife on the counter.* [Provider B]

While the suggested time spent on the program ranged from 15 minutes to an hour, most providers said they would spend an hour. Two providers suggested incorporating the program into community events that their programs participate in, such as parent seminars that are held on a regular basis. Some suggested breaking up the experience across multiple sessions. Providers had questions about cost, and while the study participants did not make budgetary decisions in their respective organizations, 3 providers wondered if small grants or existing funds could be used to purchase IVR equipment.

> *...we're pretty much federally funded. So, I guess it would have to go back to whether they deemed it something that we could use that'd be beneficial.* [Provider A]

Another said, "I think in the past we have had, like, a technology fund for a certain amount."

Parents

In total, 7 parents (6 women and 1 man) were recruited for Phase 1 across 2 focus groups. Parents reported car seat installation, "baby proofing" their home, and safe sleeping as main safety topics of interest, with car seats mentioned most frequently. They reported a range of sources consulted when seeking home safety information, including professionals, their own social network, and internet sources. Professionals from whom parents received home safety information included pediatricians, health care professionals at the hospital postdelivery, and certified car seat installation technicians at local fire departments.

> *I think we received, like, a huge amount of pamphlets when he was born from the hospital, and I think we have gotten things from our pediatrician.* [Parent C]

They also sought information from friends and from other parents in social media parent groups. Parents reported searching for home safety topics using online search engines, YouTube (Google), apps, and ChatGPT (OpenAI). Online search engines (ie, Google) and YouTube were the most common sources used when seeking information about home safety on their own (ie, without a professional or another individual in their social network), with 3 participants reporting use of each of these approaches. One parent described the usefulness of online search engines, saying, "So usually when I'm needing information, it's, like, quick and in the moment, and I'm just Googling." Another parent said, "I Google a lot – like, a lot." Some parents also reported that home safety topics appeared in their social media feeds, and it could be confusing to identify reputable sources and sort through conflicting information.

> *I feel like what comes to my mind initially is just Instagram. And sometimes it's like a blessing and a curse. There's a lot of information out there, so sometimes it makes me a little paranoid.* [Parent D]

> *I feel like I have to do a lot of research myself just to figure out how trust those online YouTube video and things on Instagram are. Very confusing and very time consuming too.* [Parent F]

> *Yeah, I think I would just echo I feel like I see a lot of conflicting information also on social media where there's accounts that are like about safe sleep habits and like preventing SIDS, but then there's accounts of 'you can totally co-sleep safely; it's your family's choice,' so it's just very, like, differing opinions and not necessarily people who are coming from, like, a research mindset. It's usually their own personal experience.* [Parent G]

Parents in the focus groups had an overall positive response to the use of IVR to learn about home safety and to ParentSHIELD-VR, describing it as "fantastic" and "something I wish I had when I was a first-time mom." One parent pointed out the element of skill practice that IVR offers, saying, "I like that because I do learn better personally by doing." As none of the parents had participated in an EBPP, they had suggestions for places where they would like to encounter the program, including prenatal visits, pediatrician visits, and use of the program on their own at home. They noted that first-time parents may be more receptive to the information and have more time to spend on it.

> *If you're at the pediatrician's office you have your kid there with you...But if you're at the OB/GYN*

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> *before you have a kid, that's a different story.* [Parent E]

As with providers, parents thought that the program would be improved with more realism in terms of the graphics and the look of the VE. Regarding graphics, one parent said "...it looks like a Minecraft game." That parent also commented on the look and feel of the VE saying, "It was also super clean...That is not realistic." One parent suggested adding a "kid's-eye view." This parent said that she had been given advice to:

> *get on the kid's level to see the hazards. So, is there a way in your program to get on the kid's level and see not just at the adult standing level but...on the ground with the kids, so you're at kid eye level...?*
>
> *[Parent A]*

One parent suggested adding a feature to assess their own home for hazards through augmented reality.

> *It would be amazing if you could maybe, like, do integrated reality as I'm looking around my actual kitchen and then you put, like, a virtual knife on the counter, similar to what you did, but it's, like, my home, so then it means more to me.* [Parent B]

In terms of time spent on the program, parent responses ranged from 5 to 60 minutes, with most saying they would spend 20 - 30 minutes on it. One parent noted that she would have been able to spend more time on such a program when her children were younger.

> *I would say 20 to 30 minutes would probably be my max, but that's just 'cause I have two kids so I don't have a lot of extra time, but when they were little [sic], I could probably do, like, 30 to 45.* [Parent B]

One parent suggested participating in the program in segments rather than in one encounter.

Phase 2

Following Phase 1, refinements were made to the program based on participant feedback, including the development of a tutorial, the addition of a child's bedroom, and addressing comments about realism through the use of a more modest, relatable home environment (eg, dust and dirt in high traffic areas, miscellaneous objects on side tables, and modest appliances and fixtures). Five parents participated in Phase 2 prototype testing. These parents were recruited through flyers distributed via a social service organization (n=2, 40%), university email communications (n=2, 40%), and the local public school system (n=1, 20%). They identified as non-Hispanic White (n=2, 40%), non-Hispanic Black (n=1, 20%), Hispanic White (n=1, 20%), and non-Hispanic multiracial (n=1, 20%), with a mean age of 30 (SD 2.12) years. Most reported an annual household income of <US $50,000 (n=3, 60%). While we did not formally collect data on prior IVR use, the research team noted through informal conversations with participants that they reported little exposure to IVR, with some having never used it before and one having used it for job-related training. In terms of injury history, all participants reported at least one injury treated at home in the past 3 months, and one reported a single injury requiring treatment by a medical professional.

The results of the UEQ indicated that participants found the program to be highly creative (median 7, IQR 4.5-7), innovative (median 7, IQR 6.5-7), and organized (median 6, IQR 6-7). There was variability in ease of learning (median 5, IQR 3-6.5) and predictability (median 5, IQR 3-5.5). See Table 1 for UEQ results. Participants provided free text responses to the Roses, Thorns, and Buds activity. Elements of the program that participants liked included learning about home safety, the use of IVR to learn about home safety, and learning how to respond to hazards that may not be in their own home (eg, considering what to do with button batteries when you have not encountered them before). Elements that participants did not like included some program elements that did not function during testing (eg, doors that were difficult to open), experiencing motion sickness, time to become accustomed to the technology, and a lack of realism (eg, "some things don't look too real which makes them hard to identify"). Regarding the lack of realism, in observation notes taken during assessments, research team members identified items in the VE that parents asked about, including cleaning products, bath soap bottles, and a button battery pack, that were difficult to identify. Finally, elements that participants wanted to add to the program were hazards outside the home (eg, pool) and an in-person component.

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Table . UEQ[a] results for Phase 2 participants (N=5). Frequencies are presented in the cells. For instance, on a scale of dull to creative (Item 3), 4 respondents selected a rating of 7.

UEQ item number and scale	Rating						
	1	2	3	4	5	6	7
1: Annoying to enjoyable	0	0	1	0	0	3	1
2: Not understandable to understandable	0	0	0	0	1	3	1
3: Dull to creative[b]	0	1	0	0	0	0	4
4: Difficult to learn to easy to learn[b]	0	1	0	1	1	1	1
5: Inferior to valuable[b]	0	1	0	0	1	2	1
6: Boring to exciting	0	1	0	1	1	2	0
7: Not interesting to interesting	0	0	0	0	0	4	1
8: Unpredictable to predictable	0	0	2	0	2	1	0
9: Fast to slow	0	1	2	1	1	0	0
11: Obstructive to supportive	0	0	0	0	1	3	1
12: Bad to good[b]	0	0	0	1	0	3	1
13: Complicated to easy	0	0	0	1	1	3	0
14: Unlikeable to pleasing	0	1	0	0	1	2	1
22: Impractical to practical	0	0	0	1	2	2	0
23: Cluttered to organized[b]	0	0	0	0	0	3	2
24: Unattractive to attractive[b]	0	0	0	1	0	3	1
25: Unfriendly to friendly[b]	0	0	0	0	0	3	2
26: Conservative to innovative	0	0	0	0	0	1	4

[a]UEQ: user experience questionnaire.

[b]Items were reverse coded.

As with Phase 1 parents, parents in Phase 2 were not recruited through EBPPs and had suggestions for alternative dissemination routes, including high school early childhood classes. Parents also provided general feedback on ParentSHIELD-VR and on research participation in an open-ended question. One participant said that she had learned about a new thing.

blinds and putting the strings up. My current blinds don't have them but I can definitely see that causing issues for a small child. [Parent I]

I've learned a lot about safety hazards through traditional methods...but this concept made me think about ways to show those hazards to new parents or caregivers.... [Parent K]

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Finally, regarding research participation, a parent noted, "I learned that there is [sic]people looking after child safety, and ways to help parents achieve it, which is great." Three parents specifically noted that the program was "fun," "enjoyable," and/or "cool" in their responses.

Discussion

Principal Findings

This proof-of-concept study found that an IVR home safety program was positively received by parents and EBPP providers, and they identified key areas for further development. While this is a small proof-of-concept study and more research is needed, this IVR approach shows promise as a child injury prevention strategy. Parents appreciated a unique opportunity for interactive and immersive learning on home safety, and EBPP providers saw the possibilities of increased engagement through IVR. Parents had a range of prior experience with and ease of learning in using IVR. Future work on ParentSHIELD-VR will incorporate approaches that bypass challenges in acclimating to the VE and reducing cognitive load. Prior research has found that, despite the many benefits of IVR, it can increase cognitive load, which has implications for learning outcomes [39,40]. This can be addressed with careful attention to design, including just enough details to maintain representational fidelity without overstimulating the user or requiring a great deal of cognitive processing [24]. For instance, in the virtual home environment in ParentSHIELD-VR, interior doors could remain open, eliminating the need for the user to open them. This could be done using additional interaction techniques based on the design of virtual hands. Future iterations of ParentSHIELD-VR will incorporate this approach.

In addition to cognitive load, other elements of parents' interaction with IVR may impact their engagement with or outcomes associated with the program. First, prior experience using IVR could have an effect. Parents who have had the opportunity to acclimate to the VE and are more confident using the IVR equipment (ie, headset and controllers) may feel more comfortable engaging with the program. This could impact their experience of the program and their openness to learning, as has been found in prior research [41,42]. While we did not collect data on prior experience with IVR, this is an area for future research. Furthermore, cybersickness (ie, experiencing motion sickness, such as nausea and dizziness, during IVR use) may affect parents' experiences with the program. One participant in our study reported motion sickness as a "thorn," or an area of the program in need of revision. The estimated extent to which cybersickness affects IVR users varies, but some studies suggest that over half of users experience cybersickness when using head-mounted display-based IVR, and a greater proportion of women report it compared with men [43]. Cybersickness can be influenced by factors including postural instability, approach to moving in the VE (eg, use of joystick locomotion as opposed to real walking in the physical space), prior experience with IVR, and individual susceptibility to motion sickness [44-46]. For instance, use of teleportation and sitting (as opposed to standing) are approaches to moving in the virtual space that are associated with reduced risk of cybersickness [44]. Additionally, novice users and those who are susceptible to motion sickness in the physical realm are at increased risk for cybersickness symptoms [45,46]. Guidance on various options for moving through the VE (ie, real walking, joystick locomotion, and teleportation) was included in the ParentSHIELD-VR tutorial in an effort to reduce the risk of cybersickness. However, the implications for cybersickness may not have been made explicit. The primary cause of cybersickness in our prototype may be the constant virtual movement required to complete the tasks. We can mitigate this risk through 3 design changes. First, we can encourage users to choose teleportation instead of continuous locomotion. Teleportation is already available as an alternative movement option in the prototype, but the tutorial should explain its benefits more clearly and show users how to switch to it if they begin to feel sick. Second, we can apply a tunnel vision effect during continuous locomotion. Temporarily reducing the user's field of view while they are moving can help minimize cybersickness. This technique has been available in the Unity VR template project and many commercial VR experiences involving virtual movement. Third, we can map the virtual environment to the available physical space. This would allow users to navigate the virtual environment by walking naturally in the real world, reducing their reliance on artificial locomotion.

ParentSHIELD-VR was designed to be implemented within the context of EBPP. Results of this proof-of-concept study shed light on potential issues related to implementation in this setting, which should be explored further. EBPP providers had questions about the costs of an IVR program. The providers in our study were not involved in budgetary and administrative decisions. However, they wondered who would be paying for the VR headset and noted that their organizations sometimes apply for small grants to purchase new technology. They also suggested implementing the program with parents who already own a VR headset. This could have the added benefit of engaging parents who are already familiar with and motivated to use IVR. Of note, some providers brought up concerns regarding lack of Wi-Fi in some families' homes. ParentSHIELD-VR would come loaded on the VR headset, preventing the need for an internet connection. Ultimately, while we propose that this program could benefit all EBPP families, it may be the case that when EBPP agencies have limited technology available, ParentSHIELD-VR should be targeted to families who would most benefit. For instance, families who have been reported to child welfare for allegations of neglect related to safety practices have a clear need for home safety education. One of our provider participants noted that she begins with home safety education when working with such families. Also, families who are already engaging in IVR and therefore have already overcome the common barriers, such as cybersickness or difficulty learning how to operate the equipment, may be most receptive to the program and derive the most benefit from it. However, more work is needed to determine approaches for identifying families who would benefit most and the contexts in which IVR is most effective [47]. Research on virtual reality in mental health and behavioral health settings has found cost to be an implementation barrier, despite clinician or provider acceptance of the technology [48]. In one study, 2 substance use disorder treatment clinics shared a VR headset to save costs, but this

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resulted in inefficiencies in scheduling patients [48]. In mental health treatment, concerns around security and patient privacy have arisen as barriers to implementing telehealth or VR therapy [49]. While this has not been studied explicitly among EBPP providers, they may share these concerns, and future work should explore this potential barrier. There is also an indication that adoption of IVR in mental health treatment settings follows organizational norms around adopting innovative practices in general (ie, technological or otherwise), and some organizations may be slower to implement new practices than others [49,50]. The potential resource constraints associated with implementing IVR programs in EBPP are an area in need of research.

Limitations

The findings in this proof-of-concept study should be interpreted in the context of several limitations. Phase 1 and Phase 2 participants were primarily from the Southeastern United States (94%), and there may be regional differences in preferences for safety and parenting information that would be identified with a sample from multiple geographic regions. Additionally, while Phase 2 parent participants represented a diverse set of races, ethnicities, and socioeconomic backgrounds, all identified as women. Gender differences may exist with regard to the receptivity of home safety education and interactions with technology. Relatedly, no sociodemographic information was formally collected on Phase 1 participants. Thus, while we have information on participant gender based on research team member interview notes, we cannot report detailed sociodemographic information that would assist in assessing sample representativeness for Phase 1. The study has limitations regarding sample size. In Phase 1, our sample sizes were slightly below recommended sizes for qualitative research due to funding constraints and challenges with recruitment, which may have resulted in some points not being identified, although studies have found that few new concepts are identified after the fifth or sixth interview [31,51]. The Phase 2 sample consisted of only 5 participants. While this is in line with conventional recommendations for usability testing using heuristic evaluation [36,37], we acknowledge the discussion regarding the need for larger sample sizes in usability testing [52,53]. Further testing (ie, beyond proof-of-concept) is needed to obtain expanded perspectives on the usability and acceptability of ParentSHIELD-VR. Finally, parents in the study were not recruited from EBPPs, as intended, which could limit generalizability to the population of EBPP participants. This was especially true with regard to Phase 1 parents, all of whom were ultimately recruited from the university environment. Data from evidence-based home visiting programs (a subset of EBPP) indicate that a substantial proportion of parents participating in these programs (21%) do not have a high school diploma, and 84% have children who are on public insurance [11]. Parents referred to EBPP are often (but not always) experiencing family stressors such as financial stress or violence in the home. These characteristics (ie, low socioeconomic status and family-level stressors) may bring unique challenges or perspectives that were not captured among our parent participants, who reported higher levels of income and education. While Phase 2 parents were not from EBPPs, 60% reported an annual family income of <US $50,000, and those parents may be similar to the average EBPP participant in that regard. Additionally, responses from Phase 1 providers often incorporated the ways they anticipated that parents might respond to the program or potential challenges, but we recognize that this is not a replacement for learning directly from parents in EBPP. Future research should include the voices of parents in EBPP, addressing recruitment challenges through strong collaborations with EBPP agencies.

Conclusion

In this proof-of-concept study, ParentSHIELD-VR emerged as a potentially feasible way to engage parents of young children in home safety education. This study was proof-of-concept, and refinements and additional testing are needed to address user recommendations for the program and to assess its efficacy in addressing outcomes related to parent behavior and child injury. Our team has begun program refinements, including the use of improved graphics and clear labels to improve the realism of products in the VE. While ParentSHIELD-VR is in the early stages of development and testing, the approach has the potential to be translated to additional populations, such as parents of older children and teenagers. As children age, new hazards and concerns emerge, and these could be incorporated into a future iteration of the program. As one provider noted in Phase 1, many families have a “wide age range” between children, and they may be experiencing multiple developmental phases simultaneously. Future development and research could explore the potential benefits and opportunities of more recent technological advancements, such as the integration of AI into the IVR system through, for example, tailored, responsive feedback throughout the program to create a more adaptive and personalized training experience. IVR opens up a range of unique opportunities to engage parents in home safety education to prevent child injury.

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Data Availability

The datasets generated during this study are available from the corresponding author on reasonable request 6 months or more after the final study publication.

Authors' Contributions

Conceptualization: MCO, LZ, AG
Data curation: MCO
Formal analysis: MCO
Funding acquisition: MCO, LZ, AG
Investigation: MCO
Methodology: MCO
Project administration: MCO, LZ, AG
Resources: AG
Software: LZ, RF
Supervision: MCO, LZ
Writing – original draft: MCO, LZ
Writing – review & editing: MCO, LZ, AG, RF

Conflicts of Interest

This paper describes proof-of-concept testing of software that was developed by the authors. The authors have no financial interest in the software.

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Abbreviations

3DUI: 3D user interface
CAMIL: cognitive affective model of immersive learning
COM-B: capability, opportunity, and motivation lead to behavior
EBPP: evidence-based parenting program
IVR: immersive virtual reality
MR: mixed reality
ParentSHIELD-VR: parent safe home immersive education and learning development–virtual reality
PI: principal investigator
UEQ: User Experience Questionnaire
VE: virtual environment

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Toward Family-Centered Patient Portals for Childhood Asthma Management Among Black Primary Caregivers: Qualitative Interview Study

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Abstract

Background: Childhood asthma places substantial burdens on caregivers, particularly in communities facing structural barriers to health care access. Patient portals, the patient-facing component of electronic health record systems, are primarily designed for clinical workflows, limiting their usefulness for caregivers managing their child's asthma.

Objective: This qualitative study aimed to elicit primary caregivers' perspectives on managing childhood asthma and their experiences with patient portals to inform the development of a community-centered and family-centered medical platform.

Methods: The authors conducted a qualitative study using in-depth, semistructured interviews between July and October 2024 with 15 Black primary caregivers of children with asthma living in the Greater Philadelphia area. Participants were recruited through purposive sampling in partnership with Philly Thrive, a community-based organization. Interviews were conducted both in person and virtually and lasted 30 to 90 minutes. A semistructured guide with 3 core questions explored experiences with managing childhood asthma, interactions with medical documentation and patient portals, and recommendations for redesigning patient portals. The number of interviews was determined by data richness and fulfillment of study aims. Data were analyzed using reflexive thematic analysis, guided by the Standards for Reporting Qualitative Research.

Results: Two themes were generated. Theme 1, lived experiences of managing childhood asthma in families and communities, revealed that caregiving involves profound emotional work, daily routines, and community knowledge sharing that health systems largely do not recognize or support. Theme 2, caregivers' perceptions and experiences of navigating patient portals for childhood asthma, revealed that caregivers used portals selectively at key care moments rather than routinely. Persistent barriers included confusing medical terminology, outdated medication records, and limited communication channels. Caregivers recommended direct provider messaging, integration of environmental trigger data, streamlined medication refill processes, and age-appropriate portal features to support children's gradual self-management.

Conclusions: Effective childhood asthma management requires information systems that honor caregiver expertise, provide transparent and accurate documentation, and actively work to reduce epistemic injustice. Community-centered platform design should integrate caregiver knowledge, environmental data, and child-appropriate tools to support equitable asthma care.

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KEYWORDS

childhood asthma; electronic health records; health portals; caregivers; qualitative research; health equity; community-based research

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Introduction

Background

Childhood asthma affects approximately 4.9 million children in the United States and is one of the most common chronic conditions in childhood, as well as a leading cause of missed school days and health care usage [1]. Globally, the condition affects approximately 10% of children and is characterized by symptoms such as wheezing, coughing, and shortness of breath that disrupt daily activities [2]. While asthma cannot be cured, it can be managed through ongoing treatment that requires consistent daily care, both inside and outside clinical settings.

The majority of childhood asthma management occurs outside clinical settings. Primary caregivers take responsibility for monitoring symptoms, administering medication, and coordinating care [3]. Recurrent exacerbations, emergency department visits, and disruptions in school attendance place emotional and practical burdens on families [4]. These challenges are frequently more pronounced in Black and Hispanic communities, which bear a disproportionate burden of asthma morbidity rooted in structural racism, including residential segregation, exposure to poor housing conditions, and disproportionate proximity to environmental pollutants that worsen air quality and increase asthma risk [5,6]. Pediatric asthma is defined as a chronic inflammatory condition of the airways characterized by variable airflow limitation and respiratory symptoms, including wheezing, coughing, and shortness of breath [7]. Current management encompasses a stepwise pharmacological approach, from inhaled corticosteroids to biological therapies, including omalizumab and dupilumab, for children with severe or poorly controlled disease [8,9].

Although effective treatments exist, many children continue to experience poorly managed symptoms in real-world settings, contributing to ongoing disease burden and health care usage [10]. Effective management depends on more than treatment availability. Collaboration between caregivers and providers, including clear communication about treatment plans, is essential for ensuring families can manage symptoms and medications at home [11].

The electronic health record (EHR), an evolving technology with widespread use, supports communication and shared decision-making between families and providers; however, limited caregiver engagement signals persistent barriers to its use [12]. EHR systems are primarily designed for clinical practice rather than patient or caregiver involvement. This design gap limits accessibility and has been described as a form of epistemic injustice: a harm done to someone specifically in their capacity as a knower [13,14]. These gaps suggest that EHR systems, designed primarily for clinical workflows, may be misaligned with the realities of how caregivers implement and navigate asthma management. Interdisciplinary and community collaboration offers a path toward addressing these barriers by reimagining how medical documentation is designed to better integrate community knowledge to meet caregiver needs [15,16].

These design gaps are compounded by health literacy challenges: caregivers who already struggle to understand medical information face additional barriers when EHR interfaces require them to navigate complex clinical terminology without support [17,18]. Variability in how clinical information is documented across systems further limits caregivers' ability to build a coherent picture of their child's health [19]. These inequities extend into the digital health environment, where patient portals designed primarily for clinical workflows may further disadvantage Black caregivers by failing to support the realities of their caregiving context [20,21]. This study, therefore, centers the perspectives of Black primary caregivers as those most affected by these intersecting inequities and least served by current portal designs.

Despite growing recognition of these disparities, qualitative research examining how Black primary caregivers specifically experience and navigate patient portals in the context of managing childhood asthma remains limited [12,20,22,23]. This study addresses that gap by centering caregivers as domain experts whose lived experiences are essential to designing health information systems that work for the communities most burdened by asthma.

Objective

This qualitative study aimed to elicit primary caregivers' perspectives on managing childhood asthma and their experiences with patient portals (the patient and caregiver-facing system of an EHR) in their child's care and to inform the development and implementation of a community-centered and family-centered medical platform.

Methods

Study Design

We conducted a qualitative study using in-depth, semistructured interviews with 15 caregivers of children with asthma, focusing on their experiences with patient-facing portal interfaces rather than clinician-facing EHR systems, as these tools present distinct design challenges for caregiver engagement. The aim was to generate community-informed insights into caregivers' information needs and their interactions with clinical documentation systems.

Participants

All participants were Black female caregivers of a child with asthma living in the Greater Philadelphia area. For this study, a primary caregiver was defined as an adult who identified as the person primarily responsible for the day-to-day health management of a child with an asthma diagnosis. Recruitment was conducted in partnership with Philly Thrive, a community-based organization serving the region. This partnership considered caregivers as domain experts whose lived experience was central to understanding asthma management, health information needs, and the limitations of current patient portal systems. We focused on Black primary caregivers because Black children experience disproportionately high asthma morbidity in the United States, and Black caregivers often manage asthma within conditions shaped by structural racism, environmental inequity, and unequal health system responsiveness [5,6]. Centering this population allowed the study to examine patient portal design and EHR documentation

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in asthma management from the perspective of caregivers most affected by these intersecting inequities. Asthma diagnoses were caregiver-reported and ranged from intermittent to persistent; the study did not collect formal spirometry or medical record data on asthma classification.

The sample consisted of 15 caregivers with an average age of 41.7 (SD 7.28, range 27‐55) years, each managing the treatment of at least one child with an asthma diagnosis. The participants included single primary caregivers (n=13) and married primary caregivers (n=2). Primary caregivers had between 1 and 8 children (mean 3.87, SD 2.03). All participants reported English as their primary language and accessed care for their child with asthma through various pediatric health systems in the Greater Philadelphia.

Procedure

In-depth one-on-one interviews were conducted between July 2024 and October 2024. The number of interviews was determined by data richness and by the fulfillment of study aims, which were assessed through ongoing review of transcripts [24]. AOO, a social work student trained in qualitative research methods with experience in health equity, conducted all interviews. All interviews were audio-recorded and video-recorded and transcribed verbatim. Primary caregivers received a US $100 gift card in recognition of their time and contributions to the research. We recognize that participants from marginalized communities contribute not only their time but also their expertise and the emotional labor of sharing lived experiences of health inequity; future community-based research should consider compensation structures that more fully reflect this contribution.

A semistructured interview guide was used to explore participants' experiences with clinicians and with medical documentation regarding their child's asthma. The guide included the following questions: (1) What was your first conversation with your clinician about your child's asthma? (2) Tell us about instances you can remember learning about your child's asthma through medical documentation and what you understood from these documents. (3) What would you do if you had the opportunity to redesign medical documentation concerning your child's asthma? Interviews were conducted in person and via Zoom and lasted 30 to 90 minutes. Quotations presented in the "Results" section were lightly edited for readability (eg, removal of false starts and filler words) while preserving the speaker's meaning and voice.

Ethical Considerations

The study received approval from the University of Pennsylvania Institutional Review Board prior to data collection (protocol number: 23‐1810). Participants provided informed consent before participation, and all transcripts were deidentified to protect confidentiality. To further protect participant privacy, all names reported in this paper are pseudonyms assigned by the research team; no real names are used. Participants were informed of the sensitive nature of the research topic and their right to withdraw at any time.

Data Analysis

Reflexive thematic analysis was conducted in 3 stages to generate key themes and categories [25,26]. This study followed the SRQR (Standards for Reporting Qualitative Research) reporting guideline [27] (Checklist 1). Drawing on Braun and Clarke's framework for quality in reflexive thematic analysis, we prioritized reflexivity, rigor, and thick description as ongoing analytic practices rather than criteria to satisfy [25,26]. Reflexivity was central to the process: AYL is a social worker and health informatics researcher whose prior work on EHR design and marginalized communities shaped the study questions, theoretical framing, and interpretive lens. AOO is a social worker with experience working with marginalized communities facing health disparities, and LAS is a nurse and doctoral student with clinical experience caring for people living with chronic conditions across the lifespan. Both researchers maintained reflexive discussions throughout data collection and analysis to examine how their subjectivities and assumptions actively shaped the interpretive process. Thick description of the study context, participant characteristics, and analytic process is provided throughout to support readers in assessing the relevance of findings to other settings. In stage 1, AYL and AOO engaged in deep familiarization with the data, repeatedly reading all interview transcripts as an active interpretive process rather than a neutral scan of content. Consistent with Braun and Clarke's reflexive approach, this stage foregrounded the researchers' subjectivities as resources rather than sources of bias, acknowledging that engagement with data is always shaped by the researcher's perspective [25,26]. Using Dedoose (SocioCultural Research Consultants, LLC), a qualitative software platform, both researchers independently coded 2 identical transcripts, attending to meaning and interpretive possibilities rather than surface content. Codes were compared and discussed within the research team to surface interpretive differences, refine the coding approach, and develop a working code set. In this phase, we constructed codes such as "Lived experience with managing asthma" and "Perceptions about patient portals."

In stage 2, the remaining transcripts were coded with active reflexive engagement, and codes were continuously interrogated and revised in relation to the dataset as a whole. Rather than mechanically sorting codes into predetermined groups, AYL and LAS worked to identify patterns of shared meaning across the data, constructing candidate themes that represented coherent interpretive accounts of caregivers' experiences. Throughout this nonlinear process, codes and themes were added, collapsed, or reconsidered as interpretations developed. LAS, a doctoral student in nursing, joined the analytic team in stage 2 after AOO completed data collection responsibilities. LAS reviewed the stage 1 codebook in full, discussed the rationale for each code with AYL, and conducted independent verification coding on 2 transcripts before proceeding to stage 2 analysis. Analytic decisions and interpretive choices were documented and discussed as a team throughout. For example, the initial code "Routine usage of patient portal" was examined to understand whether and how caregivers used patient portals. This analysis led to 2 new codes: "Positive experiences with patient portal" and "Negative experiences with patient portal," which were

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grouped into the category "Accessing health records for care needs."

In stage 3, the research and community team collaboratively reviewed and defined each theme, ensuring that it told a coherent and grounded story in relation to the dataset as a whole. Theme names were developed as interpretive acts, chosen to be vivid and analytically meaningful rather than simply being descriptive. For example, the candidate themes "The emotional and practical work of asthma care" and "Building understanding to support asthma management" were brought together and defined as the central theme "Lived experiences of managing childhood asthma in families and communities," capturing the relational and community-embedded nature of caregiving that ran across both themes.

Results

Overview

Two themes were generated from the analysis: (1) lived experiences of managing childhood asthma in families and communities, encompassing the emotional, practical, and social dimensions of asthma caregiving; and (2) caregivers' perceptions and experiences of navigating patient portals for childhood asthma, capturing how caregivers access patient portals and medical records, the barriers they encounter, and their recommendations for improvement.

Theme 1: Lived Experiences of Managing Childhood Asthma in Families and Communities

This theme highlights how managing a child's asthma is an emotional, relational, and practical process embedded within family life and community (Table 1). A distinct type of fear runs through many caregivers' accounts, arising from watching their child struggle to breathe, intensified by the reality that children may not fully understand or communicate the seriousness of their symptoms (Q1-Q2). This emotional burden is inseparable from the practical, everyday work of asthma care. Toni's account—constantly reminding her son to take his medications, laying them out each morning before she leaves for work, and rehearsing inhaler technique with him the night before—makes this interplay of vigilance and routine concrete (Q3).

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Table . Theme 1: Lived experiences of managing childhood asthma in families and communities.

Subthemes	Illustrative quotes
Emotional and practical work of asthma care	• Q1: *As a parent, to see your children struggle, oh my god. That's a different type of fear*. [Natasha] • Q2: *The advice that I would like to give is to be mindful, always be alert. I think it's vitally important to be alert, mindful, and watchful, especially when watching a child, because children are so innocent and may not fully understand the seriousness of certain things*. [Laura] • Q3: *I constantly speak, talk to him, and let him know it is very important that he takes his medication. Make sure that his medication is laid out on the sink each morning, as I leave home before he leaves for school. And so, in case my daughter, who takes him to school, forgets, I make sure that each night the medication is laid out and remind him in the morning before I leave: "Make sure you shake your pumps up before you take them." And so basically, I have these talks quite often*. [Toni]
Building understanding to support asthma management	• Q4: *They (health workers) talked to me. They broke it down and explained exactly what asthma is, what can cause flare-ups, how to treat it, and how to manage it*. [Maya] • Q5: *I had asthma classes. Asthma studies. I think that's really good 'cause you learn more and more about your child's health, which can help decrease the number of times you have to go to the hospital*. [Katherine] • Q6: *If you're going into the hospital, I would think maybe flyers would be more effective because your appointment is only for a specified amount of time. However, if you're going into schools, webinars will most certainly be of interest to parents, allowing them to sit, watch, and learn. It might be more interesting than just hearing somebody speak*. [Denise] • Q7: *I want the medical field to take asthma a whole lot more seriously. Because you have parents at home, that's literally just like losing their mind. The child feels like they're losing their life, and the mom or the dad feels like they're losing their mind. I never in life had to make this decision, but I did last week, and I was just like you're going to go home with daddy because I have to go to work, and if you're home with me, I have to be up all night and still get up for work at 6:00 o'clock. And my baby screamed and hollered and cried and looked me in my eyes and said, you need to tell them your child is sick*. [Natasha]
Confidence through shared experience and support	• Q8: *When my 14-year-old had her first asthma attack at the age of three, because I have asthma, I knew the signs and symptoms*. [Keesha] • Q9: *It was easier because she knew (grandmother) what to do because both my sister and my dad had it (asthma), so it definitely killed my nervousness or anxiety*. [Gabby] • Q10: *So everyone in my support system knows what to do, what to look for. We are basically familiar with this asthma thing. It's unfortunate, but we're just on point with it*. [Toni]

Building understanding through clear and accessible information was central to effective asthma management. Caregivers valued plain-language explanations from health workers and participation in asthma education programs, which some believed reduced hospital visits (Q4-Q5). When asked how information could be better delivered, caregivers offered format-specific suggestions based on the demands of different settings: flyers might work better in time-pressured hospital appointments, while webinars could allow parents in school settings to learn at their own pace (Q6). These accounts reflect caregivers' active pursuit of knowledge and the considerable effort it requires. Natasha's account makes the weight of that effort concrete: she describes the medical field's failure to take asthma seriously as something felt in the body, in sleepless nights, and ultimately in an impossible choice between her child's safety and her livelihood (Q7). Work and caregiving demands do not simply compete; they reveal the structural and economic pressures that make asthma management far harder than any educational program alone can address.

For many participants, personal and family experience with asthma served as a source of confidence and readiness. Those who had asthma themselves or had family members with the condition felt better equipped to recognize early warning signs and respond quickly (Q8-Q9). This shared knowledge extended to broader support networks, with participants ensuring that

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everyone involved in their child's care knew what to look for and what to do during an episode (Q10). Such collective familiarity, though born of difficult circumstances, provided reassurance that children would be safe even when caregivers were absent. In this sense, the practical knowledge caregivers have accumulated over years of managing asthma within their families constitutes a form of clinical familiarity that is neither captured in nor recognized by existing documentation systems.

Theme 2: Caregivers' Perceptions and Experiences of Navigating Patient Portals for Childhood Asthma

This theme captures how primary caregivers access, interpret, and respond to patient portals and medical documentation, as well as the challenges they encounter in doing so (Table 2). Engaging with the patient portal was a selective, need-based practice, shaped by time constraints, trust in existing systems, and the immediacy of care demands. Rather than consulting records routinely, Denise relied on automated processes such as prescription refills, accessing documentation only when changes arose or when clarification was needed (Q11). Gabby used the portal to verify clinical information following appointments, particularly when co-parenting arrangements limited direct communication about what had been discussed with the doctor (Q12). Katherine described using the portal to send a doctor's note directly to her child's school, eliminating the need to print and hand-deliver paper documentation (Q13). Alicia highlighted a specific limitation of current portal systems: records from visits to different hospitals or health systems are not automatically consolidated in one place, and her suggestion that all visits from any provider appear in a single portal reflects the reality that patients who receive care across multiple institutions must navigate fragmented records that do not follow them from provider to provider (Q14).

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Table . Theme 2: Caregivers' perceptions and experiences of navigating patient portals for childhood asthma.

Subthemes	Illustrative quotes
Accessing health records for care needs	**Q11:***I'm very busy, I don't have time to go in and look for stuff. But I'll refer when I need to refer to anything. But his (child) prescriptions have been with his doctor and his pharmacy forever, so they're like on automatic refill unless he runs out or the dosage changes. So, there's really no need for me to keep doing all of that because they do it*. [Denise]
	Q12:*I normally just compare his progress or their progress. I look from last year to this year. Make sure it's nothing I missed since I don't take him to the doctor. His dad is not really good at explaining what the doctors say. I work in healthcare, and I can kind of figure some things out. But I just like to go in there to read and make sure the paperwork matches what's in the portal*. [Gabby]
	Q13: (Caregivers) *Send a note through your medical record to give to your teacher*. [Katherine]
	Q14:*I would suggest they put everything onto the portal. In case you lose the papers, you can still see everything (all medical information across medical institutions and settings). All visits from whatever doctor that patient sees should all be in one place*. [Alicia]
Barriers to understanding and accuracy	**Q15:***They have to remove it (old prescriptions) because it is still there. When she gets other medicines, they just add up. And I have to go and tell 'em like, you gotta take that off and that off because she doesn't take that anymore. So I don't want them to think that that's what she takes*. [Alicia]
	Q16:*It's so much. It's not easy. It's a lot. You have to figure out what....If it's an app or a website, I want it to be easy to understand. I don't have patience for figuring it out when my child is sick*. [Natasha]
	Q17:*I honestly, in my opinion, feel like there are things that the medical professional knows and is knowledgeable of that we don't....That they don't share with us, for whatever reason. So, I definitely would appreciate and love to take advantage of an AI's assistance when it comes to helping me review notes, charts, and gain an understanding of what's going on*. [Laura]
	Q18:*I had to do too much to get certain diagnoses when I already knew what the problem was. No parent should have to go through that. You had to jump through hurdles to get results*. [Jill]
Caregivers' recommendations for improving patient portals	**Q19:***I would also like to reach out to the physicians on the app, instead of waiting for a phone call, or having to constantly call and call*. [Christina]
	Q20:*Every day, I'm looking at the pollen levels for him. Every day, because it's like, okay, if the pollen levels are high, we cannot go outside*. [Nicole]
	Q21:*So, say if my child was having symptoms that I'm unfamiliar with, I think I should be able to go on the app and search those symptoms, and then I think the app should have a contact where the doctor or nurse, whoever reviews it, is able to get in contact with you. Like we, as the parent, get to leave our information so the professionals can get back to us*. [Toni]
	Q22:*When you are diagnosed with asthma, you should be able to get a refill for your child's asthma pump as soon as possible. You should not have to set up a doctor's appointment. They already have the diagnosis, so it should just be sent to the pharmacy*. [Shonte]
Fostering autonomy in children living with asthma	**Q23:***I told my daughter to download it. You can send messages to your doctor yourself at 13. You've got a problem, go to your doctor. I can always see it. But you can go to your doctor on your own. So, he's turning 18 soon, he's gonna have access to his own chart, and they better not limit me, but I think they will*. [Gabby]
	Q24:*I actually think the health portal should be easy for anybody. I use it for myself too. I recently had blood work done and was able to look at the results with definitions right there. I believe children could use it the same way*. [Simone]
	Q25:*Now that she's getting older, I'm starting to tell her what's what and how it means for her, or how to take care of herself in regard to that. Now, more because I feel like she understands more now*. [Maya]

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Many participants described having to exert substantial effort to obtain accurate information, correct errors, and secure recognition of what they already knew about their child's condition. Alicia described having to actively advocate for the removal of outdated medications from her child's record concerned that persistent errors could lead to clinical mistakes (Q15). Many participants expressed frustration that critical information was not always fully shared or explained to them (Q16). Laura felt excluded from aspects of her child's care and expressed interest in AI-assisted tools to help interpret medical notes and bridge the knowledge gap between herself and providers (Q17). Jill described having to fight repeatedly to secure her child's diagnosis, reflecting a broader pattern in which caregivers must exert significant effort simply to be heard (Q18).

Participants offered concrete recommendations for improving the patient portal, grounded in their daily experiences. Direct messaging with physicians was a consistent priority, with Christina describing frustration with having to wait for phone calls rather than sending a message through the app (Q19). Nicole described checking pollen levels daily to inform decisions about her child's outdoor activity (Q20). While environmental data are available through weather applications, integrating them directly into the patient portal may allow caregivers to connect real-time trigger information to their child's documented symptoms and medication use. Toni proposed a symptom-search feature that would allow parents to look up unfamiliar symptoms and receive clinical follow-up (Q21). Shonte highlighted unnecessary friction in medication refills, arguing that a confirmed diagnosis should be sufficient to authorize a prescription without requiring a new appointment (Q22).

Several participants described gradually involving their children in managing their own asthma care. Gabby encouraged her daughter to use the patient portal independently starting at age 13, sending messages to her own doctors while still keeping a parental view of the account (Q23). Simone noted that the health portal should be accessible and easy for anyone to use, including children, pointing to its potential for youth engagement with health information (Q24). As Maya explained, she began sharing more details about asthma management as her daughter grew older and could better understand what it meant for her health (Q25). Taken together, these accounts suggest that caregivers view the patient portal not only as a tool for adult management but also as a scaffold for children's gradual development of health self-agency—a function that current portal design does not explicitly support.

Discussion

Principal Findings

This qualitative study offers several insights from Black primary caregivers about their lived experiences managing childhood asthma and their interactions with EHR-generated information, patient portals, and medical documentation. These perspectives contribute to the development of a community-centered and family-centered medical platform that addresses caregivers' information needs while reducing epistemic injustice in health care systems [13]. Two primary themes illustrate how caregivers navigate childhood asthma care and engage with health information systems. The first illuminates the lived experience of childhood asthma caregiving, encompassing the emotional weight, daily routines, and community knowledge that sustain management outside clinical settings. The second turns to caregivers' engagement with patient portals, revealing patterns of selective use, persistent barriers to accurate and accessible information, and a set of grounded recommendations for redesign.

Caregivers described the emotional and practical day-to-day work of asthma care as an ongoing process that extends beyond the provision of medication. They articulated a distinct type of fear associated with watching their child struggle to breathe, intensified by the reality that children may not fully understand or communicate their symptoms. The ongoing work involves establishing daily routines, preparing medications, and providing reminders to ensure treatment adherence. These findings are consistent with prior research documenting caregiver burden associated with childhood asthma [3,4] and underscore opportunities for technology to reduce the informational and logistical burden of daily asthma management, particularly for caregivers navigating care largely outside clinical settings.

Caregivers consistently described clear, accessible information as central to their ability to manage their child's asthma confidently. They valued plain-language explanations from health workers and participation in asthma education programs, which some believed had reduced hospital visits. These findings support previous research on health literacy and asthma management [17,18] and add specificity regarding preferred educational formats. Caregivers suggested that flyers may be more effective in busy hospital settings, while webinars may be useful in school contexts, as they allow parents to learn at their own pace. These preferences suggest opportunities to integrate multimodal educational content that adapts to different caregiving contexts.

Managing childhood asthma is inseparable from the conditions of daily life. When work obligations and caregiving responsibilities collide, caregivers face choices that no health information system can resolve, yet that directly shape their ability to manage their child's condition. These tensions are consistent with research documenting the compounding demands faced by caregivers, particularly Black caregivers, who disproportionately face employment precarity and insufficient institutional support when managing chronic illness in their children [5,6]. Platform design should therefore support caregivers not only in understanding medical information but also in navigating the broader competing demands of daily life.

Families' lived experience with asthma created expertise in managing the condition. Caregivers with a personal or family history of asthma felt better equipped to recognize early warning signs and respond quickly. These findings align with prior research on caregiver knowledge in pediatric chronic illness management and extend this work by demonstrating how family knowledge and lived experience serve as strengths in childhood asthma management [3,4]. Lived experience represents a form of domain expertise that is often unrecognized in health

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information systems, suggesting opportunities to enhance the sharing of experiential knowledge alongside professional medical knowledge.

Caregivers did not describe patient portals as resources for routine, everyday asthma management. Rather, they used them selectively at times when documentation was needed for coordination, verification, or urgent decision-making, such as reviewing what was discussed at appointments, sharing information with schools, confirming medications, or referencing medication details during emergency care visits. Seen this way, selective use reflects not low engagement but the limited usefulness of current systems for the day-to-day work of asthma care [12,20,21]. This pattern is consistent with evidence from a study of diverse caregivers of children with asthma showing that limited digital health app engagement reflects barriers related to design and accessibility rather than caregiver willingness or motivation [22].

Caregivers described encountering records that were outdated, difficult to understand, and sometimes incomplete. Medication lists retained prescriptions their children no longer took, requiring caregivers to intervene directly to prevent errors. Clinical terminology left caregivers searching elsewhere for explanations, and many felt providers did not share the full picture of their child's condition. These findings reflect broader patterns of medical mistrust among Black patients, which research has linked to histories of discrimination and perceived asymmetries in clinical encounters [28]. This dynamic extends into digital communication channels: research demonstrates that portal messages from Black patients receive physician responses at lower rates than those from White patients, a structural disparity that may compound the trust deficit caregivers described [29]. Caregiver perspectives on AI-assisted interpretation of medical notes were mixed, reflecting both interest in tools that could bridge the clinical knowledge gap and concern that AI may be too general to address a specific child's needs, a tension that warrants attention in future platform design. These findings extend prior work on documentation inconsistencies [15] by demonstrating that documentation problems directly affect caregiver trust and engagement. These documentation barriers may constrain caregivers' ability to engage with and act on health information, a process prior research has linked to poorer asthma outcomes [10,17]. Rather than indicating individual disengagement, participants' accounts point to EHR design as an underexamined factor shaping the gap between treatment availability and everyday asthma management. Addressing these barriers requires both technical solutions and a shift in how caregiver knowledge is recognized within health records [15].

Caregivers' perspectives reflect knowledge emerging at the intersection of health and lived experiences, and their suggestions underscore that community-informed design is essential for addressing asthma disparities rooted in structural racism and environmental injustice, particularly for Black caregivers in urban settings like Philadelphia [6]. While the findings are specific to this population and context, they offer insights relevant to other marginalized caregiver communities managing pediatric chronic illness through health information systems designed primarily for clinical use. Improvements to EHR systems based on day-to-day experiences, including direct messaging with physicians, integration of environmental data such as pollen levels, the ability to search for symptoms with clinical follow-up, and improved medication refill processes, signify opportunities to enhance EHR design. The integration of their recommendations aligns with emerging frameworks for shared decision-making in asthma care [11] and broader efforts to develop patient-centered clinical decision support tools [16,30] to advance better outcomes.

Finally, caregivers described efforts to involve their children in managing their asthma care, including engaging them with their health records. However, existing systems often do not support age-appropriate engagement or youth-centered design [31]. These findings point to opportunities to develop interfaces and features that facilitate meaningful child participation and acknowledge young people's distinct lived experiences with chronic illness.

Implications for Developing a Community- and Family-Centered Medical Platform

Without structural changes to patient portal design, existing disparities in asthma management are likely to persist despite advances in clinical care. Platform design should integrate community knowledge alongside professional medical expertise rather than treat caregiver experience as supplementary. When caregivers access their patient portal, their documented observations and concerns should be visible alongside clinician notes, creating a shared record that positions caregiver knowledge as a legitimate input rather than a supplement [15].

Key platform features directly requested by participants include easy-to-understand translations of medical terminology, direct messaging with physicians, symptom-search functionality with clinical follow-up, and streamlined medication refill processes. The research team also proposes design directions informed by but extending beyond the data: AI-assisted interpretation of medical notes, integration of environmental data such as pollen levels, and caregiver-facing tools for annotating or correcting records. These represent researcher-generated extrapolations rather than direct caregiver recommendations, and they should be co-designed with community members before implementation [30]. Integrating environmental data, such as air quality and pollen counts, can help families identify and respond to environmental triggers [32]. Child-friendly interfaces could support developmental transitions toward independence by offering age-appropriate education and tools that help young people gradually assume self-management responsibilities.

Platforms should also facilitate peer-to-peer knowledge sharing through moderated community forums where caregivers exchange insights on managing asthma, identifying environmental triggers, and navigating care systems [33]. Customizable views can show only relevant information to different stakeholders while allowing caregivers to control what gets shared across the distributed network of parents, children, family members, and schools involved in asthma care [34].

Although this study centers on childhood asthma, these findings may extend to other pediatric chronic conditions in which caregivers carry substantial responsibility for coordination,

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monitoring, and interpretation outside clinical settings. More broadly, they suggest that patient-facing health information systems should treat caregiver knowledge as essential rather than peripheral.

Limitations

This research has several noteworthy limitations. First, we interviewed only primary caregivers from one region in the United States; future research should include caregivers from diverse geographic locations to gain broader perspectives. Additionally, asthma diagnoses were caregiver-reported rather than clinically verified, and the distribution of intermittent versus persistent diagnoses was not systematically recorded, which limits the specificity of clinical context available for interpreting caregiver experiences. Second, all participants were Black female caregivers. Future studies should include fathers, grandparents, other guardians, caregivers from diverse racial and ethnic backgrounds, and children and adolescents with asthma themselves. Third, this qualitative study does not allow generalization to all caregivers of children with asthma. Because the recommended platform features have not yet been developed, caregiver suggestions reflect proposed rather than validated interventions. Future research should use participatory design methods to develop and evaluate these features with community members. Fourth, participants received a US $100 gift card incentive, which may have influenced willingness to participate and introduced self-selection bias; caregivers who chose to participate may differ systematically from those who did not in ways that shaped their portal experiences and perspectives.

Implications for Future Research

Additional research is needed in four areas: (1) expanding participant diversity to include different caregiver types, children and adolescents with asthma, and multiple geographic locations and health care systems; (2) using participatory design to translate caregiver recommendations into platform features and testing whether these reduce caregiver burden, improve health outcomes, and advance health equity; (3) examining how health information systems intersect with environmental and health justice, and whether technology designed with community input reduces epistemic injustice by shifting power dynamics and enhancing caregiver agency; and (4) examining whether the community-centered, caregiver-as-expert model developed here is transferable to other pediatric chronic conditions in which caregivers carry primary responsibility for coordination, monitoring, and interpretation outside clinical settings.

Conclusions

This study elicited Black primary caregivers' perspectives on managing childhood asthma and their experiences with EHR-generated information and patient portals to inform the development of a community- and family-centered medical platform. In this study, participants described the profound emotional and practical work of asthma management, emphasized the importance of accessible health information and education, and articulated how family and community knowledge supports their confidence. When engaging with EHR-generated information and patient portals, the majority of primary caregivers used these systems selectively and strategically, identified barriers related to accuracy and medical terminology that undermined trust, and offered meaningful recommendations for improvement.

Our findings show that effective childhood asthma management requires more than clinical treatment. It requires information systems that honor caregiver expertise while reducing burden, provide transparent and accurate documentation, integrate environmental and social context, and actively work to reduce knowledge inequities. By centering caregivers' voices through a partnership with a community organization, this research contributes to the design of platforms that advance health equity rather than perpetuate existing disparities.

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Data Availability

The data underlying this article cannot be publicly shared to maintain the privacy of the individuals who participated in the study. Data will be shared upon a reasonable request to the corresponding author.

Authors' Contributions

Conceptualization: AYL, AH, KC
Data curation: AOO, SS
Formal analysis: AOO
Funding acquisition: SS, AH, KC
Investigation: AOO
Methodology: AYL
Project administration: AYL

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Resources: LAS
Supervision: AYL
Writing – original draft: AYL
Writing – review & editing: AYL, AOO, LAS, LA, JF, HK, SS, AH, KC

Conflicts of Interest

None declared.

Checklist 1
SRQR checklist.
[DOCX File, 22 KB - pediatrics_v9i1e100502_app1.docx]

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Abbreviations

EHR: electronic health record
SRQR: Standards for Reporting Qualitative Research

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Parental Media Literacy and Children's Epistemic Curiosity in Screen-Based Media Use: Cross-Sectional Survey Study

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Abstract

Background: Research on children's media use has traditionally focused on risks and negative outcomes. However, screen-based media may also provide opportunities for learning and curiosity-driven exploration. As young children increasingly engage with digital media within family contexts, parental media literacy may represent an important competency associated with children's media experiences and developmental outcomes.

Objective: This study examined the associations between parental media literacy and children's epistemic curiosity during screen-based media use. Specifically, it investigated how 4 dimensions of parental media literacy—technological use, critical understanding, self-expression, and norm compliance—were associated with 2 dimensions of children's epistemic curiosity: interest-type and deprivation-type curiosity.

Methods: Between July 31, 2024, and August 21, 2024, we conducted an online cross-sectional survey of 1020 parents of children aged 7 to 9 years in South Korea, including 340 parents in each age group. Household income, parental media literacy, and children's epistemic curiosity were assessed using validated 5-point Likert scales. Separate structural equation models were estimated to examine the direct associations between parental media literacy and children's epistemic curiosity and the indirect associations between household income and children's epistemic curiosity through parental media literacy.

Results: Technological use was positively associated with both interest-type (β=.32; *P*<.001) and deprivation-type (β=.18; *P*<.001) curiosity. Critical understanding, self-expression, and norm compliance were also positively associated with both interest-type (β=.20 to .26; *P*<.001 in all cases) and deprivation-type (β=.21 to .23; *P*<.001 in all cases) curiosity. Household income showed significant indirect associations with interest-type curiosity through all 4 dimensions of parental media literacy (β=.005 to .009; *P*<.05 in all cases), whereas indirect associations with deprivation-type curiosity were observed only through critical understanding (β=.007; *P*=.003), self-expression (β=.011; *P*<.001), and norm compliance (β=.004; *P*=.03).

Conclusions: The findings suggest that parental media literacy may extend beyond an individual competency and be associated with children's curiosity-driven engagement with digital media. By highlighting parental media literacy as a potentially modifiable factor, this study underscores the importance of supporting parents as active participants in children's digital learning environments.

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KEYWORDS

epistemic curiosity; parental media literacy; family dynamics; parent-child interaction; screen-based media; digital childhood

Introduction

Parental Media Literacy and Children's Epistemic Curiosity in Screen Media Use

In the pervasive and rapidly evolving digital environment, parents play a pivotal role in shaping young children's media use, bearing primary responsibility for guiding their engagement with digital media [1]. Children's early exposure to digital technology is influenced by multiple family-level factors [2], including socioeconomic status (SES) and parental educational level [3], parents' expectations of and attitudes toward children's media use [4], and everyday patterns of family interaction with digital technologies [5]. These factors shape children's media experiences and may affect their developmental and social outcomes. Although parental factors have been widely studied across environmental, social, and emotional domains, the interpersonal and dynamic aspects of parent-child interactions around media use—particularly those related to parental competencies—remain underexplored [1].

Media literacy refers to the ability to access, interpret, evaluate, and create media messages in contemporary digital environments [6]. Previous research suggests that media literacy can reduce

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negative media influences while supporting more positive and informed media experiences [7]. By fostering critical thinking, media literacy can encourage more reflective media practices and protective attitudes [8]. However, traditional media literacy studies primarily emphasize risk mitigation and self-referential effects (eg, parents' own media efficacy), often neglecting the critical impact of parental media literacy on children's positive media experiences and cognitive development. Unlike parental mediation, which refers to specific behavioral strategies used to manage children's media use, parental media literacy reflects a broader competency encompassing how parents access, understand, evaluate, and engage with media.

Rather than examining specific parental mediation behaviors, this study conceptualized parental media literacy as a broader parenting competency and investigated how it relates to children's epistemic curiosity during screen-based media use. Epistemic curiosity refers to a desire for new information that motivates knowledge acquisition and exploratory behavior [9]. In digital environments where children encounter vast amounts of information, epistemic curiosity may support learning, problem-solving, and meaningful engagement with media content [10,11].

This study was conducted in South Korea, a highly digitalized society where children are exposed to digital media from an early age and where parents face increasing responsibility for guiding children's media use. This issue may be particularly salient in South Korea, where digital media adoption is widespread and parents are increasingly expected to support children's media experiences. However, many contemporary parents grew up without formal media literacy education and must navigate rapidly evolving digital environments while helping their children engage with media. Examining parental media literacy in this context provides valuable insights into how family-level competencies relate to children's positive media experiences and learning-related outcomes in everyday digital environments.

Media Literacy: Evolution and Outcomes

Media literacy originally referred to the knowledge and skills that enable individuals to understand media critically and use it appropriately [12,13]. Early conceptualizations emphasized the ability to access, analyze, evaluate, and create media messages in various forms [14]. As media environments have become more complex, the scope of media literacy has expanded beyond protection from harmful content to include competencies related to participation, privacy management, information evaluation, self-expression, ethical engagement, and the ability to maximize opportunities while minimizing risks in digital media use [7]. Although the specific dimensions of media literacy continue to evolve alongside technological change, scholars broadly agree that media literacy supports more informed, responsible, and effective media use.

Most research on media literacy has focused on its effects at the individual level. A substantial body of literature has demonstrated that media literacy is associated with greater critical thinking, improved understanding of media messages, stronger awareness of persuasive intent, and healthier media-related attitudes and behaviors [8,15,16]. However, media use rarely occurs in isolation. Individuals engage with media within social environments where interactions with family members, peers, and other social actors shape how media content is interpreted and experienced. Consequently, media literacy may extend beyond an individual competency and function as a form of social influence, affecting not only the person who possesses it but also those with whom they interact.

Although this possibility has received limited empirical attention, there are theoretical reasons to expect that media literacy may have implications beyond the individual. Media experiences are embedded within interpersonal relationships, where people exchange information, discuss media content, model behaviors, and influence one another's interpretations of media messages. Consequently, media literacy may function not only as an individual competency but also as a form of social influence.

This possibility may be particularly relevant in family settings, where parents play a central role in structuring children's media environments and guiding their engagement with digital media. Parent-child relationships are characterized by frequent interaction and asymmetries in knowledge and experience, making them a likely context in which media-related competencies may extend beyond the individual. Young children rely heavily on their parents to interpret media content, navigate digital environments, and make decisions about media use. Examining parental media literacy, therefore, provides an opportunity to explore how media-related competencies may shape children's media experiences and learning-related outcomes.

Parental Media Literacy as a Parenting Competency

Parents play a central role in shaping children's media experiences. Existing research has primarily examined this influence through parental mediation strategies, such as restrictive mediation, explanatory mediation, and coviewing [17,18]. However, parents' influence extends beyond observable mediation behaviors. Parents shape children's media experiences through the media environments they create, the beliefs and attitudes they communicate, the resources and technologies they provide, and the ways in which they themselves engage with media [19].

For contemporary parents, these influences are particularly important in digital environments. Many parents grew up during a period of rapid technological change and did not receive formal media literacy education. Instead, they developed their understandings, habits, and beliefs through direct experiences with emerging media technologies. Paradoxically, these same individuals are now expected to guide their children's media use and help them navigate increasingly complex digital environments. As a result, parents vary substantially in their ability to critically evaluate media, support children's engagement with digital content, and foster constructive media experiences. In this study, these competencies were conceptualized as parental media literacy.

SES may further shape the development of parental media literacy. Parents with greater educational and economic resources often have broader access to digital technologies,

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information resources, and learning opportunities, which may facilitate the acquisition of media-related knowledge and skills [20-22]. Higher-SES families may also be more likely to adopt and engage with emerging technologies, providing parents with greater opportunities to develop familiarity with and competence in digital environments. Consequently, SES may influence children's media experiences not only through material resources but also through its association with parents' media literacy. Examining SES alongside parental media literacy, therefore, provides a more comprehensive understanding of the family factors associated with children's media engagement and learning-related outcomes.

Much of the existing literature on children's media use has focused on risks and problematic outcomes, reflecting concerns about excessive screen time, problematic use, and exposure to harmful content. Although these concerns remain important, digital media has become an unavoidable part of children's everyday lives. Rather than viewing media solely as a source of risk, it is equally important to understand the conditions under which children experience positive and developmentally beneficial outcomes. One such outcome may be epistemic curiosity, a desire for knowledge and understanding that motivates learning and exploration. Examining whether parental media literacy is associated with children's epistemic curiosity may therefore provide insights into how family environments support constructive engagement with digital media.

Epistemic Curiosity in Digital Media Environments

Epistemic curiosity refers to a desire for knowledge and understanding that motivates information seeking, exploration, and learning [9]. Because it encourages children to engage with new ideas, ask questions, and resolve uncertainty, epistemic curiosity is considered an important developmental outcome linked to cognitive growth and learning [23-25].

Prior research distinguishes between 2 dimensions of epistemic curiosity: interest-type and deprivation-type curiosity [26]. Interest-type curiosity reflects enjoyment of novelty and discovery, whereas deprivation-type curiosity arises from a desire to resolve gaps in knowledge or understanding [27,28]. Although these dimensions differ in motivation, both are associated with active information seeking and intellectual exploration [26,29,30].

The development of epistemic curiosity begins early in life, when children are actively constructing knowledge about the world around them. Prior research suggests that curiosity can be fostered through exposure to novel information, opportunities for exploration, and encounters with uncertainty that motivate information seeking [31-34]. Because epistemic curiosity supports learning, problem-solving, and knowledge acquisition, it is increasingly recognized as an important developmental resource during childhood.

Epistemic curiosity may be particularly relevant in contemporary digital environments. Children are routinely exposed to novel information, diverse perspectives, and new learning opportunities through screen-based media. As digital media increasingly serves as a gateway through which children encounter and learn about the world, media experiences may play an important role in stimulating curiosity and exploration. While much research has focused on the risks of digital media use, these environments may also provide opportunities for curiosity-driven learning and intellectual engagement. Given parents' central role in shaping children's media experiences, parental media literacy may be associated with how children engage with these opportunities and experience epistemic curiosity during media use.

The Current Study

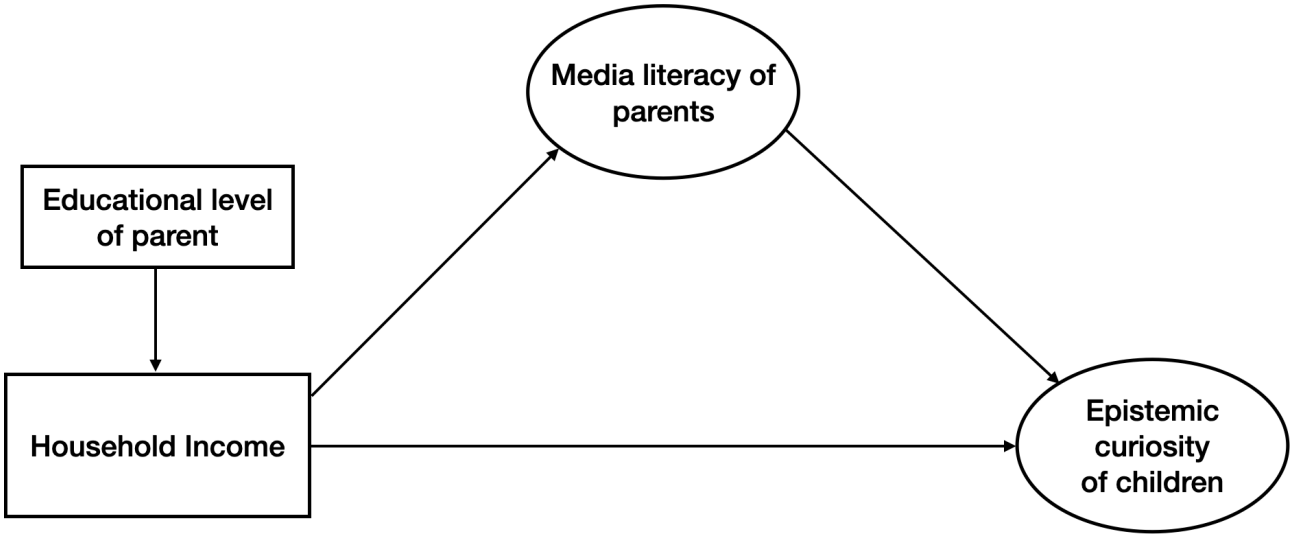
On the basis of the theoretical arguments and empirical gaps discussed above, this study examined the relationships among parental media literacy, SES, and children's epistemic curiosity, including both interest type and deprivation type. Specifically, this study investigated whether parental media literacy was associated with children's epistemic curiosity during screen-based media use and whether parental media literacy may help explain the relationship between SES and children's epistemic curiosity.

Figure 1 shows the conceptual model linking household income, parental media literacy, and children's epistemic curiosity. On the basis of prior literature, parental media literacy is expected to be positively associated with children's epistemic curiosity, and SES is expected to be associated with both parental media literacy and children's epistemic curiosity. The following hypotheses were proposed:

- *Hypothesis 1*—higher levels of parental media literacy (technological use, critical understanding, self-expression, and norm compliance) will be positively associated with children's epistemic curiosity (interest type and deprivation type) during screen-based media use.
- *Hypothesis 2*—higher SES will be positively associated with children's epistemic curiosity during screen-based media use.
- *Hypothesis 3*—parental media literacy will mediate the association between SES and children's epistemic curiosity during screen-based media use.

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Figure 1. Research model.



Methods

Participants and Procedure

Data were collected from a target population of 1020 primary caregiver parents of children aged 7 to 9 years in South Korea via a professional online research panel. The survey was administered between July 31, 2024, and August 21, 2024, and included 340 parents of children in each age group (7, 8, and 9 years). Most respondents (n=887, 87%) were mothers, and 13.0% (n=133) were fathers. The survey, designed for quantitative analysis, commenced with a screening question to confirm the respondent's status as the primary caregiver and included detailed measures regarding the child's media exposure, device access, use patterns, and the control variables used in the final analysis. All items were measured on a 5-point Likert scale except SES, which was measured categorically.

Ethical Considerations

This study received ethics approval from the Ewha Womans University Institutional Review Board (protocol number ewha-202103-0028-04). Participants provided informed consent through the online platform.

Measurements

All constructs were assessed using previously validated scales. Confirmatory factor analyses (CFAs) were conducted to evaluate the measurement properties of the scales. Table 1 shows the CFA results, reliability estimates, and validity indicators for all study variables.

Table . Measurement properties of the study variables[a].

Construct	Mean (SD)	Loading range	McDonald ω	AVE[b]
TU[c]	4.31 (0.52)	0.63-0.83	0.84	0.51
CU[d]	3.95 (0.56)	0.31-0.87	0.75	0.44
SE[e]	3.80 (0.69)	0.56-0.76	0.83	0.46
NC[f]	4.14 (0.54)	0.35-0.88	0.68	0.37
Interest-type curiosity	3.77 (0.55)	0.65-0.76	0.80	0.50
Deprivation-type curiosity	3.36 (0.65)	0.70-0.83	0.84	0.56

[a]The 4-factor confirmatory factor analysis provided partial support for the proposed multidimensional structure (comparative fit index [CFI]=0.87; Tucker-Lewis index [TLI]=0.85; root mean squared error of approximation [RMSEA]=0.07; standardized root mean squared residual [SRMR]=0.07), whereas the 2-factor model for epistemic curiosity demonstrated good fit (CFI=0.97; TLI=0.96; RMSEA=0.06; SRMR=0.04). Discriminant validity was considered acceptable because the squared latent correlations were lower than the average variance extracted estimates for most constructs.

[b]AVE: average variance extracted.

[c]TU: technological use.

[d]CU: critical understanding.

[e]SE: self-expression.

[f]NC: norm compliance.

For parental media literacy, a 4-factor model demonstrated modest fit (χ^2_{146}=959.8; comparative fit index [CFI]=0.87; root mean squared error of approximation [RMSEA]=0.07; standardized root mean squared residual [SRMR]=0.07). For epistemic curiosity, a 2-factor model demonstrated good fit (χ^2_{19}=85.0; CFI=0.97; RMSEA=0.06; SRMR=0.04).

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Standardized factor loadings ranged from 0.31 to 0.88 for parental media literacy and from 0.65 to 0.83 for epistemic curiosity. Internal consistency was assessed using the McDonald ω.

Epistemic Curiosity

Epistemic curiosity during screen-based media use (parent reported) was measured using a 10-item scale adapted from the work by Piotrowski et al [25] that assesses children's curiosity through caregiver observation. The scale was previously translated into Korean and validated [29].

The scale consists of 2 dimensions: intellectual interest (5 items; mean 3.77, SD 0.55; ω=0.80) and informational deprivation (5 items; mean 3.36, SD 0.65; ω=0.84). A 2-factor CFA supported the distinction between interest- and deprivation-type curiosity. Standardized factor loadings ranged from 0.65 to 0.76 for interest-type curiosity and from 0.70 to 0.83 for deprivation-type curiosity. Items were measured on a 5-point Likert scale ranging from 1 ("strongly disagree") to 5 ("strongly agree").

Parental Media Literacy

Parental media literacy was measured using a validated multidimensional scale developed by Ahn et al [35]. On the basis of their established relevance to child outcomes and parent-child mediation effectiveness, 4 key dimensions were selected for this study: technological use (5 items; mean 4.31, SD 0.52; ω=0.84), critical understanding (4 items; mean 3.95, SD 0.56; ω=0.75), self-expression (5 items; mean 3.80, SD 0.69; ω=0.83), and norm compliance (4 items; mean 4.14, SD 0.54; ω=0.68). The reliability coefficient for norm compliance was somewhat lower than those observed for the other dimensions. However, the value remained within the range often considered acceptable for established multidimensional scales in social science research, particularly when constructs encompass heterogeneous behavioral indicators. Accordingly, the scale was retained to preserve the theoretical breadth of the parental media literacy framework.

A 4-factor CFA generally supported the multidimensional structure of parental media literacy. Standardized factor loadings ranged from 0.63 to 0.83 for technological use, 0.31 to 0.87 for critical understanding, 0.56 to 0.76 for self-expression, and 0.35 to 0.88 for norm compliance. Items were measured on a 5-point Likert scale ranging from 1 ("strongly disagree") to 5 ("strongly agree").

Household SES and Control Variables

SES was operationalized using 2 parent-reported measures. Household income, the primary SES proxy for the main hypothesis (hypotheses 2 and 3), was measured using a 10-point categorical scale (from less than KRW 2.5 million to more than KRW 10.5 million, with intervals of KRW 1 million [KRW 1=US $0.00072 as of August 20, 2026]). For the analysis, this categorical variable was treated as a continuous ordinal variable. Parental educational level, categorized into 5 options (eg, high school graduate and bachelor's degree), was measured to serve as a control variable in the analysis. The gender of the primary caregiver (mother=0; father=1) was also included as a control variable.

Analysis Plan

Prior to hypothesis testing, the psychometric properties of all latent variables were rigorously assessed through CFA. Through the validated measurement models established via CFA, this study used structural equation modeling via the *lavaan* package in R (R Foundation for Statistical Computing) [36] to test the hypothesized relationships, including the mediation effect (hypothesis 3).

Because parental media literacy was conceptualized as 4 distinct dimensions and epistemic curiosity was conceptualized as 2 theoretically distinct outcomes (interest and deprivation type), separate structural equation models were estimated for each combination of media literacy and curiosity dimensions (4 × 2 = 8 models). This approach allowed the associations between specific dimensions of parental media literacy and specific dimensions of epistemic curiosity to be examined independently, consistent with the study's aim of understanding the role of each media literacy dimension rather than evaluating their relative effects within a single model.

Given the observed nonnormal distribution of the variables and the categorical nature of SES, indirect effects were tested using 5000 bias-corrected bootstrap samples, following the recommendations of Preacher and Hayes [37].

Parental educational level was included as a covariate in all structural equation models. This decision was made because the educational level was observed to influence both household income and parental media literacy and the sample exhibited a skew toward highly educated parents. The primary caregiver's gender was also included as a covariate in all models.

Results

Descriptive Statistics

A total of 1020 completed questionnaires were collected and statistically analyzed. The age range for participating parents was 27 to 56 years. Mothers' ages ranged from 27 to 51 years (mean 40.37, SD 3.72 years), and fathers' ages ranged from 27 to 56 years (mean 41.41, SD 3.97 years). The sample exhibited a higher educational attainment compared to the national average (41% with higher education), with 92.5% (n=944) having an associate college degree or higher. Specifically, 21.8% (n=222) had an associate college degree, 57.5% (n=586) had a bachelor's degree, and 13.3% (n=136) had a graduate degree or higher. Only 0.2% (n=2) had not completed middle school, and 7.3% (n=74) were high school graduates. The sample also reported relatively high household incomes (mean KRW 5.5 million to 6.5 million, SD KRW 2.13 million). The distribution was near normal (skewness=0.25; kurtosis=–0.62), with 46.3% (n=472) reporting a household income exceeding KRW 6.5 million.

Correlations between all study variables were examined and are shown in Table 2. Findings indicated statistically significant correlations among most variables except between parental educational level and 2 dimensions of media literacy: technological use and norm compliance.

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Table . Correlation between study variables (N=1020).

	Interest type	Deprivation type	TU[a]	CU[b]	SE[c]	NC[d]	Income	Educational level
Deprivation type	0.52[e]	1	0.14[e]	0.20[e]	0.26[e]	0.19[e]	0.11[e]	0.10[f]
TU	0.31[e]	0.14[e]	1	0.48[e]	0.49[e]	0.42[e]	0.08[f]	–0.04
CU	0.26[e]	0.20[e]	0.48[e]	1	0.42[e]	0.37[e]	0.11[e]	0.13[e]
SE	0.26[e]	0.26[e]	0.49[e]	0.42[e]	1	0.36[e]	0.14[e]	0.10[f]
NC	0.26[e]	0.19[e]	0.42[e]	0.37[e]	0.36[e]	1	0.08[f]	0.03
Income	0.11[e]	0.11[e]	0.08[f]	0.11[e]	0.14[e]	0.08[f]	1	0.26
Educational level	0.06[f]	0.10[f]	–0.04	0.13[e]	0.10[f]	0.03	0.26[e]	1

[a]TU: technological use.

[b]CU: critical understanding.

[c]SE: self-expression.

[d]NC: norm compliance.

[e]*P*<.001.

[f]*P*<.05.

Parental Media Literacy and Children's Epistemic Curiosity

The results of the structural equation models with interest-type epistemic curiosity as the dependent variable are shown in Table 3. Model fit indexes for interest-type epistemic curiosity as the dependent variable indicated acceptable fit across all dimensions of parental media literacy (technological use: χ^2_2=7.5, *P*<.001, CFI=0.97, RMSEA=0.05, and SRMR=0.02; critical understanding: χ^2_2=11.9, *P*<.001, CFI=0.94, RMSEA=0.07, and SRMR=0.03; self-expression: χ^2_2=4.8, *P*=.09, CFI=0.98, RMSEA=0.04, and SRMR=0.02; norm compliance: χ^2_2=1.4, *P*=.50, CFI=1.00, RMSEA=0.00, and SRMR=0.00). All structural equation models were estimated under the same analytical framework and included the same set of covariates. The models were overidentified (df=2), allowing model fit to be evaluated using conventional fit indexes.

Table . Interest-type curiosity results.

PML[a] dimension	Income→PML, β	PML→interest-type curiosity, β	Income→interest-type curiosity, β	Indirect effect, β
TU[b]	.02[c]	.32[d]	.02[d]	.006[c]
CU[e]	.03[d]	.24[d]	.02[c]	.007[c]
SE[f]	.05[d]	.20[d]	.02[c]	.009[d]
NC[g]	.02[c]	.26[d]	.02[d]	.005[c]

[a]PML: parental media literacy.

[b]TU: technological use.

[c]*P*<.05

[d]*P*<.001.

[e]CU: critical understanding.

[f]SE: self-expression.

[g]NC: norm compliance.

Consistent with hypothesis 2, the direct effect of household income on children's interest-type epistemic curiosity was statistically significant across all 4 dimensions of parental media literacy (β=.02; *P*<.05). This finding suggests that higher household income is consistently associated with greater experience of interest-type epistemic curiosity in children during media use.

Regarding the mediation hypothesis, the indirect effect of parental media literacy significantly mediated the relationship between household income and interest-type epistemic curiosity across all 4 parental media literacy dimensions, supporting hypothesis 3 for interest-type curiosity. The standardized indirect effects were significant through technological use (β=.006; *P*=.02), critical understanding (β=.007; *P*=.003), self-expression (β=.009; *P*<.001), and norm compliance (β=.005; *P*=.005).

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Although statistically significant, the indirect effects were small in magnitude.

The results of the structural equation model with deprivation-type epistemic curiosity as the dependent variable are shown in Table 4. The model fit indexes for all 4 models suggested an adequate fit (technological use: χ^2_2=14.0, *P*<.001, CFI=0.91, RMSEA=0.07, and SRMR=0.04; critical understanding: χ^2_2=15.0, *P*<.001, CFI=0.91, RMSEA=0.08, and SRMR=0.04; self-expression: χ^2_2=8.2, *P*=.02, CFI=0.96, RMSEA=0.06, and SRMR=0.03; norm compliance: χ^2_2=5.8, *P*=.06, CFI=0.97, RMSEA=0.04, and SRMR=0.02).

Regarding the direct effect of household income (hypothesis 2), the relationship with deprivation-type epistemic curiosity was statistically significant for 3 dimensions of parental media literacy: critical understanding (β=.03; *P*=.005), self-expression (β=.02; *P*=.01), and norm compliance (β=.02; *P*=.002). However, the direct effect was not significant for the technological use dimension (β=–.00; *P*=.79). This finding partially supports hypothesis 2.

Regarding the mediation hypothesis (hypothesis 3), the indirect effect of household income on deprivation-type epistemic curiosity mediated by parental media literacy was significant for critical understanding (β=.007; *P*=.003), self-expression (β=.011; *P*<.001), and norm compliance (β=.004; *P*=.03). In contrast, the indirect effect through technological use was not statistically significant (β=.00; *P*=.74). This finding partially supports hypothesis 3 concerning deprivation-type curiosity. Although these indirect effects were statistically significant, their magnitudes were small and should be interpreted with caution.

Table . Deprivation-type curiosity results.

PML[a] dimension	Income→PML, β	PML→deprivation-type curiosity, β	Income→deprivation-type curiosity, β	Indirect effect, β
TU[b]	.001	.18[c]	.001	.000
CU[d]	.03[c]	.21[c]	.03[e]	.007[e]
SE[f]	.05[c]	.23[c]	.02[e]	.011[c]
NC[g]	.02[e]	.22[c]	.02[e]	.004[e]

[a]PML: parental media literacy.
[b]TU: technological use.
[c]*P*<.001.
[d]CU: critical understanding.
[e]*P*<.05
[f]SE: self-expression.
[g]NC: norm compliance.

Discussion

Principal Findings

This study examined the role of parental media literacy in children's epistemic curiosity during screen-based media use. In contemporary digital environments, children are routinely exposed to diverse information and learning opportunities through screen-based media, making it increasingly important to understand the factors that shape how they engage with these experiences. Across the 4 dimensions of parental media literacy, higher levels were generally associated with greater epistemic curiosity among children during media use. Although the magnitude of the associations varied across dimensions, the findings suggest that parental media literacy may be linked to children's curiosity-driven engagement with digital media. Among the 4 dimensions, technological use showed a distinct pattern: it was directly associated with both interest- and deprivation-type curiosity, but the indirect association between household income and deprivation-type curiosity through technological use was not statistically significant.

Parental Media Literacy and Children's Epistemic Curiosity

Critical understanding, self-expression, and norm compliance were positively associated with both interest- and deprivation-type curiosity. Technological use was also positively associated with both forms of curiosity, although its association with deprivation-type curiosity was relatively weaker than that observed for interest-type curiosity.

One notable finding was that technological use showed a different pattern from those of the other dimensions of parental media literacy. While critical understanding, self-expression, and norm compliance demonstrated significant indirect associations linking household income to deprivation-type curiosity, technological use did not. Although technological use was directly associated with both interest- and deprivation-type curiosity, its indirect association between household income and deprivation-type curiosity was not statistically significant.

Technological use may increase children's opportunities to encounter novel content and diverse information, thereby stimulating interest-based exploration (interest-type curiosity). One possible explanation is that deprivation-type curiosity, which reflects a desire to resolve uncertainty and knowledge

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gaps, may depend more heavily on higher-order competencies such as critical understanding, self-expression, and reflective engagement with media.

This distinct pattern warrants further investigation. Future research should examine why technological media skills appear to support children's curiosity directly but do not function as a significant pathway linking household income to deprivation-type curiosity.

Parental Media Literacy as a Pathway Linking SES and Epistemic Curiosity

The findings also suggest that parental media literacy may represent one potential pathway through which socioeconomic resources are associated with children's media-related experiences. Household income was positively associated with parental media literacy, and indirect effects emerged across several dimensions of epistemic curiosity. These findings are consistent with those of previous research showing that families with greater socioeconomic resources often have increased access to educational opportunities and digital technologies that may support the development of media-related competencies.

The association between household income and parental media literacy may be particularly understandable for dimensions such as technological use, which often requires access to digital devices, platforms, and opportunities for hands-on engagement with emerging technologies. In contrast, competencies such as critical understanding, self-expression, and norm compliance may be more amenable to educational interventions and learning opportunities.

Importantly, unlike socioeconomic resources, parental media literacy represents a potentially modifiable competency. Although the present findings do not imply that media literacy can eliminate socioeconomic disparities, they suggest that parental media literacy may be one factor associated with children's positive engagement with digital media regardless of family income. From this perspective, media literacy education may represent a promising avenue for supporting families as they navigate increasingly complex digital environments.

Although the indirect associations were statistically significant, their effect sizes were small in magnitude. Consequently, parental media literacy should be viewed as one of several factors that may be associated with the relationship between socioeconomic resources and children's epistemic curiosity.

Implications for Media Literacy Education

The present findings highlight the potential value of parental media literacy education. Contemporary parents are increasingly expected to guide children's media use, yet many developed their own media practices through personal experience rather than formal media literacy training. As digital environments continue to evolve, parents face growing challenges in helping children navigate complex media ecosystems. The present findings suggest that parental media literacy may be associated with children's curiosity-driven engagement with media, underscoring the importance of supporting parents as active participants in children's digital learning environments.

Notably, parental media literacy represents a competency that can potentially be strengthened through education and intervention. Although media literacy education cannot eliminate broader socioeconomic inequalities, it may provide parents with practical tools to support children's engagement with digital media. Educational programs that promote critical understanding, self-expression, and responsible media use may help parents create media experiences that encourage exploration, learning, and curiosity.

Given the importance of epistemic curiosity for children's learning and development, future research should continue to explore how parental media literacy education may support positive media experiences and learning-related outcomes in childhood.

Limitations

This study has several limitations. First, the data were cross-sectional, preventing conclusions regarding the direction of the associations observed. Although the findings suggest that parental media literacy is associated with children's epistemic curiosity during screen-based media use, future longitudinal research is needed to better understand how these relationships develop over time.

Second, children's epistemic curiosity was assessed through parent reports rather than direct observations or child self-reports. Although parent reports are commonly used when studying young children, they may not fully capture children's subjective experiences during media use. In addition, because both predictor and outcome variables were obtained from the same respondent, shared method variance may have inflated some of the observed associations. Future research should incorporate multiple sources of data, including child reports, behavioral measures, observational approaches, and longitudinal designs.

Third, this study was conducted in South Korea, a highly digitalized society characterized by widespread media use and strong parental involvement in children's education. In addition, participants were recruited through an online panel, which may have resulted in a sample with relatively high levels of parental engagement. Furthermore, mothers constituted most respondents. Although mothers often serve as primary caregivers for children in the target age group for this study, future research would benefit from including a more balanced representation of fathers to examine potential differences in parental media literacy and children's media experiences.

Conclusions

In conclusion, this study contributes to the growing literature on media literacy by examining parental media literacy in relation to children's epistemic curiosity during screen-based media use. The findings suggest that parental media literacy may extend beyond an individual competency and be associated with children's media-related experiences within family contexts. By highlighting parental media literacy as a potentially modifiable factor linked to children's curiosity-driven engagement with digital media, this study underscores the importance of supporting parents as they navigate increasingly complex media environments. Future research should continue

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to explore how parental media literacy can be fostered and how it may contribute to positive media experiences and learning-related outcomes in childhood.

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Authors' Contributions

YC and PJS contributed to the conceptualization of the study. YC conducted the formal analysis and wrote the original draft of the manuscript. PJS provided supervision and methodological guidance, including advice on the revised analyses. Both authors contributed to reviewing and editing the manuscript and approved the final version.

Conflicts of Interest

None declared.

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Abbreviations

CFA: confirmatory factor analysis
CFI: comparative fit index
RMSEA: root mean squared error of approximation
SES: socioeconomic status
SRMR: standardized root mean squared residual

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Original Paper

Parental Smartphone Use and Children's Emotional Well-Being in Everyday Family Life: Experience Sampling Study

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Abstract

Background: Over the past decade, smartphones have become an integral part of family life, shaping both daily routines and parent-child interactions. Although parental smartphone use in the presence of children is frequently framed as harmful through concepts such as phubbing and technoference, these constructs emphasize disruptive smartphone use and may bias interpretations toward negative effects. Moreover, most previous research has relied on cross-sectional self-report data, limiting insight into how parental smartphone use relates to children's well-being in everyday life.

Objective: This study examined the associations between parental smartphone use in the presence of the child and children's affective well-being, as well as perceived threats to children's fundamental needs, using both self-reported and device-logged measures of smartphone use.

Methods: Individual parents (N=131) participated in a 10-day daily diary study. Each evening, parents reported their smartphone use in the presence of a selected target child, their child's positive and negative affect, and perceived threats to their child's fundamental psychological needs. In addition, Android users who provided consent installed a mobile sensing app that continuously recorded objective smartphone use throughout the study period. Multilevel models were used to examine both within-person (day-to-day fluctuations) and between-person associations separately for mothers and fathers while controlling for day of study, weekday vs weekend, and daily working hours.

Results: Higher parental smartphone use was largely unrelated to children's affective well-being. However, mothers who, on average, reported greater overall smartphone use perceived greater threat to their child's fundamental needs. Similarly, on days when fathers reported using their smartphones more than usual, they also perceived greater threats to their child's fundamental needs. In regard to positive affect, no significant associations were found for children's positive affect perceived by their parents, indicating that parents who, on average, used their smartphones more frequently around their child did not report lower child positive affect. Regarding negative affect, fathers who reported higher overall smartphone use also reported higher child negative affect. Additionally, on days when mothers used their smartphone more than usual, they perceived their child as displaying more negative affect. None of these associations emerged when parental smartphone use was assessed using device-logged data.

Conclusions: Taken together, these findings suggest that perceived child need threat may be linked to parents' subjective perceptions and interpretations of their smartphone use rather than to their digitally traced smartphone behavior. This discrepancy underscores the importance of distinguishing between subjective and objective assessments of parental smartphone use and highlights the need for future research that integrates children's perspectives and interactional context to clarify when and how parental smartphone use may impact children's well-being.

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KEYWORDS

child well-being; parental phubbing; parental smartphone use; parent-child bonding; parent-child interaction; technoference

Introduction

Overview

Over the past decade, smartphones have inevitably become part of family life, shaping both daily routines and leisure activities. While this connectivity offers many benefits, growing evidence suggests that parental smartphone use in the presence of a child may have negative consequences, as parental attention is diverted from the child to the device [1]. In the present literature, parental smartphone use is often used interchangeably with phubbing and technoference. Phubbing—a blend of "phone" and "snubbing"—refers to instances in which an individual ignores another person in a social setting by directing attention to their smartphone [2], whereas technoference refers to interruptions in social interactions resulting from smartphone use in the presence of others [3]. However, both phubbing and technoference carry a negative connotation and may, as a result of this connotation, bias interpretations, as parental smartphone use may not inherently be negative [4]. In addition, most prior studies use self-report and a cross-sectional design that only allows comparisons between people [5]. Therefore, this study leverages longitudinal self-report and mobile sensing data to obtain a more nuanced understanding of the association between parental smartphone use in the presence of children and children's affective well-being.

Parental Smartphone Use and Its Effects

Through the lenses of phubbing and technoference, prior work suggests that parental smartphone use in the presence of a child should have a detrimental effect on the child's well-being [6]. Studies on phubbing indicate that phone use in the presence of a child is associated with the development of unhealthy screen habits and behaviors in the child, with especially strong implications for younger children [7,8]. These detrimental consequences may extend into children's future lives, underscoring the importance of raising parental awareness and reducing habitual phone use in the presence of children. In line with this research, other studies found that higher levels of phubbing by one or both parents are associated with children experiencing more negative emotions and feeling disconnected from their parents [9]. Phubbing has also been linked to lower maternal happiness, which in turn predicts reduced child happiness and poorer self-regulation skills in children [10]. Meanwhile, from the perspective of technoference, higher technoference in parent-child contexts is linked to greater externalizing and internalizing behaviors [11,12], such as depressive symptoms [13] and anxiety [14], along with lower prosocial behaviors [15] and problematic smartphone use [16] among children. Furthermore, parental technoference was associated with lower self-esteem [17], higher incidence of cyberbullying [14], and higher levels of smartphone addiction [13] in adolescents. Taken together, these findings suggest that parental smartphone use in the presence of children appears to be consistently linked to poorer child well-being.

In the literature on phubbing and technoference, this detrimental effect is often explained through 2 perspectives. First, parental smartphone use in the presence of a child is thought to displace parental attention, leading to a disruption in parent-child attachment. This displacement hypothesis suggests that when parents spend more time on their smartphones, they displace the quality time they could otherwise spend with their children, which is important for fostering a secure parent-child attachment [18]. Secure attachment is often considered the hallmark of a healthy parent-child relationship [19], as it has consistently been linked to positive outcomes such as higher academic achievement, better comprehension, enhanced cognitive functioning, and stronger socioemotional competence compared to less secure attachment styles [20,21]. Consistent with the displacement hypothesis, past work suggests that children's perceptions of parental neglect, arising from parents' phubbing behavior, were negatively associated with the quality of parent-child attachment.

Second, the potential negative effects of parental smartphone use on children's affective well-being can be understood through the fundamental need-threat framework proposed by Williams [22]. According to this framework, the use of a smartphone in the presence of others elicits ostracism, reflecting feelings of being invisible and/or excluded that threaten individuals' fundamental psychological needs, thereby decreasing positive affect and increasing negative affect. Accordingly, parental smartphone use may undermine children's affective well-being by threatening the fulfillment of children's fundamental needs and through feelings of ostracism [23,24]. In contrast, parental engagement can fulfill children's fundamental needs (eg, need for belonging, need for self-esteem, and sense of meaningful existence) and prevent feelings of ostracism [25-28]. Together, the displacement hypothesis and fundamental need-threat framework highlight that parental smartphone use may have tangible psychological consequences for a child, particularly when the child's needs become unfulfilled.

A critical limitation of the above frameworks is that they are heavily derived from the phubbing and technoference literature. Both phubbing and technoference are often presented as highly negative concepts, thus biasing the overall narrative toward the idea that any parental phone use in the presence of a child will be detrimental [4]. Most measures of phubbing and technoference are negatively framed, often inquiring about moments when smartphone use was experienced as disturbing. As a result, these studies primarily capture situations in which smartphone use is indeed perceived as disruptive, which—unsurprisingly—are also associated with negative outcomes. Such framing thus fails to capture the many moments in which smartphone use is neutral or even integrated into positive interactions [5,29]. Using more neutral approaches, which do not frame parental smartphone use as phubbing or technoference, we see that the association between parental phone use and child well-being is more nuanced. On the one hand, the detrimental consequences of parental smartphone use may still be present. For instance, one study showed that

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child-observed parental phone use was associated with children experiencing increased anger and sadness as a result of less parental attention [30]. On the other hand, one study showed that self-reported parental smartphone use had only minimal effects on parental listening qualities, so that meaningful child-parent interactions were still possible [31]. Meanwhile, another study suggested that higher levels of social connectedness were found when parents used their phones to complement the interaction with their children [32]. Taken together, the current body of literature may thus present a skewed perspective of parental smartphone use. To obtain a more comprehensive understanding of the influence of parental smartphone use on child well-being, it may be advantageous to adopt more neutral measures that allow us to capture the full spectrum of smartphone use, including its potentially neutral or beneficial aspects.

A second limitation of prior work is its overreliance on cross-sectional data [33]. Cross-sectional studies only allow between-person comparisons, which reflect stable differences in child outcomes across parents with different levels of smartphone use. This allows us to differentiate whether higher or lower parental smartphone use is differentially linked to child well-being. However, previous research and theoretical frameworks suggest that a within-person perspective might give more insight into the processes underlying parental smartphone use. Parental smartphone use likely varies on a day-to-day basis—the same parents are likely to experience days with higher or lower smartphone use, and these fluctuations are likely to have different influences on child well-being. Consistent with this notion, one study demonstrated that there is substantial variability in daily parental smartphone use, altering the associations between parental smartphone use, technoference, and the perception of child restlessness (within-person) [5]. Another study showed no differences in parental engagement with their children between parents with higher and lower smartphone use (between-person), but higher parental smartphone use was associated with higher parental engagement at a later time (within-person) [34]. Therefore, to obtain a more comprehensive portrait of the influence of parental smartphone use on child well-being, it is beneficial to not only capture stable between-person differences but also the effects of day-to-day fluctuations in parental smartphone use.

A final limitation of past studies is that parental smartphone use has almost exclusively been measured using self-reported data [33]. Studies have shown that self-reported smartphone use data is a poor representation of actual, "objective" smartphone use data [35]. That is, findings based on self-reported amounts of smartphone use can be unreliable, as participants may misremember or underreport their behavior (eg, to appear socially acceptable). Interestingly, one of the first pioneering studies using objectively measured parental smartphone use found no association between the duration or frequency of parental smartphone use and parents' perceptions of child restlessness [5]. Combining self-report measures with more objective markers (eg, phone logs, observer ratings, and mobile sensing) may thus yield more nuanced insights into the effects of parental smartphone use on children.

Study Objectives

Based on these limitations, there is a recognizable need for further research that more precisely conceptualizes parental smartphone use and its interaction with children, using an objective and unbiased approach in the measurement of smartphone use [36]. Building on prior research and in response to the limitations described above, this study aims to examine the association between parental smartphone use in the presence of the child and the child's affective well-being.

Our study makes the following contributions: first, through its intensive longitudinal, ecological momentary assessment (EMA), our study allows us to compare effects between parents and at the same time also offers insight into the (within-person) effects of day-to-day fluctuations in parental smartphone use on the child's outcome. Second, using mobile sensing data, our study was able to compare the subjective self-report data with device-logged data. Third, by examining both parents, our study extends prior research that has predominantly focused on primary caregivers and, consequently, largely reflects the maternal perspective. Based on the above framework, this study aims to investigate the following preregistered hypotheses concerning both within-person and between-person associations between parental smartphone use in the presence of the child and children's well-being (the preregistration is available on the Open Science Framework (OSF) [37].

At the within-person level (H1), we expected that day-to-day fluctuations in parental smartphone use would be meaningfully related to children's affective well-being. Specifically, on days when parents used their smartphones more than usual in the presence of their child, we expected children to be rated as experiencing greater fundamental need threat, higher negative affect, and lower positive affect compared to their own average levels. This hypothesis reflects the idea that momentary increases in parental smartphone use may interfere with ongoing parent-child interactions and be associated with short-term changes in children's affective well-being.

At the between-person level (H2), we expected that stable differences in parental smartphone use across the study period would be associated with differences in children's overall affective well-being. That is, parents who, on average, reported higher levels of smartphone use in the presence of their child were expected to report greater fundamental need threat, higher negative affect, and lower positive affect in their children compared to parents with lower average levels of smartphone use. This hypothesis captures the assumption that more frequent exposure to parental smartphone use may be linked to more enduring differences in children's well-being.

Finally, we additionally explored whether these associations differed between mothers and fathers, given potential differences in parenting roles, expectations, and perceptions related to smartphone use. While our preregistration referred to the construct as "parental phubbing," we revised the terminology to "parental smartphone use" to ensure a more neutral and objective operationalization.

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Methods

Sample

A total of 70 romantic parental couples (N=140 individuals) took part in the study. Parents were recruited via (social) media (eg, radio podcasts, a popular German psychology magazine, and social media posts), distribution of flyers in shopping malls, daycare centers, and doctoral practices, and through snowball sampling. Eligibility criteria included (1) being 18 years of age or older, (2) understanding and speaking German fluently, (3) owning a smartphone, (4) being in a romantic relationship for at least 6 months, (5) both partners agreeing to take part in the study, and (6) having a child aged 1 to 16 years. A total of 9 partners did not complete any questionnaires and were therefore not included in the analyses. This resulted in a final sample of 131 individual parents (n=61 parental couples and n=9 individual parents without a participating partner), aged between 26 and 61 years (mean 37.34, SD 6.02). The age of the target children ranged between 1 and 16 years (mean 6.59, SD 3.95, including 60/131, 46%, girls). On average, partners had been in a relationship for 10.6 (SD 6.22) years. The majority of participants were married, including 77% (50/65) of mothers and 71% (47/66) of fathers. Our compliance rate for the daily reports ranged between 83% and 86%. Additional social demographics separately for mothers and fathers are shown in Table 1.

Table 1. Demographic characteristics of the study sample.

Demographics	Mothers		Fathers	
	Mean (SD; min-max)	n (%)	Mean (SD; min-max)	n (%)
Parent's age (years)	36.5 (5.41; 26-53)	65 (100)	38.1 (6.50; 27-61)	66 (100)
Target child's age (years)	6.43 (3.87; 1-15)	65 (100)	6.74 (4.05; 1-15)	66 (100)
Number of children in the household	1.82 (0.82; 1-5)	65 (100)	1.80 (0.81; 1-5)	66 (100)
Relationship duration (years)	10.9 (6.16; 1-32)	65 (100)	10.3 (6.32; 1-32)	66 (100)
Daily working hours	2.47 (2.12; 0-7.8)	51 (78.5)	4.07 (1.93; 0-7.7)	63 (95.5)
Weekly working hours	11.1 (9.56; 0-35.1)	51 (78.5)	18.3 (8.68; 0-34.6)	63 (95.5)
Subjective socioeconomic status (1=lowest to 10=highest)	6.05 (1.53; 1-8)	65 (100)	6.26 (1.48; 2-9)	66 (100)
Employment status				
Fulltime	N/A[a]	11 (17)	N/A	53 (80)
Halftime	N/A	38 (58)	N/A	10 (15)
Other (without a job, student)	N/A	16 (24)	N/A	3 (5)
Educational level				
Secondary school (Hauptschulabschluss)	N/A	3 (5)	N/A	8 (12)
Intermediate school (Realschulabschluss)	N/A	10 (15)	N/A	12 (18)
Qualification for university ([Fach-] Abitur)	N/A	20 (31)	N/A	12 (18)
University degree	N/A	28 (43)	N/A	28 (42)
PhD	N/A	4 (6)	N/A	4 (6)

[a]N/A: not applicable.

Procedure

Data were collected as part of the larger experience-sampling project eMotion, which combines an intensive longitudinal EMA design with mobile sensing to investigate the well-being of romantic couples in an increasingly digital world. Data collection took place between 2022 and 2025. Parents could sign up for the study online by filling out a contact form. Those who did not fulfill the inclusion criteria were automatically screened out. Those who were eligible for the study could sign up for an intake procedure, in which a trained recruiter provided information and instructions about the study. Subsequently, parents were asked to select one target child for whom the questionnaires were completed and filled out an intake questionnaire, providing informed consent and responding to demographic and trait measures. This survey took about 30-45 minutes. Couples were screened out if one or both partners did not fill out the questionnaire by midnight the day before the start of the experience sampling method (ESM) period. Then, over a period of 10 days, both parents were simultaneously beeped 5 times per day between 9:30 AM and 9:00 PM. The parents received an SMS text message with the link to the questionnaire programmed in formR [38]. An additional sixth beep included a short evening questionnaire (administered at 9:30 PM), with several (other) questions about the entire day. For this study, we only used the data from the evening questionnaire. At the end of the ESM period, parents answered a final questionnaire, including several postmeasures (ie, a few trait scales), and questions about their experience with the study. To reduce the likelihood of parents changing their target child during the study, each evening questionnaire included a reminder before the child-related questions: "When answering the

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following questions, please refer to the child you selected at the beginning of the study." For the mobile sensing component, participants with Android smartphones who provided additional consent installed the movisensXS app, which continuously recorded smartphone trace data throughout the 10-day study period. At the end of the study, participants completed a final questionnaire assessing additional trait measures, were thanked and reimbursed. Furthermore, they could receive individualized feedback on their personality, burnout, emotions, emotion regulation strategy use, sleep quality and mood, partner contact and relational well-being.

Ethical Considerations

The study procedure was approved by the ethics committee of the Psychology Department of the University of Münster, Germany, with approval number 2021-81-AM.

Written informed consent was obtained from all participants as part of the eMotion study prior to data collection. The consent covered the collection of questionnaire and smartphone sensing data and permitted the use of these data for secondary analyses. Participants were informed that participation was voluntary and that they could withdraw from the study at any time without consequences.

The data used in these analyses were deidentified prior to analysis. Participant confidentiality was maintained throughout the study, and all data were stored securely in accordance with applicable data protection regulations.

Parents received financial compensation on a pro rata basis with a maximum reimbursement of €118 (US $132.91) per person, including a €10 (US $11.26) bonus for all parents who completed more than 80% of the experience-sampling prompts. Alternatively, participating students could opt for course credit.

Measures

Overview

All variables used in this project were part of the evening questionnaire and were thus answered once a day in the evening by both parents during the 10-day study period. We implemented different ways to estimate the internal consistency of our self-reported measures. For multi-item EMA measures, we first estimated Cronbach α separately for each study day. We then report the average of daily α values as a pragmatic indicator of reliability. For 2-item measures, we report mean daily interitem correlation and Spearman-Brown reliability. For single-item measures, where internal consistency is not applicable, we instead report intraclass correlation coefficient (ICC) across days.

Child Fundamental Need Threat

Child fundamental need threat was measured by asking participants to reflect on the extent to which their child felt "rejected" (Belonging), "it had the situation(s) under control," "irritated" (Control), "at ease" (Self-Esteem), "invisible" (Meaningful existence), and "excluded" (Ostracism) because of their smartphone use that day. Participants rated these statements on a 7-point scale (1: "not at all"; 7: "very much"). An average of these 6 items was calculated to obtain an aggregate measure of child fundamental need threat, with higher scores reflecting higher need threat due to smartphone use. Mean daily α suggested that the internal consistency for the child fundamental need threat items was good (α=.84).

Child Positive Affect

Child positive affect was measured by averaging the 2 items ("My child was happy today" and "My child was relaxed today"). Before reporting on any child-related smartphone use items, parents were asked to rate these statements on a 7-point scale (1: "not at all"; 7: "very much"), with higher scores reflecting more positive affect. Mean daily interitem correlation and Spearman-Brown coefficients suggested that the internal consistency of the 2 items was acceptable (r=0.55; r_{SB}=0.71).

Child Negative Affect

Child negative affect was assessed by averaging the following 6 items per day: "My child was sad today," "My child was upset today," "My child was worried today," "My child was exhausted today," "My child was stressed today," and "My child was down today." Before reporting on any child-related smartphone use items, parents rated these statements on a 7-point scale (1: "not at all"; 7: "very much"), with higher scores reflecting more negative affect. Mean daily α suggested that the internal consistency for the child negative affect items was acceptable (α=.75).

Self-Reported Parental Smartphone Use in the Presence of a Child

Parental smartphone use in the presence of a child was assessed using one self-report item ("To what extent did you use your smartphone today in the presence of your child? (Not counting answering the questionnaires on the smartphone)"). Both parents rated this item separately on a 7-point scale (1: "not at all"; 7: "very much") every evening, with higher scores reflecting more parental smartphone use. The ICC for this item was relatively modest ($ICC_{adjusted}$=0.41), suggesting that participants' patterns of phone use in the presence of their child tended to vary over time.

Overall Device-Logged Parental Smartphone Use

Device-logged parental smartphone use was assessed using a mobile sensing app (movisensXS [39]). The app recorded when a participant's smartphone screen was turned "on" and when it was turned "off" throughout the entire ESM period. Similar to the procedure used in Denecker et al [5], we calculated 2 separate parental smartphone use indicators per day: "screen frequency" represents the number of times per day a participant's phone screen was turned on. "screen duration" reflects the total amount of time (in hours) per day participants' devices were in use. It should be noted that while parental smartphone use was captured via device-logging, we did not collect information on whether the child was present during these logged episodes. Device-logged parental smartphone use was added as an additional predictor after the completion of the preregistration. Hence, analyses including screen duration or frequency must be considered exploratory.

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Data Analysis

Our analysis plan was preregistered on OSF [37]. As preregistered, in a first step, we tested whether the same target child was chosen by both parents by matching the target child's gender and age in both parental reports. Despite being instructed otherwise, 22% (n=29) of the parents did not choose the same target child. Hence, we refrained from using double intercept actor-partner-interdependence models to analyze our intensive longitudinal data (preregistered Strategy A). We therefore followed preregistered Strategy B, where traditional multilevel models with random intercept and random slopes for all time-varying effects would be computed separately for mothers and fathers, and for each outcome. As a result, no partner effects could be tested.

The daily evening reports constituted level 1 (L1, within-person level) and were nested within individuals at level 2 (L2, between-person level). Parental smartphone use was entered into the model as within-person (L1) and between-person (L2) components. To calculate the within-person component of parental smartphone use (L1), the variable parental smartphone use was person-mean centered. A deviation from zero can thus be interpreted as a deviation from the individual's own average level of parental smartphone use. The between-person component (L2) was extracted by (gender-specific) grand-mean centering the within-person means of parental smartphone use. By entering this between-person component into the model, we controlled for deviations of an individual's average level of parental smartphone use from the mean level across all mothers or fathers, respectively. The outcome variables were neither transformed nor centered. To account for potential (linear) trends of the outcome over time, we included day as a control variable, recoded such that day=0 reflected the first day of the study. We also controlled for weekday (0) or weekend day (1), to account for the possibility that parental smartphone use would differ between weekdays and weekends, since we assume that parents have more time available for their children. Additionally, hours worked in a paid job (assessed every evening) were included as control variables on level 1 (within-person centered) and level 2 (between-person centered), to account for time (not) spent with the child. Primary analyses were run using the *lme4* [40] and *lmerTest* [41] packages in R.

During the review process, the question arose whether child age might qualify our findings, as it was suggested that parental smartphone use may have more detrimental effects on younger children. Therefore, we decided to include the target child's age as a moderator in the models. For significant interactions, we conducted simple slope analyses to further examine how the association between variables varied across different levels of children's age. This analysis was not preregistered and should be considered exploratory. The original tables of our preregistered analysis can be found in Tables S1.1-S1.6 in Multimedia Appendix 1.

Results

Descriptive Statistics

Means, SDs, and zero-order correlations for all variables were calculated for the within- and between-level (separately for mothers and fathers). To test for potential differences between mothers and fathers, paired-sample t tests were conducted for all variables of interest (Tables 2 and 3). These tests revealed that mothers reported higher self-reported smartphone use in the presence of the child than fathers. Device-logged smartphone use, reflected through screen duration and screen frequency, did not significantly differ between mothers and fathers.

Table 2. Descriptive statistics and paired-samples t tests comparing mothers and fathers (baseline)[a].

Variable	Mothers, mean (SD)	Fathers, mean (SD)	*t* test (*df*)	*P* value	Cohen *d*
Child fundamental need threat	3.13 (1.39)	2.63 (1.04)	1.72 (34)	.09	0.29
Child positive affect	5.01 (1.10)	5.08 (1.10)	–0.48 (51)	.63	–0.07
Child negative affect	2.15 (0.98)	2.16 (0.97)	–0.06 (51)	.96	–0.01
Self-reported smartphone use	2.70 (0.89)	2.14 (0.75)	3.92 (58)	<.001	0.51
Screen duration (hours)	4.35 (1.94)	4.20 (2.16)	0.54 (36)	.60	0.09
Screen frequency	106 (39.5)	115 (47.3)	–0.95 (36)	.35	–0.16

[a]All tests are paired-samples *t* tests. Effect sizes are reported as Cohen *d*. Missingness varied between 12% and 17%.

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Table 3. Correlation matrix for key study between-person variables (Pearson r and 2-tailed *P* value)[a].

Variable	Self-reported smartphone	Screen duration	Screen frequency	Fundamental need threat	Positive affect	Negative affect
Self-reported smartphone						
r	0.11	0.06	–0.22	0.14	0.02	0.10
P value	.43	.66	.11	.36	.90	.50
Screen duration						
r	0.28	0.67	0.23	–0.11	–0.09	0.05
P value	.06	<.001	.09	.50	.55	.76
Screen frequency						
r	–0.14	0.12	0.15	0.03	0.10	0.10
P value	.35	.42	.39	.86	.49	.52
Fundamental need threat						
r	0.27	–0.03	0.11	0.06	–0.42	0.51
P value	.06	.87	.50	.74	.004	<.001
Positive affect						
r	–0.12	–0.01	–0.20	–0.23	0.58	–0.59
P value	.39	.97	.21	.10	<.001	<.001
Negative affect						
r	0.18	0.07	0.02	0.14	–0.58	0.51
P value	.18	.64	.88	.32	<.001	<.001

[a]Sample sizes ranged from 31 to 60. Mothers' correlations are below and fathers' correlations are above the diagonal; intercorrelations between mothers and fathers are on the diagonal. The correlation is significant at the .05 level (2-tailed).

Parental Smartphone Use and Children's Emotional Well-Being

Below, we present the results of the different models on the association between parental smartphone use and child emotional well-being outcomes. We first present our findings for self-reported parental smartphone use, disentangling between- and within-person associations among mothers and fathers. Finally, we summarize the additional exploratory analyses linking device-logged parental smartphone use and child emotional well-being.

Self-Reported Parental Smartphone Use and Child Fundamental Need Threat

Overview

Key model estimates of the association between self-reported parental smartphone use and parental perceptions of child fundamental need threat are presented in Table 4, while a complete list of model estimates can be found in Table S2.1 in Multimedia Appendix 1.

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Table 4. Fixed-effect estimates for within- and between-person predictors of parents' reports of child fundamental need threat[a].

Predictors	Need threat maternal report		Need threat paternal report	
	Estimates (95% CI)	*P* value	Estimates (95% CI)	*P* value
Self-reported smartphone use[b,c]	0.07 (–0.15 to 0.28)	.54	0.22 (0.03 to 0.42)	.03
Self-reported smartphone use[b,d]	1.13 (0.56 to 1.70)	<.001	0.46 (–0.06 to 0.99)	.08
Self-reported smartphone use[b,c] × child age	0.02 (–0.01 to 0.05)	.15	–0.02 (–0.05 to 0.01)	.13
Self-reported smartphone use[b,d] × child age	–0.08 (–0.15 to –0.01)	.03	–0.05 (–0.11 to 0.02)	.15
Screen duration[c]	–0.02 (–0.20 to 0.16)	.85	–0.01 (–0.13 to 0.12)	.89
Screen duration[d]	–0.01 (–0.40 to 0.39)	.98	–0.22 (–0.49 to 0.05)	.12
Screen duration[c] × child age	0.01 (–0.02 to 0.03)	.62	0.00 (–0.02 to 0.02)	.85
Screen duration[d] × child age	–0.01 (–0.05 to 0.03)	.73	0.02 (–0.02 to 0.06)	.25
Screen frequency[c]	–0.00 (–0.01 to 0.00)	.41	0.00 (–0.01 to 0.01)	.95
Screen frequency[d]	–0.01 (–0.03 to 0.01)	.18	–0.00 (–0.01 to 0.01)	.42
Screen frequency[c] × child age	0.00 (–0.00 to 0.00)	.96	0.00 (–0.00 to 0.00)	.56
Screen frequency[d] × child age	0.00 (–0.00 to 0.00)	.10	0.00 (–0.00 to 0.00)	.60

[a]In all models, time, work hours, and weekday/weekend were included as control variables.

[b]In the presence of the child.

[c]Within-person level.

[d]Between-person level.

Between-Person Associations

At the between-person level, self-reported parental smartphone use predicted higher levels of perceived child need threat for mothers (*b*=1.13, 95% CI 0.56-1.70; *P*<.001), but not for fathers. Crucially, the interaction between maternal smartphone use and the target children's age was significant. Simple slope analyses indicated that higher maternal self-reported smartphone use was associated with higher perceived need threat for younger children (–1 SD; *b*=0.922, SE 0.213, 95% CI 0.496-1.349) but not for older children, although the slope remained positive (*b*=0.320, SE 0.142, 95% CI –0.042 to 0.682; Table S3.1 in Multimedia Appendix 1). Overall, this pattern of findings suggests that mothers who reported higher smartphone use tended to perceive greater need threat in their children compared to mothers with lower smartphone use, and that this association became less relevant for older children.

Within-Person Associations

Self-reported smartphone use was linked to child need threat for fathers (*b*=0.22, 95% CI 0.03-0.42; *P*=.03), but not for mothers. This pattern of findings thus suggests that on days when fathers reported greater smartphone use than usual, they perceived their child to display greater need threat. No statistically meaningful interaction effects of target child's age were found for either parent.

Self-Reported Parental Smartphone Use and Child Positive Affect

Overview

Key model estimates of the association between self-reported parental smartphone use and parental perceptions of their child's positive affect are presented in Table 5, while a complete list of model estimates can be found in Table S2.2 in Multimedia Appendix 1.

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Table 5. Fixed-effect estimates for within- and between-person predictors of parents' reports of child positive affect[a].

Predictors	Positive affect maternal report		Positive affect paternal report	
	Estimates (95% CI)	*P* value	Estimates (95% CI)	*P* value
Self-reported smartphone use [b,c]	–0.10 (–0.27 to 0.06)	.21	–0.09 (–0.27 to 0.08)	.30
Self-reported smartphone use [c,d]	–0.15 (–0.58 to 0.28)	.48	–0.16 (–0.67 to 0.36)	.55
Self-reported smartphone use [b,c] × child age	0.01 (–0.01 to 0.03)	.32	0.01 (–0.01 to 0.03)	.35
Self-reported smartphone use [c,d] × child age	–0.01 (–0.06 to 0.05)	.78	0.03 (–0.03 to 0.09)	.33
Screen duration[c]	–0.01 (–0.20 to 0.18)	.90	–0.04 (–0.17 to 0.08)	.53
Screen duration[d]	0.20 (–0.14 to 0.55)	.24	0.07 (–0.16 to 0.29)	.55
Screen duration[c] × child age	0.01 (–0.02 to 0.03)	.63	0.01 (–0.01 to 0.03)	.26
Screen duration[d] × child age	–0.02 (–0.05 to 0.01)	.21	–0.01 (–0.04 to 0.01)	.29
Screen frequency[c]	0.00 (–0.01 to 0.01)	.85	–0.00 (–0.01 to 0.01)	.84
Screen frequency[d]	0.01 (–0.01 to 0.03)	.21	–0.00 (–0.01 to 0.01)	.99
Screen frequency[c] × child age	0.00 (–0.00 to 0.00)	.69	0.00 (–0.00 to 0.00)	.96
Screen frequency[d] × child age	–0.00 (–0.00 to 0.00)	.13	–0.00 (–0.00 to 0.00)	.59

[a]In all models, time, work hours, and weekday/weekend were included as control variables.

[b]In the presence of the child.

[c]Within-person level.

[d]Between-person level.

Between-Person Associations

At the between-person level, self-reported parental smartphone use was not significantly associated with perceived child positive affect for both parents. Further, no significant interactions between self-reported smartphone use and target child age were found. Overall, this pattern of findings suggests that parental perceptions of child positive affect did not differ between mothers and fathers with differing levels of smartphone use.

Within-Person Associations

At the within-person level, day-to-day fluctuations in self-reported parental smartphone use were also not significantly associated with perceived child positive affect for both parents. Similarly, no significant interactions between self-reported smartphone use and target child age were found. This suggests that parental perceptions of child positive affect were not contingent on day-to-day differences in parental smartphone use.

Self-Reported Smartphone Use and Child Negative Affect

Overview

Key model estimates of the association between self-reported parental smartphone use and parental perceptions of their child's negative affect are presented in Table 6, while a complete list of model estimates can be found in Table S2.3 in Multimedia Appendix 1.

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Table 6. Fixed-effect estimates for within- and between-person predictors of parents' reports of child negative affect[a].

Predictors	Negative affect maternal report		Negative affect paternal report	
	Estimates (95% CI)	*P* value	Estimates (95% CI)	*P* value
Self-reported smartphone use [b,c]	0.20 (0.06 to 0.34)	.006	0.04 (–0.13 to 0.20)	.66
Self-reported smartphone use [c,d]	0.24 (–0.09 to 0.57)	.16	0.45 (0.06 to 0.85)	.03
Self-reported smartphone use [b,c] × child age	–0.02 (–0.04 to –0.00)	.04	–0.01 (–0.03 to 0.01)	.55
Self-reported smartphone use [c,d] × child age	0.00 (–0.04 to 0.04)	.96	–0.05 (–0.09 to –0.00)	.04
Screen duration[c]	–0.00 (–0.01 to 0.00)	.63	0.00 (–0.00 to 0.01)	.81
Screen duration[d]	–0.01 (–0.02 to 0.01)	.29	0.00 (–0.01 to 0.01)	.74
Screen duration[c] × child age	0.00 (–0.00 to 0.00)	.37	–0.00 (–0.00 to 0.00)	.58
Screen duration[d] × child age	0.00 (–0.00 to 0.00)	.17	0.00 (–0.00 to 0.00)	.72
Screen frequency[c]	0.05 (–0.10 to 0.21)	.50	0.03 (–0.07 to 0.13)	.53
Screen frequency[d]	–0.16 (–0.43 to 0.11)	.24	0.03 (–0.15 to 0.21)	.76
Screen frequency[c] × child age	–0.01 (–0.02 to 0.01)	.57	–0.01 (–0.02 to 0.01)	.45
Screen frequency[d] × child age	0.02 (–0.00 to 0.05)	.11	0.00 (–0.02 to 0.02)	.96

[a]In all models, time, work hours, and weekday/weekend were included as control variables.

[b]In the presence of the child.

[c]Within-person level.

[d]Between-person level.

Between-Person Associations

At the between-person level, self-reported parental smartphone use was significantly associated with perceived child negative affect in fathers (*b*=0.45, 95% CI 0.06-0.85; *P*=.03), but not for mothers. In addition, the interaction between paternal self-reported smartphone use and target child age was statistically significant: simple slope analyses revealed a significant positive association between paternal self-reported smartphone use and their perceptions of negative affect among younger children (–1 SD; *b*=0.320, 95% CI 0.027-0.613), but not older children (+1 SD; *b*=–0.073, 95% CI –0.315 to 0.169; Table S3.1 in Multimedia Appendix 1).

Within-Person Associations

Conversely, at the within-person level, self-reported parental smartphone use was significantly associated with perceived child negative affect in mothers (*b*=0.20, 95% CI 0.06-0.35; *P*=.006), but not in fathers. In addition, the interaction between maternal smartphone use and target child age was significant, suggesting that this association was prominent for younger target children (–1 SD; *b*=0.149, SE 0.052, 95% CI 0.046-0.251), but was attenuated among older target children (+1 SD; *b*=–0.010, SE 0.054, 95% CI –0.117 to 0.096). Thus, this pattern of findings suggests that on days when mothers reported higher smartphone use than usual, they perceived more negative affect in their children, but that this association became less prominent when target children were older.

Self-Reported vs Device-Logged Smartphone Use

We additionally investigated whether the above associations between self-reported parental smartphone use and child emotional well-being outcomes could be replicated using device-based measures of parental smartphone use, namely screen time frequency and duration. At the between- and within-person levels, these analyses revealed that neither screen time frequency nor duration were significantly associated with parental perceptions of child fundamental need threat, child positive affect, or child negative affect. This pattern of nonsignificant associations was consistent for both parents, irrespective of target child age. Key model estimates of the association between device-logged smartphone use and parental perceptions of children's emotional well-being can be found in Tables 4-6, and a complete list of model estimates is documented in Tables S2.4-S2.6 in Multimedia Appendix 1.

Discussion

Summary

This study examined the association between parental smartphone use in the presence of a child and the child's emotional well-being, using a multimethod approach that combines self-reported measures and device-based log data. By examining several indicators of child emotional well-being, our findings provide partial support to the notion that daily fluctuations in parental smartphone use are meaningfully associated with children's well-being. For mothers, our findings show that higher-than-usual self-reported smartphone use was associated with higher child negative affect. Notably, this

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association was evident only among mothers with younger children, suggesting that younger children may be particularly sensitive to maternal smartphone use in their presence. Meanwhile, for fathers, higher-than-usual smartphone use was associated with greater perceived child need threat, regardless of their children's age. Next, our findings provide partial support to the idea that stable differences in parental smartphone use are associated with differences in child emotional well-being. Mothers reporting higher smartphone use reported greater perceived child need threat, compared to mothers with lower smartphone use, and this association was particularly noticeable among mothers with younger children compared to older children. On the other hand, fathers reporting higher smartphone use reported greater perceived negative affect in their children compared to fathers with lower smartphone use. Lastly, our exploratory findings suggest that the above self-report findings are not replicable using objective, device-logged smartphone use measures. Together, this pattern of findings suggests that the association between parental smartphone use and child emotional well-being is more nuanced than presented in recent studies. Specifically, our findings suggest that parents' subjective perceptions of their own smartphone use may be more closely related to their children's emotional well-being than their actual, objectively recorded smartphone use.

Between vs Within-Person Effects

By distinguishing within-person (daily fluctuations from a parent's own average) and between-person (stable differences between parents) effects, this study scrutinizes the displacement theory and technoference framework in a daily-life setting. Displacement theory posits that time spent on smartphones reduces opportunities for parent-child interaction, thereby undermining child well-being. Similarly, technoference and phubbing research view technology-related interruptions as relational stressors that disrupt attentional availability and responsiveness [12], evoking feelings of being ostracized [23,24].

Based on these frameworks, it is reasonable to expect that these mechanisms operate at the micro level: on days when parents use their smartphones more than usual in their child's presence, children should show lower positive affect or higher negative affect. We found this to be true for mothers in terms of negative affect. Particularly, young children are perceived as having more negative affect on days when mothers use their smartphones more than usual in their presence.

This finding is in line with observational studies documenting increased child frustration or bids for attention when parental attention is diverted to smartphones [42]. However, these findings suggest that these short-term associations are neither universal nor consistent across parents. Specifically, daily increases in smartphone use were associated with greater child negative affect only for mothers, and only among mothers with younger children. One possible explanation is that mothers, on average, spend more time in direct caregiving and emotionally salient interactions with young children than fathers. Consequently, temporary reductions in maternal attentional availability may be more noticeable to young children and may therefore be reflected more strongly in maternal perceptions of children's affective experiences. This finding is in line with experimental research showing that interruptions due to smartphone use can temporarily reduce parental responsiveness and elicit increased bids for attention from young children, reflecting children's sensitivity to disruptions in caregiver availability [43]. Notably, Braune-Krickau et al [43] found that similar responses were observed following nondigital interruptions (ie, paper-and-pencil tasks), suggesting that the critical mechanism is not smartphone use itself but the temporary disruption of responsive parent-child interaction. This interpretation is consistent with developmental research using the still-face paradigm, which demonstrates that even brief interruptions in caregiver responsiveness evoke distress and attempts to reengage with the caregiver [44,45].

In addition to children's affect, we examined children's perceived fundamental need threat. Here, a different pattern emerged. On days when fathers reported higher-than-usual smartphone use in their child's presence, they also perceived greater threats to their child's needs (eg, belonging, meaningful existence, and control). This association was not observed for mothers and was not moderated by child age. One possible explanation is that fathers may be more likely to perceive the relational implications of their smartphone use (ie, children's threatened fundamental needs) than immediate changes in children's affect. While negative affect reflects observable emotional states, perceived need threat might represent a broader interpretation of the quality of the parent-child interaction. Importantly, perceived need threat was assessed immediately after smartphone use reports and explicitly framed as attributable to that use. The temporal proximity and explicit causal framing may activate self-evaluative processes, particularly in light of prevailing societal narratives that portray parental smartphone use as problematic. Under such conditions, fathers may infer need threat as a consequence of their behavior independent of observable changes in the child's affect. In contrast, children's positive and negative affect were assessed prior to smartphone use reports and were not explicitly framed as consequences of that use. This temporal and conceptual separation may therefore have reduced the likelihood that affect ratings were influenced by immediate reflections on fathers' own behavior.

At the between-person level, associations emerged between mothers' smartphone use and perceived threat to their child's fundamental needs, and between fathers' smartphone use and perceived child negative affect, particularly among young children. The differing patterns for mothers and fathers may reflect differences in caregiving roles and the contexts in which mothers and fathers use their smartphones. Given that mothers, on average, take over a larger share of daily caregiving [46,47], their habitual smartphone use may more frequently coincide with emotionally salient caregiving interactions. Over time, stable patterns of reduced availability may align more closely with displacement-based mechanisms, potentially shaping the relational climate of the dyad. This interpretation is consistent with research highlighting the central role of maternal interaction quality in children's emotional adjustment [18,48]. By contrast, the association with fathers' smartphone use was observed for children's negative affect rather than perceived need threat. One possible explanation is that negative affect may be more readily

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observable than underlying threats to children's fundamental psychological needs.

Children's Age as a Moderator

An important finding of this study was that several associations between parental smartphone use and child emotional well-being were evident only among younger children. These findings suggest that child age represents an important developmental context that shapes parental perceptions of children's susceptibility to their smartphone use. This notion is consistent with previous research showing that the detrimental effects of parental smartphone use are particularly pronounced during early childhood [7,8]. One explanation is that younger children require more direct parental care, supervision, and emotional responsiveness than older children. During early childhood, parents remain children's primary source of emotional coregulation, social interaction, and need fulfillment. Consequently, temporary reductions in parental attentional availability due to smartphone use may be perceived by parents as particularly salient and disruptive for younger children. In contrast, as children grow older, they become increasingly autonomous, develop more advanced emotion regulation skills, and rely more heavily on peers than on parents for social interaction and support. Older children may therefore be better able to compensate for temporary reductions in parental attention, rendering them less susceptible to the immediate effects of parental smartphone use. Together, these findings suggest that displacement and technoference processes do not operate uniformly across development but are likely to be strongest during developmental periods characterized by greater dependence on parental attention and responsiveness.

Self-Report vs Device-Logged Smartphone Use

This study used 2 distinct operationalizations of smartphone behavior: contextualized self-reports of smartphone use in the child's presence and device-logged measures of overall smartphone use independent of context. Prior work suggests that parental smartphone use in the presence of a child—often framed in terms of technoference or parental phubbing—is inherently detrimental to children's well-being [12,30]. However, device-logged overall use was unrelated to child affect and perceived need threat. The divergent findings between self-reported and objectively device-logged smartphone use may reflect psychological appraisal processes: awareness of one's own smartphone use—regardless of the actual device-logged use—may increase the perception of its potentially harmful consequences for the child, thus leading to more negative ratings of child well-being. Further, greater overall smartphone use (as indexed by device-logged data) does not necessarily imply more frequent interruptions of emotionally salient parent-child interactions—particularly, given that it is not differentiated between the child being present or not. Consequently, total smartphone use may be a relatively poor proxy for the interactional processes through which smartphone use is hypothesized to affect children's well-being.

Gender differences further underscore the importance of measurement mode. Mothers reported higher smartphone use in their child's presence than fathers, whereas no gender differences emerged in device-logged overall use. This discrepancy suggests that mothers and fathers may use their smartphones for similar total durations, yet differ in the contextual cooccurrence of smartphone use and caregiving. Because mothers typically spend more time in direct interaction with children, their smartphone use may more frequently overlap with caregiving contexts and thus be more likely to be perceived as technoference. Moreover, stronger societal norms regarding maternal attentiveness may heighten mothers' sensitivity to perceive their smartphone use as "phubbing" behavior, contributing to stronger associations between self-reported use and perceived need threat. In line with this interpretation, parental phubbing has been linked to negative maternal emotions [10], consistent with guilt-based or norm-based self-evaluative processes.

Taken together, the findings indicate that the impact of parental smartphone use depends critically on how smartphone behavior is operationalized. Device logs provide objective indicators of overall use but lack contextual information about whether use occurred in the presence of the child. Self-reports capture relational context but also incorporate subjective interpretation and cultural meaning. Integrating both approaches is therefore essential for avoiding overgeneralized claims about the effects of parental smartphone use on children's affective well-being. Most importantly, future research should also integrate children's self-reports and independent observational indicators of affect to disentangle perceived from actual need threat and to more precisely assess the role of parental reporting biases. Incorporating interactional context and multi-informant data will be essential for clarifying when and for whom parental smartphone use meaningfully relates to children's well-being.

Limitations, Strengths, and Future Directions

Several limitations need to be considered, offering opportunities for future studies. First, the generalizability of our findings is limited by the characteristics of our sample. We included romantic parental couples in relatively stable relationships (ie, an average relationship duration of 10 years), which may not reflect the experiences of more diverse family structures or dynamics. Moreover, parents reported, on average, high levels of positive affect and low levels of negative affect in their children, indicating a generally high level of affective well-being. This restricted range likely reduced variability in key outcome measures, thereby limiting our ability to detect associations between parental smartphone use and children's affective responses. Importantly, children's high affective well-being—characterized by elevated positive affect and low negative affect—may function as a resilience factor, enabling them to cope more effectively with brief disruptions in parent-child interactions [49]. As a result, parental smartphone use may be less detrimental in this sample than suggested by previous research. In contrast, children growing up in more stressed family contexts or with lower baseline affective well-being may be more vulnerable to smartphone disruptions, potentially leading to stronger associations between parental smartphone use and child affect. Future studies should therefore examine whether similar patterns emerge in samples characterized by higher parental stress, greater relational strain, or lower child affective well-being.

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Next, we did not directly assess whether parental smartphone use actually resulted in interruptions of parent-child interactions, nor whether smartphone use had immediate effects on children's positive or negative affect. Only perceived need threat was smartphone use explicitly assessed in direct relation to smartphone use in the presence of the child. Moreover, the device-logged measures reflect overall daily smartphone use rather than smartphone use specifically during interactions with the child. While higher overall usage increases the likelihood that smartphone use occurred in the child's presence, this approach introduces substantial measurement error and does not capture the quality, timing, or interactional context of smartphone use. This distinction is particularly important given that secondary distractions are a normative part of everyday parenting. Although parents are often judged for using their smartphones as a distraction, such use may be comparable to other routine interruptions, such as attending to household chores. As Knitter and Zemp [29] noted, it may therefore be critical to differentiate between parental smartphone use that occurs during quality parent-child interactions and smartphone use during more arbitrary moments. Without this differentiation, overall measures of smartphone use may conflate potentially disruptive "phubbing" with benign or unavoidable everyday distractions. Similarly, different smartphone activities are likely to vary in the extent to which they interfere with parent-child interaction. For example, passively scrolling through social media may reduce opportunities for responsive engagement more than engaging in a video call with family members in which the child can actively participate. Consequently, the absence of associations between device-logged smartphone use and children's well-being should not be interpreted as evidence that digitally traced smartphone use is unrelated to child well-being. Rather, it highlights the need for more context-sensitive assessments that distinguish between smartphone use occurring outside the child's presence, smartphone use during everyday shared activities, and smartphone use that disrupts emotionally salient parent-child interactions. Future research should therefore distinguish between different smartphone activities and their interactional context to better understand which forms of parental smartphone use are most relevant for children's emotional well-being. In addition, future studies could combine device-based smartphone logs with proximity-sensing technologies (eg, Bluetooth beacons), observational methods, or EMAs to capture not only the timing and duration of smartphone use but also its interactional context and its immediate implications for children's lived experiences.

Another limitation refers to our use of parental report instead of self-report. We acknowledge that children's self-reports are generally considered the preferred source for assessing subjective emotional well-being whenever developmentally appropriate [50]. However, parent-proxy reports are widely used in developmental and child psychology research, because parents are often the primary informants of children's emotional and behavioral functioning [50]. Therefore, our findings should be interpreted as reflecting parents' perceptions of their children's emotional well-being rather than children's subjective experiences. Consequently, we do not know how children themselves experienced their parents' smartphone use, as all measures of child well-being relied on parental reports. Future research should incorporate children's self-reported experiences to examine whether parental judgments accurately reflect children's subjective perceptions. To more precisely assess when and how parental smartphone use affects children, future studies could combine device-based smartphone logs with proximity-sensing technologies (eg, Bluetooth beacons), observational methods, or EMAs, allowing for a more fine-grained analysis of interactional context and children's lived experiences.

Another limitation of our study concerned the interpretation of the device-logged smartphone data. Although device logs provide an objective estimate of smartphone use and are not subject to recall bias, they do not provide information about the context in which smartphone use occurred, nor do they provide information on the reason for the smartphone use. The absence of associations between device-logged smartphone use and child well-being should therefore not be interpreted as evidence that objectively measured smartphone use is unrelated to children's well-being. Instead, this may indicate the need for more nuanced objective measures to distinguish between smartphone use that occurs outside the child's presence and smartphone use that takes place together with the child and is therefore not necessarily perceived as negative by the child.

A further limitation is that we relied on parents' adherence to the target-child instruction throughout the EMA period. Although reminders were provided before child-related questions, we were unable to independently verify whether parents consistently reported on the same child across all assessments. Therefore, some uncertainty remains regarding whether target-child switching may have influenced the results.

Finally, we did not assess parental characteristics, including neuroticism and psychological distress that may influence parental reports [51]. As these parental characteristics were not measured, we cannot determine the extent to which they influenced the observed associations. Future studies would benefit from including measures of parental psychological functioning alongside child self-reports of emotional well-being to provide a more comprehensive assessment.

Despite these limitations, this study contributes to the growing research on parental smartphone use around children by incorporating several key strengths. First, we included both mothers and fathers, addressing the persistent underrepresentation of fathers in prior research on parental smartphone use. This inclusion is particularly important given that our findings revealed differential associations for mothers and fathers, suggesting that parental smartphone use may play distinct roles within family dynamics and child-rearing contexts, with potentially different implications for children's well-being. Second, by integrating daily diary self-report data with device-logged data, this study provides both ecologically valid and more objective indicators of parental smartphone use. This multimethod approach reduces common-method bias and allows for a more robust examination of smartphone use across measurement modalities. Importantly, the daily diary design enabled the distinction between within-person (day-to-day fluctuations) and between-person (stable individual differences)

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effects, offering a more nuanced understanding of how parental smartphone use relates to children's emotional well-being over time. Notably, the relatively limited evidence for negative effects of parental smartphone use on children's well-being—particularly at the between-person level—may be related to how parental smartphone use was operationalized in this study. Rather than framing smartphone use as inherently problematic through negatively connoted constructs such as phubbing or technoference, we adopted a neutral and descriptive approach that aimed to reflect the everyday digital context in which families live. This broader perspective may have captured a wider range of everyday smartphone behaviors than measures focusing exclusively on phubbing or technoference, thereby contributing to a more nuanced understanding of how parental smartphone use relates to children's well-being. At the same time, this approach aligns with our call for a more nuanced examination of parental smartphone use by allowing for a more fine-grained assessment of how routine smartphone use naturally occurs in family life and how it relates to different dimensions of children's well-being. Furthermore, we assessed multiple dimensions of child well-being, including positive affect, negative affect, and fundamental need threat. This comprehensive measurement approach allows for differentiation between distinct affective and psychological outcomes, highlighting that parental smartphone use may be more strongly related to certain aspects of children's well-being than others.

Finally, previous research investigating child age as a moderator of the association between parental smartphone use and child well-being is limited [6]. While the majority of studies have been conducted with younger children [6], evidence regarding whether younger children are indeed more susceptible to the effects of parental smartphone use remains scarce. Our inclusion of a broader child age range therefore represents a strength of this study, as it enabled us to examine age-related differences in these associations. However, the number of adolescents in our sample was relatively small. Future research should include larger samples of older children and adolescents to further investigate developmental differences in the effects of parental smartphone use. Practically, our findings suggest that parental smartphone use should not be viewed as inherently detrimental. Parents should not fear that any smartphone use in the presence of their child is inherently harmful. Rather, potential negative effects may arise from specific patterns of use, such as reduced responsiveness or interference with parent-child interactions. Our findings may help reduce parental guilt by highlighting that their smartphone use is not necessarily harmful in itself, particularly when in the presence of younger children. However, potential negative effects may arise when parental smartphone use repeatedly interferes with responsive parent-child interactions.

Conclusion

This study examined the association between parental smartphone use in the presence of the child and children's affective well-being using both parental self-reports and device-logged data. Taken together, our findings suggest that parental smartphone use is not uniformly or inherently detrimental to children's well-being. Stable differences between parents who, on average, use their smartphones more frequently around their children were largely unrelated to children's affective well-being, indicating that higher habitual smartphone use does not necessarily coincide with poorer child outcomes. In fact, our results point to a more nuanced, situational pattern: momentary increases in parental smartphone use were associated with less favorable child outcomes in some cases. This suggests that the impact of parental smartphone use may depend less on overall use in the child's presence and more on the timing and context of use within parent-child interactions, potentially shaped by psychological processes such as parental guilt. More broadly, these findings challenge prevailing narratives that portray parental smartphone use as categorically harmful. In line with calls for a more balanced and objective perspective [4,29], our results highlight the importance of moving beyond moralized framings of technology use in families. Smartphones are embedded in daily family life and serve both disruptive and facilitative functions. Understanding their role in parent-child relationships therefore requires approaches that acknowledge this complexity rather than assuming uniformly negative effects. In sum, advancing research on parental smartphone use will require a shift toward more nuanced, context-sensitive, and theoretically grounded perspectives that distinguish between habitual use and situational dynamics, and that better reflect the realities of contemporary family life.

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During the preparation of this work, the authors used ChatGPT to refine the writing of the manuscript. After using this tool/service, the authors reviewed and edited the content as needed and take full responsibility for the content of the published paper.

Data Availability

Data will be made available on request. The project is preregistered on OSF [37].

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Authors' Contributions

Conceptualization: EKM (lead), AM (equal)
Data curation: KIS (lead), KA (equal)

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Formal analysis: EKM (lead), AM (support)
Funding acquisition: AM
Methodology: EKM (lead), AM (equal)
Project administration: AM (lead), LSP (support)
Supervision: AM
Writing–original draft: EKM
Writing–review & editing: AM (lead), KA (equal), KIS (supporting), LSP (supporting)

Conflicts of Interest

None declared.

Multimedia Appendix 1
Complete list of data used in this study.
[DOCX File , 79 KB - pediatrics_v9i1e95447_app1.docx]

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Abbreviations

EMA: ecological momentary assessment
ESM: experience sampling method
ICC: intraclass correlation coefficient
OSF: Open Science Framework

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Timely Initiation of Breastfeeding and Associated Factors in 20 Sub-Saharan African Countries: Cross-Sectional Multilevel Analysis of Recent Demographic and Health Surveys

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Abstract

Background: An important strategy to decrease infant morbidity and mortality is timely initiation of breastfeeding (TIBF), which is defined as putting the newborn to the breast within 1 hour of delivery. Delayed initiation of breastfeeding may contribute to high neonatal and infant mortality in sub-Saharan Africa.

Objective: This study assessed the prevalence of TIBF and associated factors using recent Demographic and Health Survey data from 20 sub-Saharan African countries.

Methods: Using recent Demographic and Health Survey data from sub-Saharan African countries, a cross-sectional study was conducted. Data were accessed on January 27, 2026. The analysis included 177,988 children after application of sampling weights. The hierarchical structure of the data was taken into consideration by conducting a multilevel logistic regression analysis. Results were presented using adjusted odds ratios (AORs) with 95% CIs. To evaluate cluster-level variance, random-effects measures such as the median odds ratio and intraclass correlation coefficient were reported.

Results: Among 177,988 weighted samples, 59.05% (95% CI 58.82%-59.28%) initiated breastfeeding within 1 hour of birth. TIBF was more likely among rural residents (AOR 1.25, 95% CI 1.21 - 1.28), mothers with primary (AOR 1.48, 95% CI 1.45-1.52), secondary (AOR 1.22, 95% CI 1.19-1.26), and higher education (AOR 1.22, 95% CI 1.15-1.28), institutional delivery (AOR 1.40, 95% CI 1.36-1.43), multiparous (AOR 1.19, 95% CI 1.15-1.23), and grand multiparous mothers (AOR 1.10, 95% CI 1.05-1.14). Lower odds were observed among cesarean births (AOR 0.31, 95% CI 0.30-0.33), twin births (AOR 0.87, 95% CI 0.82-0.92), delayed antenatal care initiation (AOR 0.84, 95% CI 0.82-0.85), female children (AOR 0.90, 95% CI 0.88-0.91), and mothers with a history of child death (AOR 0.90, 95% CI 0.86-0.94).

Conclusions: TIBF remains suboptimal in sub-Saharan Africa and is influenced by maternal, obstetric, and health care factors. Enhancing antenatal counseling and postnatal breastfeeding support, particularly after cesarean delivery and among vulnerable groups, may improve timely initiation practices.

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KEYWORDS

timely initiation breastfeeding; associated factor; sub-Saharan Africa; demographic health survey; DHS

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Introduction

Timely initiation of breastfeeding (TIBF) is defined as placing the newborn to the breast within the first hour of delivery. This practice is strongly recommended by the World Health Organization (WHO), as it plays a vital role in promoting optimal infant and young child feeding. This behavior is favorable for the provision of colostrum to the infant, which contains high concentrations of immunoglobulin and other bioactive constituents, including growth factors that are essential for optimal neonatal nutrition, growth, development, and the establishment of passive immunity [1,2]. During the first 6 months of life, breast milk is the primary and most appropriate source of nutrition for newborns. It should be initiated within the first hour after birth, ideally even before the placenta is delivered, in line with recommendations from the WHO [2-4]. TIBF has the following advantages for infants: it decreases upper respiratory tract infections, promotes the development of dentition, enhances cognitive development, and reduces childhood obesity [5]. TIBF helps to reduce the risk of postpartum hemorrhage by promoting uterine contraction and faster uterine involution, supports quicker physical recovery after delivery, and strengthens mother-infant bonding [3,5,6]. It stimulates breast milk production and helps transfer protective antibodies to the infant, strengthening early immunity. For mothers, it reduces the risk of postpartum hemorrhage and supports quicker uterine recovery. It also promotes emotional attachment and strengthens the mother-child bond [7].

The Baby-Friendly Hospital Initiative (BFHI), established by the WHO and United Nations Children's Fund (UNICEF) in 1991, developed a platform of 10 steps to improve maternal and neonatal care in health care institutions and promote optimal breastfeeding practices, including TIBF [8].

Worldwide, the magnitude of TIBF ranged from 17.7% to 98.4%, with an average magnitude of 57.6%. A global study demonstrated that an estimated 78 million newborns were not put to the breast within the first hour of delivery, based on a joint report by the UNICEF and the WHO [3,8]. A pooled analysis of Economic Community of West African States countries found that the magnitude of TIBF was 43%, highlighting notable differences in breastfeeding practices across the region [9].

Delayed initiation of breastfeeding (DIBF) is highly practiced, and reports have highlighted that it is linked with increased neonatal morbidity and mortality, particularly in low- and middle-income countries [10]. The 2019 mini-demography health survey of Ethiopia revealed that the prevalence of TIBF was 73.6% [11]. Evidence from sub-Saharan African countries from the 2013 Demographic and Health Survey (DHS) revealed that the prevalence of TIBF was 57% [12] and 34.7% [13], which were below the recommendations.

Maternal complications during pregnancy and cesarean delivery were associated with DIBF. Health facility deliveries that adhered to postnatal care protocols promoted TIBF among mothers [8,9,12]. Antenatal care attendance, having female infants, urban residence, multiparity, larger birth size, maternal unemployment status, and belonging to wealthier households were significantly associated with TIBF [9,11,12].

Although there are different recommendations by the WHO and UNICEF about the importance of TIBF within 1 hour, many newborns are not put to the breast within the recommended time [14]. Nowadays, different evidence demonstrates that TIBF reduces infant mortality by 22% [15]. Countries in sub-Saharan Africa had an infant mortality rate of 52 per 100 live births, which is higher than the global level, and this could be reduced by TIBF [12].

While the national policies and recommendations in Africa advocate and promote timely breastfeeding initiation, countries are not adhering to these recommendations [6,7,13,16]. There are other programs that promote TIBF in African countries, such as the national policy on infant and young child feeding, the WHO, and the Community-Integrated Management of Childhood Illness [2,17].

Reports from previous studies on the continent demonstrated that TIBF is complex and shaped by many factors, notably maternal sociodemographic characteristics like age, education, and residence, as well as use of maternal health services, including antenatal care visits and place of delivery [18].

Countries in sub-Saharan Africa continue to face high neonatal and infant mortality rates, and one contributing factor could be the DIBF after birth. There is a need to determine the updated pooled estimate level of TIBF and its key determinants at the continent level. Recent DHS data from 20 sub-Saharan countries can provide important information to estimate the magnitude and identify factors. Therefore, the aim of this study was to assess the prevalence of TIBF and to identify factors associated with this among women who delivered in the last 5 years preceding the survey in the selected countries, using data from the recent DHS.

Methods

Study Design and Setting

The study included 20 countries in sub-Saharan Africa that had recent Demographic and Health Survey data available. The countries were selected based on the availability of recent DHS datasets and included Angola, Burkina Faso, the Democratic Republic of the Congo, Côte d'Ivoire, Gabon, Ghana, The Gambia, Kenya, Liberia, Lesotho, Madagascar, Mali, Mauritania, Mozambique, Nigeria, Rwanda, Sierra Leone, Senegal, Tanzania, and Zambia.

Data Source and Extraction

We obtained the required authorization to access the dataset online after submitting a request for the data via the DHS online platform, accompanied by a detailed explanation of the study's objectives and research methodology. The data were accessed using the following login link [19].

Populations

The study population comprised children aged 6 to 59 months from 20 sub-Saharan African countries with available DHS data conducted between 2019 and 2024. We used the DHS Kids'

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Recode files for the analysis. The countries included in the study, their respective regions, DHS survey periods, and sample sizes are presented in Table 1. Countries were eligible for inclusion if they had a DHS conducted from 2019 onward and the available dataset contained the variables required for the present analysis. Countries without an eligible DHS conducted during the study period, including those whose most recent DHS was conducted before 2019, were excluded.

Table . Countries, regions, Demographic and Health Survey periods, and sample sizes included in the analysis.

Region and country	DHS[a] dataset	Survey period	Sample size, n (%)
West Africa			
Burkina Faso	BF8	2021	8277 (4.65)
Côte d'Ivoire	CI8	2021	6599 (3.71)
Ghana	GH8	2022 - 2023	6429 (3.61)
The Gambia	GM7	2019 - 2020	7494 (4.21)
Liberia	LB7	2019 - 2020	5087 (2.86)
Mali	ML8	2023 - 2024	12,667 (7.12)
Mauritania	MR7	2019 - 2021	11,188 (6.29)
Nigeria	NG8	2023 - 2024	22,542 (12.66)
Senegal	SN8	2023	6830 (3.84)
Sierra Leone	SL7	2019	9461 (5.32)
Central Africa			
Democratic Republic of the Congo	CD8	2023 - 2024	17,173 (9.65)
Gabon	GA7	2019 - 2021	5639 (3.17)
East Africa			
Kenya	KE8	2022	6594 (3.7)
Madagascar	MD7	2021	11,989 (6.74)
Rwanda	RW7	2019 - 2020	8205 (4.61)
Tanzania	TZ8	2022	8365 (4.7)
Southern Africa			
Angola	AO8	2023 - 2024	8092 (4.55)
Lesotho	LS8	2023 - 2024	1548 (0.87)
Mozambique	MZ8	2022 - 2023	7647 (4.3)
Zambia	ZM8	2024	6162 (3.46)
Total (20 countries)	—[b]	2019 - 2024	177,988 (100)

[a]DHS: Demographic and Health Surveys.

[b]Not applicable.

Sample Size Determination and Sampling Procedure

Sample Size Determination

The sample size for this study included all children who were born within the last 5 years preceding the survey and were documented in the dataset. After eliminating and adjusting for relevant variables and applying sampling weights, a total weighted sample of 177,988 was extracted and included in the analysis.

Sampling Procedure

The DHS used a stratified 2-stage sample design. Stratification was achieved by separating each of the countries' states and the Federal Capital Territory into urban and rural areas. Samples were selected independently in every stratum via a 2-stage selection. The first stage involved selecting sample points (clusters) consisting of enumeration areas. Enumeration areas were drawn with probability proportional to their size within each sampling stratum.

Variables of the Study

Dependent Variable

The primary outcome variable of the study is the magnitude of TIBF in 20 sub-Saharan African countries.

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Independent Variables

These were categorized as individual-level factors and community-level factors, as described below:

- Individual-level factors: maternal age, educational level of the mother, media exposure (mass media and print), parity, wanted the last child, sex of household head, ever had died children, wanted pregnancy, getting permission to visit a medical health facility, transport cost, respondent's occupation.
- Health sector–related factors: mode of delivery (delivered by cesarean section or vaginal birth), ever had history of terminated pregnancy (abortion)
- Community-level factors: residence, distance from health facility, and wealth index

Operational Definition

TIBF

It was defined as the proportion of children aged 0 to 59 months who were put to the breast within the first hour of delivery [20].

Parity

This is the total number of live births that a woman has given birth to. It was classified as primiparous (1 birth), multiparous (2 - 5 births), and grand multiparous (>5 births), consistent with prior DHS analyses [21].

Media Exposure

If a woman reads, listens to, or watches mass media (radio, TV, and newspaper) at least once a week, she is considered to have media exposure [22].

Data Management, Processing, and Analysis Methods

Secondary data obtained from the DHS survey were used, and the extracted dataset was analyzed. The data were obtained from an online source. They were cleaned, recoded, and analyzed using Stata (version 17; StataCorp). In line with DHS survey recommendations, sampling weights were applied to adjust for sampling probabilities and nonresponse, ensuring nationally representative and statistically reliable estimates before analysis.

Bivariable logistic regression followed by multivariable logistic regression analyses was conducted. Variables with a *P* value less than .25 in the bivariable regression were considered for inclusion in the multivariable logistic regression model. Both crude odds ratios and adjusted odds ratios (AORs) with 95% CIs were calculated. Variables with *P* values less than .05 were considered statistically significant. Three models were constructed: Model I included individual-level variables, Model II included community-level variables, and Model III (final model) included both individual- and community-level variables simultaneously. Multicollinearity among independent variables was assessed using the variance inflation factor (VIF). A VIF value greater than 10 was considered evidence of multicollinearity. To obtain statistically valid regression coefficient estimates, clustering information was used.

A multilevel analysis was employed to account for both person-level and community-level predictors, with a random effect for variations between clusters. Model I included individual-level factors, Model II included community-level factors, and Model III included both individual- and community-level factors. The significance of the random intercept variation was assessed using the likelihood ratio test. Measures of variation for the random effect between clusters were determined using the intraclass correlation coefficient (ICC), proportional change in variance, and median odds ratio (MOR).

Ethical Considerations

Ethical approval for data collection was obtained from the relevant institutional review boards overseeing the DHS Program in each participating country. Permission to use the dataset was requested from the DHS Program, and approval was obtained. The institutional review board–approved procedures for DHS public-use datasets do not in any way allow respondents, households, or sample communities to be identified. There are no names of individuals or household addresses in the data files. This study analyzed publicly available, deidentified secondary data and was therefore exempt from further ethical review. All analyses were conducted in accordance with established ethical standards of the Declaration of Helsinki.

Results

Sociodemographic and Other Factors

A total of 177,988 weighted samples were extracted and included from the DHS Kids' Record dataset. The mean age of the respondents was 28.90 (95% CI 28.86 - 28.93) years. Among the study participants, 64,260 (36.1%) were from urban residences. The majority of households were male-headed (n=140,983, 79.21%), and regarding age distribution, 70.59% (n=125,642) of women were in the age group of 20 to 34 years. Concerning media exposure, more than half (n=90,233, 50.7%) had media exposure (Table 1).

The largest contribution to the pooled sample came from Nigeria (NG8), accounting for 12.66% (22,542/177,988) of the total population, with 14,106 late initiations and 8436 timely initiations. This was followed by the Democratic Republic of the Congo (CD8), which contributed 9.65% (17,173/177,988) of the sample, including 7387 late and 9786 timely initiations. In contrast, Lesotho (LS8) contributed the smallest proportion (1548/177,988, 0.87%) with 442 late initiations and 1106 timely initiations (Table 2).

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Table . Sociodemographic and other factors for the timely initiation of breastfeeding evidenced from the Demographic and Health Surveys of 20 sub-Saharan African countries.

Variables and categories	Late	Timely	Total (%)
Place of residence			
Urban	28,208	36,052	36.1
Rural	44,671	69,056	63.9
Sex of head of the household			
Male	58,679	82,304	79.21
Female	14,201	22,804	20.79
Women’s educational level			
No education	27,783	35,364	35.48
Primary	18,467	33,524	29.21
Secondary	22,625	31,518	30.42
Higher and above	4005	4703	4.89
Media exposure			
No media exposure	35,196	52,560	49.3
Has media exposure	37,684	52,549	50.7
Respondents occupation			
Has no job	27,902	39,955	38.12
Has job	44,977	65,153	61.88
Wealth index			
Poor	32,845	49,475	46.25
Middle	14,390	21,180	19.98
Rich	25,644	34,453	33.76
Respondents’ age in years			
15 - 19	4929	6638	6.5
20 - 34	51,910	73,732	70.59
35 - 49	16,041	24,738	22.91
Place of delivery			
Home delivery	16,526	20,108	20.58
Institutional delivery	56,354	84,999	79.42
Delivered by cesarean section			
No	64,310	100,368	92.52
Yes	8569	4741	7.48
Sex of the child			
Male	42,139	63,611	59.41
Female	30,740	41,498	40.59
Had history of abortion			
No	59,134	85,394	81.2
Yes	13,745	19,714	18.8
Getting permission to go to medical help			
Not a big problem	47,782	67,201	64.6
Big problem	25,097	37,907	35.4
Distance to medical health facility			

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Variables and categories	Late	Timely	Total (%)
Not a big problem	28,306	44,562	40.94
Big problem	44,573	60,546	59.06
Parity			
Primiparous	11,972	15,481	15.42
Multiparous	37,927	56,817	53.23
Grand multiparous	22,980	32,810	31.35
The child is a twin			
No (single)	70,089	101,989	96.68
Yes (twin)	2789	3120	3.32
Had ever died children			
No	67,934	98,807	93.68
Yes	4945	6302	6.32

The Magnitude of TIBF Among Sub-Saharan African Countries

The magnitude of TIBF was 59.05% (95% CI 58.82% - 59.28%) within 1 hour of delivery.

Factors Associated With the TIBF

All included individual- and community-level variables were candidates for multivariable logistic regression as they had a *P* value less than .25. Individual-level and community-level factors were entered into separate regression models initially, followed by a final model (Model III) in which both sets of factors were included simultaneously. The analysis identified several factors associated with the TIBF. In the final model (Model III), type of place of residence, sex of head of household, sex of the child, women's educational level, media exposure, respondents' occupation, respondents' age, place of delivery, getting permission to seek medical help, distance to a health facility, initiation of first antenatal care, parity, twin status of the child, delivery by cesarean section, and history of child death were significantly associated with TIBF (*P*<.05).

Mothers living in rural areas had higher odds of TIBF compared with urban residents (AOR 1.25, 95% CI 1.21 - 1.28). Maternal education showed a positive association, where women with primary education had 48% (AOR 1.48, 95% CI 1.45 - 1.52) compared to no education, secondary education has 22% (AOR 1.22, 95% CI 1.19 - 1.26), and higher education and above had 22% (AOR 1.22, 95% CI 1.15 - 1.28) more likely to initiate breastfeeding timely compared with women with no education. Mothers who delivered by cesarean section had reduced odds of TIBF (AOR 0.31, 95% CI 0.30 - 0.33). Similarly, mothers of twin births had significantly lower odds of TIBF compared with singleton births (AOR 0.87, 95% CI 0.82 - 0.92). Multiparous and grand multiparous mothers were more likely to timely initiate breastfeeding (AOR 1.19, 95% CI 1.15 - 1.23 and AOR 1.10, 95% CI 1.05 - 1.14, respectively). Mothers who initiated their first ANC visit late had lower odds of TIBF (AOR 0.84, 95% CI 0.82 - 0.85), while mothers who delivered at a health institution had higher odds of TIBF (AOR 1.40, 95% CI 1.36 - 1.43) (Table 3).

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Table . Distribution of timing of breastfeeding initiation across selected sub-Saharan African countries.

Country	Late (n)	Timely (n)	Total (%)
Angola (AO8)	3477	4615	4.55
Burkina Faso (BF8)	2869	5408	4.65
Democratic Republic of the Congo (CD8)	7387	9786	9.65
Côte d'Ivoire (CI8)	3487	3112	3.71
Gabon (GA7)	1378	4261	3.17
Ghana (GH8)	2566	3863	3.61
The Gambia (GM7)	4694	2800	4.21
Kenya (KE8)	2593	4001	3.70
Liberia (LB7)	1694	3393	2.86
Lesotho (LS8)	442	1106	0.87
Madagascar (MD7)	4409	7580	6.74
Mali (ML8)	6627	6040	7.12
Mauritania (MR7)	4664	6524	6.29
Mozambique (MZ8)	1465	6182	4.30
Nigeria (NG8)	14,106	8436	12.66
Rwanda (RW7)	1093	7112	4.61
Sierra Leone (SL7)	2100	7361	5.32
Senegal (SN8)	3937	2893	3.84
Tanzania (TZ8)	2033	6332	4.70
Zambia (ZM8)	1857	4305	3.46
Total	72,879	105,108	100

Random Effects and Model Comparisons

In the empty (null) model, the ICC revealed that variations between cluster areas accounted for 8.3% (ICC 0.083) of the overall variation in TIBF after delivery, while individual differences accounted for the remaining 91.7% of the variability (Table 4). In the null model, the odds of TIBF differed between higher- and lower-risk clusters by a factor of 1.68 (MOR 1.68).

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Table . Factors associated with timely initiation of breastfeeding among children in sub-Saharan Africa, evidence from the Demographic and Health Surveys.

Variables and categories	Model I, AOR[a] (95% CI)	Model II, AOR (95% CI)	Model III, AOR (95% CI)
Type of place of residence			
Urban	—[b]	1	1
Rural	—	1.21 (1.18 - 1.24)	1.25 (1.21 - 1.28)[c]
Sex of head of the household			
Male	1	—	1
Female	1.13 (1.10 - 1.16)[c]	—	1.14 (1.12 - 1.17)[c]
Sex of the child			
Male	1	—	1
Female	0.90 (0.88 - 0.92)[c]	—	0.90 (0.88 - 0.91)[c]
Women's educational level			
No education	1	—	1
Primary	1.48 (1.44 - 1.52)[c]	—	1.48 (1.45 - 1.52)[c]
Secondary	1.17 (1.13 - 1.20)[c]	—	1.22 (1.19 - 1.26)[c]
Higher and above	1.12 (1.07 - 1.18)[c]	---	1.22 (1.15 - 1.28)[c]
Media exposure			
No media exposure	1	—	1
Has media exposure	0.93 (0.91 - 0.95)[c]	—	0.97 (0.95 - 0.99)[c]
Respondents' occupation			
Has no job	1	—	1
Has job	0.98 (0.96 - 1.01)	—	0.97 (0.95 - 0.99)[c]
Wealth index			
Poor	—	1	1
Middle	—	1.04 (1.02 - 1.07)	1.00 (0.97 - 1.03)
Rich	—	1.04 (1.01 - 1.07)	1.02 (0.99 - 1.05)
Respondents' age in years			
15 - 19	1	—	1
20 - 34	1.06 (1.02 - 1.11)[c]	—	1.07 (1.03 - 1.12)[c]
35 - 49	1.24 (1.18 - 1.31)[c]	—	1.26 (1.20 - 1.33)[c]
Place of delivery			
Home delivery	1	—	1
Institutional delivery	1.37 (1.33 - 1.40)[c]	—	1.40 (1.36 - 1.43)[c]
Getting permission to go to medical help			
Not a big problem	1	—	1
Big problem	0.98 (0.96 - 1.01)	—	0.96 (0.93 - 0.99)[c]
Distance to medical health facility			
Not a big problem	—	1	1
Big problem	—	1.03 (1.00 - 1.05)	1.04 (1.02 - 1.07)[c]
Initiation of first antenatal care			
Early	1	—	1

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Variables and categories	Model I, AOR[a] (95% CI)	Model II, AOR (95% CI)	Model III, AOR (95% CI)
Late	0.84 (0.82 - 0.86)[c]	—	0.84 (0.82 - 0.85)[c]
Parity			
Primiparous	1	—	1
Multiparous	1.19 (1.15 - 1.22)[c]	—	1.19 (1.15 - 1.23)[c]
Grand multiparous	1.10 (1.06 - 1.14)[c]	—	1.10 (1.05 - 1.14)[c]
The child is twin			
Single	1	—	1
Twin	0.87 (0.82 - 0.92)[c]	—	0.87 (0.82 - 0.92)[c]
Delivered by cesarean section			
No	1	—	1
Yes	0.31 (0.30 - 0.33)[c]	—	0.31 (0.30 - 0.33)[c]
Had ever died children			
No	1	—	1
Yes	0.90 (0.86 - 0.94)[c]	—	0.90 (0.86 - 0.94)[c]

[a]AOR: adjusted odds ratio.

[b]Not applicable.

[c]$P<.05$.

Model fitness was assessed using the Akaike information criterion, Bayesian information criterion, and deviance statistics. The model with the lowest deviance value was considered the best-fitting model. Accordingly, the final model (Model III) had the lowest deviance (230,786.96) compared with the null model (236,767.84), Model I (231,114.1), and Model II (236,494.74), indicating better model fitness for identifying factors significantly associated with TIBF among children born within the 5 years preceding the DHS survey. Similarly, Model III had the lowest Akaike information criterion (230,833) and a relatively lower Bayesian information criterion (231,065.8) compared with the other fitted models.

In the final model (Model III), the cluster-level variation in TIBF remained at 8.3% (ICC 0.083), suggesting the presence of unobserved community-level factors influencing breastfeeding initiation practices. The MOR slightly decreased from 1.69 in Model I to 1.68 in Model III, indicating persistent but relatively stable cluster-level heterogeneity after controlling for both individual- and community-level factors. The proportional change in variance indicated that the variables included in the final model explained only a minimal proportion of the variation (−0.01%) in TIBF compared with the null model. In addition, the mean VIF (1.74) in Model III suggested no evidence of problematic multicollinearity among explanatory variables (Table 5).

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Table . Model comparison for timely initiation of breastfeeding among children in sub-Saharan Africa: evidence from the Demographic and Health Surveys data[a].

Parameters	Null model	Model I	Model II	Model III
AIC[b]	236,771.8	231,152.1	236,506.7	230,833
BIC[c]	236,792.1	231,344.4	236,567.5	231,065.8
Cluster level variance	0.2962864	0.3054656	0.2838114	0.2963245
ICC[d]	0.0826195	0.0849617	0.0794171	0.0826293
MOR[e]	1.680719	1.6941875	1.662252	1.6807751
PCV[f]	Reference	−3.10%	4.21%	−0.01%
Deviance	236,767.84	231,114.1	236,494.74	230,786.96
Mean VIF[g]	—	1.76	1.38	1.74

[a]*P*<.05.

[b]AIC: Akaike information criterion.

[c]BIC: Bayesian information criterion.

[d]ICC: intraclass correlation coefficient.

[e]MOR: median odds ratio.

[f]PCV: proportional change in variance.

[g]VIF: variance inflation factor.

Discussion

Pirncipal Findings

The analysis in these 20 sub-Saharan African countries showed that 59.05% (95% CI 58.82% - 59.28%) of children initiated breastfeeding within the first hour of delivery, indicating suboptimal TIBF. This finding was slightly higher than the pooled estimate of 58.3% reported from 35 sub-Saharan African countries between 2008 and 2019 [23]. This similarity could reflect persistent regional barriers, including inadequate breastfeeding counseling [24], limited access to maternal health care services [25], and sociocultural practices that delay timely breastfeeding initiation [26]. This increment might also be attributed to gradual improvements in maternal and child health services and breastfeeding promotion programs across the region, including BFHI programs, increased antenatal counseling, and expanded awareness campaigns emphasizing the importance of initiating breastfeeding within 1 hour of birth. These initiatives are known to improve mothers' knowledge and attitudes toward timely breastfeeding [8,16,17].

The finding from the analysis in the included countries revealed that the magnitude of TIBF is lower than that reported in studies conducted in many sub-Saharan African countries. Higher magnitudes were reported in Ethiopia (73.6% from Mini DHS 2019), Burundi (85%), Uganda (71.6%), Malawi (76.9%), and Mozambique (75.03%) [11,13,27-29]. This variation may be attributed to the inclusion of pooled data from 20 sub-Saharan African countries with differences in health care systems, socioeconomic contexts, and breastfeeding promotion strategies, which could influence the overall estimate. Conversely, findings from individual countries may reflect more favorable maternal health services and country-specific progress in breastfeeding practices [13,30]. Higher rates of TIBF in some countries could be attributed to better implementation of maternal health care services, particularly skilled birth attendance and institutional delivery care [8]. Effective integration of breastfeeding promotion into antenatal care and immediate postpartum support, particularly early skin-to-skin contact and adherence to BFHI guidelines, contributed to significant improvements in the initiation of breastfeeding within 1 hour of delivery [10,31]. In settings where health facilities provide consistent postpartum breastfeeding support within the first hour of birth, higher rates of TIBF have been reported, highlighting the importance of strengthening immediate postnatal care practices across health facilities [32].

Community-based health promotion activities may explain the differences. Countries with strong community health worker programs that deliver breastfeeding counseling after delivery tend to achieve a higher magnitude of TIBF [33,34]. In contrast, poor counseling quality, shortages of trained health professionals in breastfeeding counseling, and absence of postnatal care can delay its initiation.

In contrast, the magnitude in the current study is higher than that in Guinea (16.6%), Congo-Brazzaville (24%), and Chad (23%) [13]. Such variations have also been documented in previous sub-Saharan African analyses, which show substantial between-country differences in TIBF, largely due to disparities in maternal health care access, socioeconomic status, and cultural practices influencing newborn feeding behaviors. Differences in study design, sample size, and sociodemographic composition may also contribute to these inconsistencies [17,30].

In this study, women from rural residences had higher odds of TIBF (AOR 1.25) compared with their counterparts. The higher odds of timely breastfeeding initiation among rural women may be attributed to urban health facilities, which may also have greater formula exposure and weaker adherence to Baby-Friendly practices. In addition, urban mothers are more

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likely to be influenced by modern feeding beliefs, face employment-related constraints, and experience inconsistent breastfeeding counseling despite better access to health services [17].

The present study findings reported that women with higher educational levels were more likely to initiate breastfeeding in a timely manner. This is supported by evidence from Ethiopia Demographic and Health Survey analyses, which show that mothers with secondary or higher education have significantly increased odds of timely breastfeeding initiation compared with uneducated women [25].

Women with media exposure demonstrated significantly decreased odds of TIBF in the current study. This finding is inconsistent with the study conducted in pooled sub-Saharan African countries using DHS data, which identified media exposure as a strong enabler of early initiation of breastfeeding [9,13]. This inconsistency may be due to differences in the type of media content accessed in the study setting, where exposure may include formula marketing or mixed infant feeding messages that discourage immediate breastfeeding. In contrast, in settings covered by DHS analyses, mass media often delivers coordinated public health campaigns promoting TIBF. Variations in media regulation and the effectiveness of breastfeeding promotion messages may therefore explain the differing associations [35].

Age of the mother was also a significant factor in TIBF. Women aged 20 to 34 years and 35 to 49 years had higher odds (AOR 1.07 and 1.26, respectively) compared with those aged 15 to 19 years, indicating an age-related disparity in TIBF. The possible reason for this is that young women could have relatively poor knowledge of the importance of timely breastfeeding and may not have received antenatal care or institutional delivery, which have a direct or indirect effect on TIBF [36]. This finding is similar to that of a study conducted in Nigeria [37]. Additionally, older women, particularly multiparous mothers, may rely on previous childbirth experience and perceived knowledge, which may positively influence TIBF. However, this pattern contrasts with studies reporting that younger mothers demonstrate higher timely breastfeeding behavior, possibly due to targeted maternal health programs, perceived vulnerability, and stronger exposure to health promotion messages [38].

Women who reported difficulty obtaining permission to seek medical care had lower odds of TIBF. This may be because restricted autonomy limits access to antenatal care, institutional delivery, and postnatal breastfeeding counseling, all of which positively influence timely breastfeeding initiation.

Women who delivered in health facilities were more likely to initiate breastfeeding timely than those who delivered at home. This finding is consistent with a study conducted in Ethiopia [39], which reported that institutionally delivered women had about 2 times higher odds of TIBF. This may be because health facility delivery provides access to skilled birth attendants, immediate breastfeeding counseling, and postpartum support, including early skin-to-skin contact, which facilitates breastfeeding within the first hour after birth [40].

The findings of this study indicated that multiparous and grand multiparous women were more likely to initiate breastfeeding within 1 hour of delivery compared with nulliparous mothers. This may be because first-time mothers often have limited experience and knowledge regarding breastfeeding, may feel uncertain about proper positioning of the baby, lack confidence to initiate breastfeeding immediately after birth, and require more guidance on breastfeeding techniques. They also experience stress and anxiety during labor and can delay skin-to-skin contact and breastfeeding initiation within the recommended hour. Nulliparous women may rely heavily on family advice, which is not always supportive of immediate breastfeeding. Elders may prioritize other newborn practices before breastfeeding, and misconceptions about colostrum may delay initiation of breastfeeding. This evidence is similar to that from studies conducted in Nepal, Bangladesh [41], Ghana, and Ethiopia [13]. This similar report could be because of the similarity in cultural perceptions and sociodemographic factors.

In this study, twin children had DIBF compared with singletons. This is because twin pregnancies are more likely to have preterm birth, low birth weight, and high fetal complications, more likely to have an elective cesarean section. These mentioned unfavorable outcomes lead for the DIBF [42,43].

Employed women had lower odds of TIBF compared with unemployed women. This may be related to work-related stress, fatigue, and competing responsibilities, which may reduce preparedness for immediate breastfeeding. Employed mothers may also be more exposed to formula-feeding alternatives and concerns about balancing breastfeeding with future work demands.

Women with a history of child death had lower odds of TIBF. This may reflect previous adverse birth experiences, maternal psychological distress, or underlying health and socioeconomic vulnerabilities that negatively influence maternal care practices, including timely breastfeeding initiation.

Limitations

Some subnational areas had relatively small sample sizes, requiring cautious interpretation of findings. As a secondary analysis of DHS data, important factors such as cultural beliefs, psychosocial influences, partner preferences, and qualitative maternal perspectives were unavailable. In addition, breastfeeding initiation was self-reported for births occurring within the 5 years preceding the survey, which may introduce recall bias. Finally, the cross-sectional nature of the data limits causal inference between explanatory variables and TIBF.

Conclusion and Recommendations

The TIBF according to the DHS survey in sub-Saharan African countries remains suboptimal. Although this reflects a modest improvement compared with previous surveys, it demonstrates inconsistent national progress toward global breastfeeding targets recommended by the WHO and United Nations Children's Fund. Individual-level and community-level factors were regressed together in the final model, and place of residence, women's educational level, media exposure, wealth index, age of the respondent, mode of delivery, wanted child,

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getting permission to go to a health facility, parity, and type of pregnancy were significantly associated with TIBF.

The substantial cluster-level variation suggests the influence of contextual and health system factors. Strengthening implementation of the BFHI, improving access to skilled delivery and postnatal counseling, particularly in rural areas, and promoting maternal education and social protection mechanisms are critical to enhancing timely breastfeeding practices in the country.

Rural-urban disparities highlight the need for expanded access to skilled birth attendance, quality antenatal counseling, and timely postnatal support in rural settings.

Educational and socioeconomic disparities observed in this study suggest that policies promoting female education, male partner involvement, media-based health promotion, and financial risk protection (including health insurance coverage) may enhance timely initiation practices. Strengthening family planning services may further contribute by reducing unintended pregnancies, which were associated with DIBF.

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Data Availability

The data used in this study are from the Demographic and Health Surveys (DHS) Program. DHS data are publicly available upon reasonable request and approval from the DHS Program. The datasets analyzed during the current study are available from the DHS Program data repository [44] after registration and submission of a data access request. Due to data use restrictions, the datasets cannot be shared publicly by the authors. Information generated or analyzed during this research is included in the main manuscript for publication, and if further information is needed, it could be available upon request from the corresponding author.

Authors' Contributions

TDK conceptualized the study, conducted data extraction and statistical analysis, and drafted the Methods and Results sections. GG, MDB, AAA, and AAE contributed to data extraction, data analysis, and manuscript editing. TS, MG, and MS contributed to writing the Background section of the manuscript. MGM and DME drafted the Discussion section. TWW and AAM critically reviewed and edited the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

AOR: adjusted odds ratio
BFHI: Baby-Friendly Hospital Initiative
DHS: Demographic and Health Survey
DIBF: delayed initiation of breastfeeding
ICC: intraclass correlation coefficient
MOR: median odds ratio
TIBF: timely initiation of breastfeeding
UNICEF: United Nations Children's Fund
VIF: variance inflation factor
WHO: World Health Organization

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AI and Chatbot-Supported Interventions for Physical Activity and Obesity-Related Lifestyle Behaviors: Scoping Review With Attention to Family Involvement

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Abstract

Background: AI-enabled chatbots and related conversational systems can facilitate human–computer interaction through natural language, personalization, and automated support. In pediatric health promotion, these tools have the potential to provide scalable and flexible approaches to support physical activity (PA) and related lifestyle behavior change within family contexts. However, evidence regarding AI and chatbot-supported interventions for PA and obesity-related lifestyle behaviors among children and adolescents remains limited, and the extent to which these interventions involve parents, caregivers, or families has not been clearly characterized.

Objective: This scoping review aimed to provide an up-to-date overview of how AI and chatbot-supported interventions are designed, delivered, and evaluated for PA and obesity-related lifestyle behaviors among children and adolescents, with attention to technology characteristics, family involvement, delivery platforms, outcomes, and research gaps.

Methods: In accordance with PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) guideline, 7 databases (PubMed, Web of Science, APA PsycINFO, Academic Search Complete, CINAHL Ultimate, IEEE Xplore, and Scopus) were searched through February 2026. Two reviewers independently conducted title and abstract screening, followed by full-text screening in Rayyan (Qatar Computing Research Institute). Eligible studies involved children, adolescents, or families; evaluated an AI-enabled chatbot, conversational agent, or related digital system; and addressed PA, exercise, sedentary behavior, screen time, obesity, overweight, or weight management. Diet, sleep, and other lifestyle outcomes were extracted when reported within otherwise eligible studies. Data were extracted and synthesized narratively in accordance with research objectives.

Results: Of 2730 records identified, 14 studies met inclusion criteria. Most were published in 2023 or later (n=12, 85.7%) and spanned 10 countries. Mobile app delivery was most common (n=9, 64.3%). AI approaches included rule-based chatbots, hybrid personalization systems, generative AI, and single studies using recommender systems or computer vision. A total of 10 studies (71.4%) included a specific parent, caregiver, or family component. Common intervention features were personalized feedback (n=10, 71.4%), self-monitoring (n=9, 64.3%), and education (n=9, 64.3%). PA was the most common target behavior, often within broader obesity or healthy lifestyle interventions. Among 8 studies reporting direct PA or fitness outcomes, 4 showed significant improvement, 2 found no significant change, and 2 reported mixed or indirect findings. Feasibility, acceptability, usability, and engagement findings were generally favorable across studies, but cultural tailoring was reported in only one study.

Conclusions: AI and chatbot-supported interventions for pediatric PA and obesity-related lifestyle behaviors represent a rapidly emerging but still early-stage field. Family involvement varies considerably across interventions and should be more clearly conceptualized and evaluated in future studies.

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KEYWORDS

artificial intelligence; chatbot; family-based intervention; physical activity; pediatric obesity; lifestyle behaviors

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Introduction

Childhood physical inactivity (PA) and obesity are persistent, high-impact challenges across the life course and often cluster within families through shared environments, routines, and resources [1]. World Health Organization (WHO) guidelines recommend that children and adolescents accumulate an average of at least 60 minutes per day of moderate-to-vigorous PA, while also reducing sedentary time [2]. Yet recent global surveillance indicates that PA levels remain low across childhood and adolescence. Global Matrix 4.0 data from 57 countries suggest that only about 27%-33% of children and adolescents aged 5-17 years meet recommended activity levels [3], and the WHO reports that 81% of adolescents aged 11-17 years are insufficiently active worldwide [4].

Pediatric overweight and obesity also represent a growing global public health challenge. In 2022, more than 390 million children and adolescents aged 5-19 years worldwide were living with overweight, including more than 160 million living with obesity. The prevalence of overweight, including obesity, among children and adolescents aged 5 - 19 years increased from 8% in 1990 to 20% in 2022, while the prevalence of obesity alone increased from 2% to 8% [5]. Important regional differences are also evident. Latin America and the Caribbean, the Middle East and North Africa, and North America have among the highest prevalence of overweight, while the largest numbers of affected children and adolescents are concentrated in East Asia and the Pacific, Latin America and the Caribbean, and South Asia [6]. These patterns reflect broader behavioral, environmental, and structural determinants of health and reinforce the need for accessible and scalable approaches to support healthy behaviors among children, adolescents, and families [1].

Families play a central role in shaping children's health behaviors [7]. Caregivers influence opportunities for PA through role modeling, encouragement, co-participation, transportation, and the organization of routines [8]. Therefore, family-based approaches are widely recognized as an important strategy for supporting healthy lifestyle behaviors and pediatric obesity prevention and treatment [7]. At the same time, participation in intensive family-based programs can be difficult to sustain because of barriers such as cost, scheduling demands, transportation, workforce limitations, and unequal access to care [7]. These challenges are particularly relevant for underserved families and have increased interest in more flexible and scalable approaches to family-centered behavior change support.

Digital health and mHealth have rapidly expanded as a delivery channel for behavior change interventions, supported by widespread mobile device access and increasing interest from health systems in scalable, low-cost approaches [9,10]. Within this broader digital health landscape, conversational tools such as chatbots and virtual agents represent one emerging delivery format that may support health promotion through interactive communication, tailored prompts, and ongoing engagement [9,10]. However, for pediatric PA and relevant lifestyle behaviors, the literature remains scattered across diverse populations, platforms, intervention designs, and outcomes.

AI has further expanded the potential of digital health interventions for children and families by enabling more tailored, interactive, and responsive (ie, real-time) support [11,12]. In contrast to static digital content, AI-enabled systems such as chatbots and conversational agents may help deliver intervention components based on user input, preferences, or real-time data [13]. In pediatric lifestyle interventions, these features may be especially relevant because children's PA and related behaviors are shaped by changing routines, developmental needs, and family context [12]. However, the evidence base remains fragmented across platforms, target behaviors, and outcome measurement strategies [14].

Despite growing interest in AI-enabled digital health tools, few studies have synthesized the current evidence on AI and chatbot-supported interventions for pediatric PA and obesity-related lifestyle behaviors while examining the extent and nature of family involvement [10,12,13]. Previous reviews have examined conversational agents in health care broadly, chatbot-supported lifestyle interventions across age groups, or the feasibility and acceptability of chatbots for nutrition and PA promotion among adolescents [10,12,13]. However, these reviews often aggregate adult and pediatric populations, emphasize individual-level interventions, or examine digital health more broadly without distinguishing AI-driven systems from traditional mobile apps [10,12]. Moreover, family engagement within digital interventions is inconsistently conceptualized and operationalized, ranging from passive caregiver monitoring to active, dyadic, or multigenerational participation [12]. Questions also remain regarding cultural responsiveness, equity considerations, accessibility for underserved families, and safeguards related to data privacy, algorithmic bias, transparency, and accountability [12]. To address these gaps, the present review focuses specifically on AI and chatbot-supported interventions for pediatric PA and related lifestyle behaviors, with particular attention to family engagement, technology characteristics, cultural tailoring, and implementation gaps.

Given the rapid evolution of AI technologies and the heterogeneity of study designs, including pilot feasibility trials, randomized controlled trials, and early-stage implementation studies, a scoping review is warranted. Thus, the objective of this scoping review was to map and characterize AI and chatbot-supported interventions targeting pediatric PA and obesity-related lifestyle behaviors. Priority areas of focus are (1) technology type and AI features, (2) delivery platforms and intervention components, (3) definition and operationalization of family engagement, (4) cultural tailoring and bilingual delivery strategies, and (5) the characteristics of the existing evidence base, including study designs, outcomes, and gaps to inform future research and equitable implementation.

Methods

Study Design

A formal review protocol was not prospectively registered. Before screening began, the research team developed the review objectives, eligibility criteria, search strategy, screening procedures, and standardized data-extraction form. The complete

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database search strategies are provided in Multimedia Appendix 1, and the completed PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) checklist is provided in Checklist 1 [15]. The review aimed to map and synthesize the existing literature on AI and chatbot-supported interventions targeting pediatric PA and obesity-related lifestyle behaviors, with particular attention to the extent and nature of family involvement.

Search Strategy

Information Sources

A comprehensive literature search was conducted across 7 electronic databases, including PubMed, Web of Science, APA PsycINFO, Academic Search Complete, CINAHL Ultimate, IEEE Xplore, and Scopus. The final search was performed on February 8, 2026. Searches were limited to English-language peer-reviewed publications published within the past 10 years. This timeframe was selected to capture contemporary AI-enabled and chatbot-supported technologies relevant to current practice, given the rapid evolution of conversational-agent platforms, natural language processing, adaptive personalization, wearable integration, and generative AI. Earlier digital interventions may be less comparable with the systems currently used in pediatric health promotion. The search was limited to peer-reviewed publications indexed in the selected databases. A formal gray-literature search and supplementary backward or forward citation tracking were not conducted.

Search Terms

Search strategies were developed to capture three primary domains: (1) AI-enabled conversational technologies, (2) PA and obesity-related outcomes, and (3) child and family populations. Terms for AI technologies included chatbot*, chat bot*, conversational agent*, virtual agent*, relational agent*, virtual assistant*, AI coach*, ChatGPT (OpenAI), large language model*, LLM*, and generative AI. Health-related terms included physical activity*, exercise*, obese*, obesity, overweight, weight management, obesity prevention, sedentary, and screen. Population terms included child*, adolescent*, youth, teen*, pediatric*, family*, parent*, caregiver*, family-based, and parent-based. Database-specific syntax adjustments were applied as needed, including title and abstract field restrictions and wildcard limits. The detailed search history was provided in supplementary material (Multimedia Appendix 1).

Review articles, systematic reviews, scoping reviews, and meta-analyses were excluded during the search process where possible using database filters.

Eligibility Criteria

Eligibility criteria were guided by the population, intervention, comparator, outcomes, and study design (PICOS) framework. Studies were included if they: (P) involved children or adolescents aged 0 - 18 years or parents, caregivers, or families supporting the health behaviors of a child or adolescent within this age range; (I) evaluated an AI-enabled chatbot, conversational agent, or related digital system designed to support PA or obesity-related lifestyle behaviors; (C) included any comparator, such as usual care or an alternative intervention, or no comparator; (O) reported outcomes related to PA or exercise, sedentary behavior or screen time, obesity, overweight, or weight management; and (S) reported empirical quantitative, qualitative, or mixed methods findings.

Studies were eligible if they involved children or adolescents or parents, caregivers, or families supporting the health behaviors of children or adolescents. Direct parent or caregiver involvement was not required because family involvement was examined as an analytic dimension rather than an eligibility criterion.

Studies were excluded if they described general digital health tools without an automated conversational, chatbot, AI-enabled, adaptive, or personalized support component, were purely technical development papers without behavioral outcomes, or were nonempirical publications such as editorials, commentaries, protocols, or review articles. Only studies published in English were included.

Study Selection

All retrieved records were imported into Rayyan (Qatar Computing Research Institute), a web-based systematic review management platform [16]. Rayyan was used to manage records, identify potential duplicates, and support blinded title and abstract screening. Potential duplicates identified through bibliographic metadata were manually reviewed and confirmed before removal. Final eligibility decisions were made by the reviewers rather than by the software. Title and abstract screening were conducted independently by 2 reviewers (DP and SA), who were blinded to each other's decisions during the initial screening phase. At this stage, records were excluded if they were clearly unrelated to pediatric, adolescent, or family populations; did not involve AI-enabled chatbots, conversational agents, or related automated digital systems; did not address PA, obesity, sedentary behavior, weight management, or related lifestyle behaviors; or were clearly nonempirical publications. Records were retained for full-text review when eligibility could not be determined from the title and abstract alone. Full-text screening was then conducted independently by 2 reviewers (DP and SA) using the complete eligibility criteria. At this stage, specific reasons for exclusion were recorded. Articles were excluded during full-text review if they did not report PA or related lifestyle outcomes, did not include children, adolescents, parents, caregivers, or families, did not include an AI-enabled or chatbot-supported intervention component, or provided insufficient information to determine eligibility. Disagreements were resolved through discussion, and unresolved disagreements were adjudicated by a third reviewer (QJ). Interrater reliability was assessed using Cohen kappa (κ=0.81).

Data Extraction and Synthesis

Data were extracted using a standardized form developed for this review. Extracted variables included publication and study characteristics (author, year, country, design, and sample size); participant characteristics (target population, age, sex, and family involvement); intervention characteristics (intervention type, delivery platform, duration, comparator, wearable or sensor

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use, and behavior change components); AI-related features (AI or automation role, intervention system or platform, reported AI technique or automation logic, input data type, and AI tasks or outputs); theoretical foundations; and reported outcomes, including feasibility, acceptability, usability, engagement, PA, and related lifestyle outcomes, secondary outcomes, and key findings. Extracted data were synthesized narratively to characterize the scope of the evidence and identify patterns across study design, intervention delivery, AI functionality, family engagement, and outcomes.

Critical Appraisal

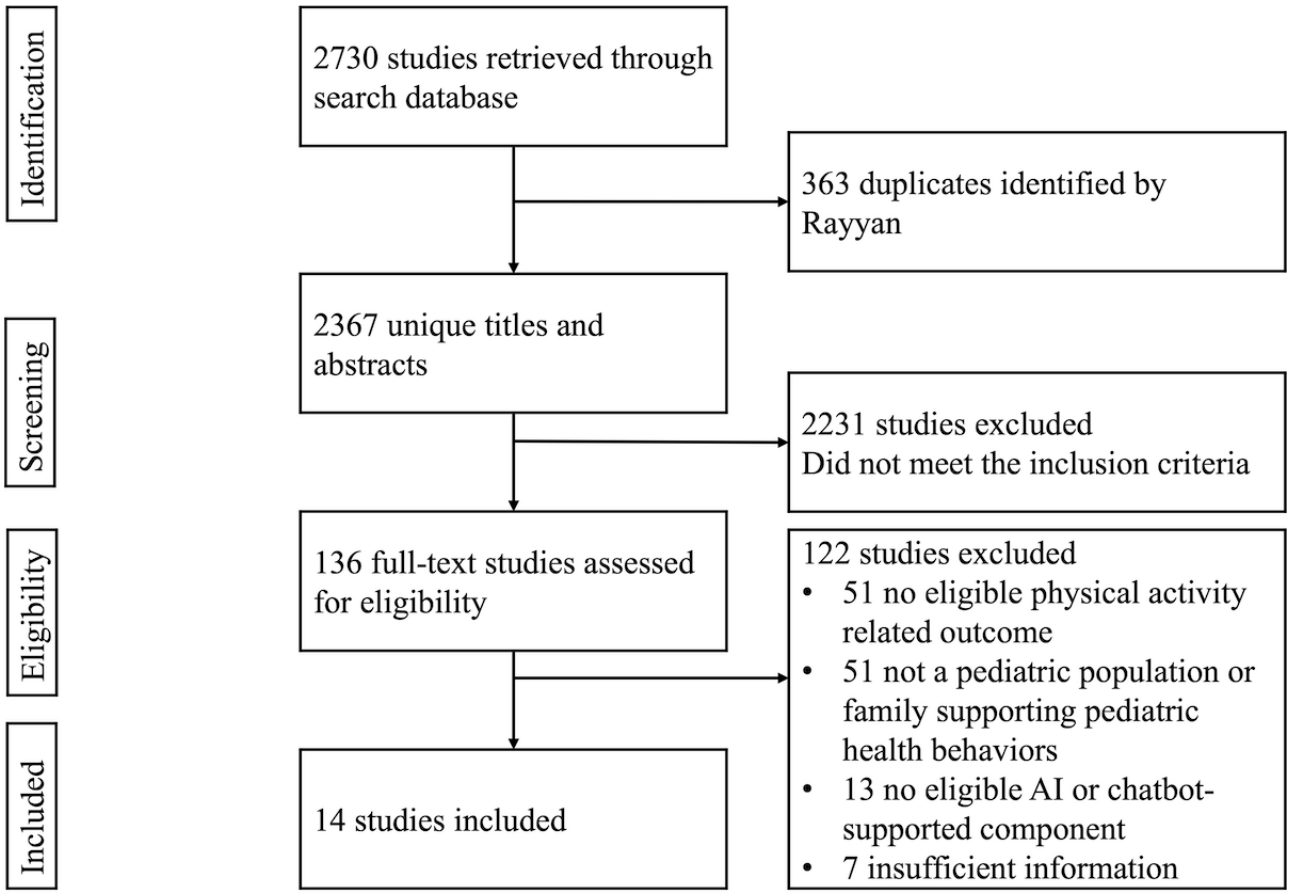
A formal critical appraisal or methodological quality assessment was not conducted. The purpose of this scoping review was to map the characteristics, applications, and gaps within an emerging and heterogeneous evidence base rather than to assess the certainty of evidence or estimate pooled intervention effects.

Results

Overview

Figure 1 presents the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram. The initial database search identified 2730 records. After removing 363 duplicate records, 2367 unique articles remained for title and abstract screening. Of these, 2231 were excluded because they were clearly outside the review scope. A total of 136 full-text articles were assessed for eligibility. During full-text review, 122 articles were excluded for the following primary reasons: no PA or related lifestyle outcome, not child-, adolescent-, parent-, caregiver-, or family-focused, no AI-enabled or chatbot-supported component, or insufficient information to determine eligibility. Ultimately, 14 studies met the inclusion criteria and were included in the final sample (Figure 1).

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart for study selection process.



Study Overview

A total of 14 original studies were included in this scoping review [17-30] (Table 1). The studies were published between 2021 and 2026, with 12 of the 14 published in 2023 or later. The 14 studies were conducted across 10 countries. The United States and South Korea were the most frequently represented settings (n=3 each), followed by one study each from Turkey, Spain, Italy, the United Kingdom, Belgium, Switzerland, Greece, and Canada. Although the included studies were geographically diverse, all were conducted in middle- or high-income contexts.

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Table . Characteristics of included studies.

Study and year	Country	Study design	Sample size
Aydemir (2025) [17]	Turkey	Pre-post feasibility study with intervention and control groups	26 parent-child dyads (13 intervention and 13 control)
de Arriba Muñoz et al (2026) [18]	Spain	Prospective single-arm observational pre-post study	40 families or pediatric patients
Emerson et al (2026) [30]	United States	Three-phase qualitative adaptation study	22 total (phase 1: n=6; phase 2: n=4; phase 3: n=12)
Heerman et al (2024) [19]	United States	Multicenter randomized clinical trial	900 parent-infant pairs
Larizza et al (2023) [22]	Italy	App development+pilot usability or acceptability study	13 children
Moore et al (2024) [23]	United Kingdom	Co-design study with mixed methods evaluation	9 co-design participants; 46 evaluation participants
Oh et al (2022) [24]	South Korea	Randomized controlled trial	24 adolescents
Peuters et al (2024) [25]	Belgium	Quasi-randomized controlled trial+process evaluation interviews	279 adolescents; interviews n=13
Stasinaki et al (2021) [26]	Switzerland	Randomized controlled trial	41 recruited; analysis n=31 at baseline after exclusions or dropout
Tan et al (2026) [27]	United States	Single-arm pilot feasibility study	172
Zarkogianni et al (2023) [29]	Greece	Feasibility pilot trial	50 children
Kim et al (2025) [20]	South Korea	User-centered design or development and usability study	Needs survey n=96; interviews n=30; UI usability n=76
Kang et al (2026) [21]	South Korea	Descriptive comparative cross-sectional survey study	160 total (80 childhood or adolescent cancer survivors >80 parents)
Willms and Liu (2024) [28]	Canada	Autoethnographic feasibility case study or development paper	No human participants; content development case study

Among included studies, 3 studies were randomized controlled trials [19,24,26], one was quasi-randomized [25], one was a pre-post feasibility study with a comparison group [17], and 3 were single-arm or uncontrolled pilot or pre-post studies [18,22,27]. The remaining 6 were noneffectiveness-focused designs, including one qualitative adaptation study [30], one co-design mixed methods study [23], 2 development or usability studies [20,28], one cross-sectional survey [21], and one autoethnographic feasibility or development paper [29]. Sample sizes ranged from 9 to 900 participants, with most studies enrolling relatively small samples; only one large, randomized trial included more than 500 participants [19].

Participant and Family Characteristics

The 14 studies targeted a broad range of pediatric populations, including infants, school-aged children, and adolescents (Table 2). Most studies focused on school-aged children or adolescents, whereas one large trial focused on infants from birth to 24 months [19]. Several studies targeted specific clinical or high-need populations, including youth with autism spectrum disorder (n=2) [17,30], children or adolescents with obesity or overweight (n=5) [18,22,24,26,29], childhood or adolescent cancer survivors (n=1) [21], and adolescents facing barriers to PA or living in under-resourced settings (n=2) [23,27].

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Table . Participant and family characteristics of included studies.

Study and Year	Target population or unit of Intervention	Population characteristics or special group	Child age	Parent age	Sex (female), n (%)	Language	Cultural tailoring
Aydemir (2025) [17]	Parent-child dyads	Children with autism spectrum disorder (ASD)	• Intervention: mean 14.38 (SD 3.06) • Control: mean 13.92 (SD 3.52)	• Intervention: mean 42.84 (SD 7.70) • Control: mean 44.07 (SD 7.95)	• Children: intervention 6/13 (46%), control 8/13 (62%) • Parents: intervention 5/13 (38%), control 4/13 (31%)	Likely Turkish / ChatGPT (OpenAI)-supported text prompts	NR[a]
de Arriba Muñoz et al (2026) [18]	Family (caregiver+ child or adolescent)	Children or adolescents with obesity receiving GLP-1[b] therapy	• Mean 14.05 (SD 1.04) years	NR	• 25/40 (62.5%)	Spanish	NR
Emerson et al (2026) [30]	Youth with ASD and caregivers; providers or therapists	Youth with autism spectrum disorder at risk of obesity	• Youth with ASD; exact ages not reported in abstract	NR	• NR	English	NR
Heerman et al (2024) [19]	Parent-child dyads	Infants from racially and ethnically diverse US families	• Birth-24 months follow-up	Adults ≥18 years	• Children: intervention: 243/449 (54.1%) • Control: 233/451 (51.7%) female	English and Spanish	Yes; all content translated into Spanish and assessed for cultural appropriateness
Larizza et al (2023) [22]	Child and parent	Children with obesity	• Age: 6 - 12 years • Mean 9.3 (SD 1.3) years	NR	• 5/13 (38.5%)	Italian context	NR
Moore et al (2024) [23]	Adolescents	Adolescents facing barriers to physical activity	• 11 - 13 years (co-design) • Adolescents in evaluation	NR	• Co-design group 5/9 (56%)	English	Personalization emphasized; no cultural tailoring reported
Oh et al (2022) [24]	Adolescents	Adolescents with obesity	• 10 - 17 years • Mean 13.2 (SD 3.6)	NR	• 4/24 (16.7%)	Korean context	NR

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Study and Year	Target population or unit of Intervention	Population characteristics or special group	Child age	Parent age	Sex (female), n (%)	Language	Cultural tailoring
Peuters et al (2024) [25]	Adolescents	General population adolescents aged 12 - 15 during COVID-19 restrictions	• 12 - 15 years	NR	• NR	Dutch	Human-centered development; no explicit cultural tailoring
Stasinaki et al (2021) [26]	Youth or adolescents	Youth with overweight or obesity receiving specialist obesity care	• 10 - 18 years • Median baseline age 13.6 years (range 10.9 - 16.9)	NR	• 13/31 (41.9%)	German/Swiss context	NR
Tan et al (2026) [27]	Children or adolescents	Primarily sixth-grade students in socioeconomically disadvantaged schools	• Mostly 12 years • Range 11 - 15 years	NR	• 96/172 (55.8%)	English	NR
Zarkogianni et al (2023) [29]	Child and parent	Overweight or obese children	• Mean 10.5 (SD 2.00) years	NR	• 26/50 (52%)	Greek context	NR
Kim et al (2025) [20]	Adolescents + parents + school health teachers	Middle school adolescents in school-based health management context	• First-year middle school students or adolescents	Range 30 - 59 years	• Students 23/36 (65%) • Parents 25/40 (83%) • Teachers 30/30 (100%)	Korean	Designed for Korean school context
Kang et al (2026) [21]	Childhood or adolescent cancer survivors and parents	Childhood or adolescent cancer survivors (aged 10 - 16 years) recruited via the Korean Pediatric Cancer Foundation; survivor-parent perspectives	• Mean 12.1 (SD 2.0) years • Eligibility 10 - 16 years	Mean 44.7 (SD 4.2) years	• CACSs[c] 41/80 (51.2%); • Parent respondents 76/80 (95.0%)	Korean	South Korean childhood cancer survivorship context; no explicit cultural tailoring intervention because no chatbot program was deployed
Willms and Liu (2024) [28]	Parents supporting child physical activity (intended target)	Family-based PA[d] content development for children aged 8 - 12 and parents	• Intended target: children 8 - 12 years	NR	• NR	English	NR

[a]NR: not reported.

[b]GLP-1: glucagon-like peptide-1.

[c]CACS: childhood or adolescent cancer survivor.

[d]PA: physical activity.

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Ten [17-21,25,26,28-30] of the 14 studies included a parent, caregiver, or family component in the target population or intervention design, such as parent-child dyads, family-based obesity management, or studies collecting both child and caregiver perspectives. The remaining 4 [22-24,27] were primarily youth-focused, although family influence was acknowledged as an important contextual factor. The degree of family involvement varied considerably, ranging from minimal parental support or consent to parent-mediated delivery, co-participation in activities, shared monitoring, and parent-facing intervention interfaces.

Reporting of demographic and contextual characteristics was inconsistent. Child age was available in all 14 studies. While parents' age was reported in only 4 studies [17,19-21]. Female participation or sex distribution was reported in 11 studies [17-24,26,27,29]. Among studies reporting child sex distribution, the proportion of female participants ranged from 16.7% to 65.0% [20,24]. Language or linguistic context could be identified in all 14 studies. However, cultural tailoring was reported in only one study [19], and 4 additional studies [20,21,23,30] described some form of contextual, linguistic, developmental, or population-specific tailoring.

Intervention Design and Delivery Characteristics

Intervention design and delivery characteristics were presented in Table 3. Mobile app– or smartphone-based delivery was the most common format, appearing in 9 studies [17-19,22,24-27,29]. Six studies [19,20,23,28-30] incorporated a clearly web-based component, such as a dashboard, web platform, online interface, or browser-based system. Other delivery modes included chatbot-supported platforms, WhatsApp (Meta)-supported programming, SMS text messaging or responsive text messaging, serious games, metaverse-supported systems, and hybrid platforms integrating child-, parent-, and clinician-facing tools.

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Table . Intervention design and delivery characteristics.

Study and year	Intervention type	Platform or delivery mode	Intervention duration	Wearable or sensor used	Family involvement	Comparator or Control	Intervention components or behavior change features
Aydemir (2025) [17]	ChatGPT (OpenAI)-delivered, parent-mediated home PA[a] intervention	ChatGPT+parent training+WhatsApp (Meta) support	4 weeks; 40 min/session; 3 days/week	None	High; parents implemented activities and could involve siblings or family	Non-ChatGPT control group	Parent training; home PA plans; warm-up, main, or cool-down; co-participation; WhatsApp support; rewards
de Arriba Muñoz et al (2026) [18]	Family digital support program adjunct to semaglutide	Adhera Caring Digital Program mobile app (Adhera Health, Inc.)	10-month active intervention; interim results at 150 days	Fitbit Inspire 3 (Google LLC)	High; caregiver-focused education, behavior support, and monitoring	None	Education; motivational messaging; progress feedback; wearable monitoring; psychometrics
Emerson et al (2026) [30]	Adaptation of WeChat (Tencent Holdings Limited) chatbot for ASD[c] accessibility	Text or email chatbot concept; interviews or focus groups	Not an intervention trial; exploratory qualitative study	Not central; some participants discussed Fitbit or Apple Watch use	High; family-centered care identified as essential	None	SMART[b] goals; SDOH[d] screening; health resources; adaptation recommendations; branching logic
Heerman et al (2024) [19]	Digital obesity prevention added to primary care counseling	Responsive text messages+web dashboard+clinic counseling	24 months	None	High; parents were the direct intervention users	Clinic-only counseling group	Goal setting; self-monitoring; tailored feedback; dashboard; growth charts; health literacy materials
Larizza et al (2023) [22]	mHealth[e] lifestyle improvement app	Smartphone app+physician or admin dashboard+chatbot	2-week home pilot after training	None	High; parents register child, enter data, monitor trends, support use	None	Goals; education; success stories; monthly questionnaires; diaries; badges; quizzes; avatar; chatbot
Moore et al (2024) [23]	Conversational agent to overcome PA barriers	Web or text-based conversational agent	Prototype evaluation; not long-term intervention	None	Low or minimal	None	Barrier identification; confidence and motivation modules; social dialogue; links or resources; personalization
Oh et al (2022) [24]	AI-based interactive home exercise exergame	Smartphone-based gesture-recognition game versus Nintendo Switch Ring Fit (Nintendo Co., Ltd.)	3 weeks; 30 min/session, 5 days/week	Camera or computer vision gesture recognition	Low or minimal	Nintendo Switch exercise game	Gamified exercise; real-time visual or auditory feedback; alarms; posture feedback

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Study and year	Intervention type	Platform or delivery mode	Intervention duration	Wearable or sensor used	Family involvement	Comparator or Control	Intervention components or behavior change features
Peuters et al (2024) [25]	Multicomponent healthy lifestyle or mental health app	LifeGoals (The University of Michigan) mobile app+Fitbit+videos+chatbot	12 weeks	Fitbit Charge 2/3 (intervention); Axivity accelerometers for measurement	Low or minimal direct family role	No-intervention control group	Goal setting; action or coping planning; self-monitoring; rewards; gamification; narrative videos; chatbot; information
Stasinaki et al (2021) [26]	Conversational agent obesity management app+ reduced on-site counseling	PathMate2 mobile app+clinic visits	5.5-month intensive phase +6-month maintenance (12 mo total)	None mentioned for intervention	Moderate; family part of counseling context but youth-focused app	Standard multicomponent behavior change intervention	Daily chatbot counseling; step or activity challenges; meal photos; breathing exercises; goal setting; educational handouts
Tan et al (2026) [27]	AI-assisted school-based health behavior chatbot or web app	Web-based app on school laptops	8 weeks	None	Low; parental consent but no active family component	None	SMART goals; self-monitoring; behavior logging; reflections; AI feedback; progress charts; daily reports; education
Zarkogianni et al (2023) [29]	Family-based mHealth + AI+serious game obesity management platform	Serious game+child app+parent app+clinician app+activity tracker	3 months (12 wk)	Fitbit Ace 2	High; parent app, personalized messages to mothers, family-based intervention	Active control and intervention versions of platform in pilot sequence	Self-monitoring; serious games; personalized messages; meal plans; PA and sleep tracking; clinician/nutritionist support
Kim et al (2025) [20]	Smart health care service design using metaverse, chatbot, wearable, and web or app ecosystem	Student app+parent app+teacher web+metaverse+chatbot+wearable	Development study; no intervention exposure period	Planned wearable device or smartwatch integration	High; parent app and parent participation central in service design	None	Tracking; personalized services; gamification; rewards; consultation; school and parent interfaces
Kang et al (2026) [21]	Cross-sectional assessment of healthy lifestyle practices and acceptability of AI chatbot use for future lifestyle management; no active intervention delivered	Online web-based survey (Google Forms); chatbot was discussed conceptually, not deployed	Cross-sectional survey	None	High for assessment purposes; survivor and parent perspectives were both collected to inform future family-tailored chatbot support	Survivors versus parents (comparative groups); no intervention control	Healthy lifestyle assessment across 7 domains; chatbot awareness or acceptability assessment; open-ended unmet-need responses analyzed with topic modeling

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Study and year	Intervention type	Platform or delivery mode	Intervention duration	Wearable or sensor used	Family involvement	Comparator or Control	Intervention components or behavior change features
Willms and Liu (2024) [28]	JITAI[f] content development using ChatGPT	ChatGPT-3+ Pathverse no-code mobile app builder	10-week planned JITAI; development process over 2 months	Intended JITAI used child MVPA[g] minutes as decision input; no specific wearable evaluated in case study	High; parent supports child PA	None	Tailored lessons; decision-tree personalization; family PA challenges

[a]PA: physical activity.

[b]SMART: Specific, Measurable, Achievable, Relevant, and Time-bound.

[c]ASD: autism spectrum disorder..

[d]SDOH: Social determinants of health

[e]mHealth: mobile health.

[f]JITAI: Just-in-Time Adaptive Intervention.

[g]MVPA: moderate to vigorous physical activity.

Nine studies [17-19,22,24-27,29] reported a defined intervention or exposure period, with durations ranging from 2 weeks to 24 months. Four studies [17,24,25,27] had relatively short intervention periods of 2-4 weeks, 3 [22,26,29] lasted approximately 8-12 weeks, and 2 [18,19] extended beyond 5 months, including one 24-month randomized trial and one 12-month obesity management program. The remaining 5 studies [20,21,23,28,30] were qualitative, developmental, survey-based, or case-based and therefore did not involve a conventional intervention period.

Most interventions were multicomponent and incorporated established behavior change strategies. Self-monitoring or tracking components were present in 9 studies [18-22,25-27,29], personalized feedback or adaptive content in 10 studies [17-20,23,25-27,29,30], and education or informational support in 9 studies [18,19,21-23,25-27,30]. Goal setting or challenge-based components were identified in 7 studies [19,22,25-28,30], gamification or reward-related elements in 7 studies [17,20,22,24-26,29], and social support, co-participation, or human-supported features in 8 studies [17-20,23,25,29,30]. Reminders or prompts were described as a distinct feature in 4 studies [17,24,26,27]. Although all studies were relevant to PA, only 5 [17,23,24,27,28] focused primarily on PA or exercise promotion; the remaining 9 [18-22,25,26,29,30] embedded PA within broader obesity-management, lifestyle, rehabilitation, or healthy living interventions.

Wearable devices, sensor-based inputs, or objective digital monitoring were reported in 6 studies [18,24,25,27-29]. These included Fitbit (Google LLC) devices, accelerometers, computer vision–based gesture recognition, smartphone- or app-linked monitoring, and planned smartwatch integration. However, most studies still relied partly or primarily on self-reported behavior, questionnaires, or user-entered information.

AI Features and Functional Characteristics

The included studies varied substantially in the sophistication and reporting of their AI and automation features (Table 4). To improve clarity, we distinguished the named intervention system or platform from the reported AI technique or automation logic. Three studies [17,27,28] used generative AI or large language model–based approaches directly in intervention delivery or content development. Several studies used scripted, predefined, or automated chatbots and tailoring functions based on structured pathways, branching logic, or automated rules [19,22,25,26,30]. Moore et al [23] described natural language understanding for intent recognition and dialogue routing. The study by de Arriba Muñoz et al [18] used a hybrid personalization engine, Zarkogianni et al [29] used a machine learning–based recommendation system, Oh et al [24] used computer vision and deep learning for gesture recognition, and Kim et al [20] described a broader integrated chatbot-supported digital health ecosystem.

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Table . AI features and functional characteristics of the included interventions.

Study	Year	AI or automation role	Intervention system or platform	Reported AI technique or automation logic	Input data type	AI task	AI contribution/claimed benefit	AI explainability/transparency reported
Aydemir [17]	2025	Generates individualized home physical activity plans and answers parent follow-up questions	ChatGPT-4 (OpenAI)	Generative AI using a large language model	Parent text prompts; child age; and ASD[b] status	Text generation; PA[a] recommendation; instructional clarification	Low-cost, home-based, scalable PA guidance for ASD families	Limited; prompts described but model logic not detailed
de Arriba Muñoz et al [18]	2026	Personalizes caregiver support content	Adhera AI Precision Digital Companion (Adhera Health, Inc)	Hybrid personalization engine; specific algorithm not fully reported	App engagement data; psychometrics; wearable metrics; clinical data	Personalization; feedback; progress support	Complement pharmacotherapy with scalable caregiver support and monitoring	Limited
Emerson et al [30]	2026	Delivers health prompts, screening questions, and resources	WE CHAT (Wellness Education to Create Healthy Habits and Actions to Thrive)	Predefined chatbot pathways or branching logic; underlying algorithm not fully reported	User responses to prompts; provider recommendations for adaptation	Goal support; screening; resource/referral prompts	Potential to support obesity prevention for youth with ASD if adapted for variability and caregiver burden	Moderate; logic and use described conceptually
Heerman et al [19]	2024	Provides automated tailoring and adaptive feedback	Greenlight Plus digital platform (Vanderbilt University Medical Center)	Automated tailoring using predefined logic; no machine learning model or large language model reported	Parent surveys; goal progress self-ratings; child anthropometrics	Tailored messaging; adaptive feedback; dashboard tracking	Frequent asynchronous support and scalable tailored obesity prevention	Moderate; tailored logic described
Larizza et al [22]	2023	Collects responses and provides practical advice through a virtual coach	V-care app (University of Pavia) with Google Dialogflow chatbot	Task-oriented conversational agent using Dialogflow natural language processing and predefined workflows	Profile, questionnaires, quizzes, daily/weekly behavior diary, BMI updates	Questionnaire administration; coaching; advice; engagement	Increase compliance and reduce dropout in pediatric obesity management	Good technical description of architecture; limited algorithmic detail beyond workflow
Moore et al [23]	2024	Identifies physical activity barriers and delivers tailored relational support	Phyllis conversational agent (Sheffield Hallam University); Google Dialogflow and MindBehind (MindBehind Inc) engine	Natural language understanding for intent recognition and dialogue routing	Open-text user barrier input; conversation responses	Intent recognition; routing; tailored dialogue; persuasive coaching	On-demand personalized support to overcome PA barriers	Moderate; NLU[c] training and F_1-score reported
Oh et al [24]	2022	Recognizes body movements and provides exergame feedback	Super Kids Adventure (Funrehab)	Computer vision and deep learning using a convolutional neural network (CNN)	Video/image-based body movement data	Gesture recognition; exercise scoring; real-time feedback	Low-cost motivational home exercise alternative	Basic model type reported (CNN), limited technical detail

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Study	Year	AI or automation role	Intervention system or platform	Reported AI technique or automation logic	Input data type	AI task	AI contribution/claimed benefit	AI explainability/transparency reported
Peuters et al [25]	2024	Delivers automated chatbot support and behavior-change content	#LIFEGOALS mobile app chatbot	Scripted or predefined chatbot support; underlying algorithm not fully reported	Self-report survey data; Fitbit (Google LLC)/self-monitoring data; accelerometer data	Support messages; information delivery; self-regulation support	Engage adolescents in healthy lifestyle behavior change and mental health promotion	Limited
Stasinaki et al [26]	2021	Delivers daily conversational coaching and challenges	PathMate2 (Pathmate Technologies AG) mobile app	Scripted or predefined conversational coaching and challenge-delivery logic; underlying algorithm not fully reported	Chat interactions; challenge completion; self-reported meal photos and exercises	Conversational coaching; reminders; challenge monitoring	Low-threshold obesity support with fewer clinic visits	Moderate; app functions described
Tan et al [27]	2026	Provides personalized feedback for self-management	ProudMe Tech (ProudMe Technologies); GPT-4 (OpenAI) API	GPT-assisted chatbot using generative AI	Self-reported goals, behavior logs, reflections, interaction logs	Feedback generation; supportive prompting; text analysis for evaluation	Scalable, low-cost personalized behavioral counseling for students	Partial; app functions described but limited model detail
Zarkogianni et al [29]	2023	Generates personalized messages and recommendations based on user profiles	ENDORSE (ENDORSE Consortium) platform	Machine learning–based recommendation and personalization system, including genetic algorithm components	Tracker data; serious game interactions; clinical/nutrition data; user profile	Personalization; recommendation; risk/behavior profiling	Coordinated family-clinician ecosystem for personalized obesity management	Moderate; AI-based model described at high level
Kim et al [20]	2025	Provides chatbot-supported health guidance and personalized service delivery	MUZZIM smart health service concept	Integrated chatbot-supported digital health ecosystem; specific technical approach not fully reported	Health information, wearable/lifelog data, user needs, app inputs	Guidance; personalization; integrated monitoring	Support sustainable adolescent health habits through school-family digital ecosystem	Conceptual only
Kang et al [21]	2026	Examines the acceptability of a proposed chatbot for future lifestyle management support	No chatbot was deployed or named	Proposed generative AI chatbot concept; no live AI system evaluated	Survey responses on healthy lifestyle practices, chatbot awareness, and open-ended unmet healthy lifestyle needs	Conceptual health education, lifestyle guidance, interaction, and support for future survivorship care	Potential to provide tailored, interactive, real-time support for holistic survivorship healthy lifestyle management	Not applicable because no live AI system was tested

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Study	Year	AI or automation role	Intervention system or platform	Reported AI technique or automation logic	Input data type	AI task	AI contribution/claimed benefit	AI explainability/transparency reported
Willms and Liu [28]	2024	Generates intervention content for a just-in-time adaptive intervention	ChatGPT-3 and Pathverse (Pathverse Ltd) no-code mobile app builder	Generative AI using a large language model for content development; predefined decision rules for intervention tailoring	Researcher prompts with theory, target behavior, and intervention structure	Content generation	Rapid, scalable creation of tailored mHealth[d]/JITAI[e] content	Prompting process described; acknowledged hallucination/privacy limits

[a]PA: physical activity.

[b]ASD: autism spectrum disorder.

[c]NLU: natural language understanding.

[d]mHealth: mobile health.

[e]JITAI: Just-in-Time Adaptive Intervention.

Across studies, the most common role of AI was to support personalization and automated interaction rather than diagnosis or prediction. Tailored feedback, adaptive support, or personalized recommendations were described in 10 studies [17-20,22,23,25-27,29]. Chatbot-based or conversational coaching features were present in 8 studies [17,21-23,25-27,29], activity generation or exercise recommendation in 4 studies [17,24,28,29], and monitoring or self-management support in 6 studies [18,19,22,25,26,29].

Input data were most commonly participant- or caregiver-entered, including text prompts, questionnaires, goal selections, behavior logs, profile information, or interaction history. Six studies [18,24,25,27-29] incorporated wearable, sensor, image, or other objectively tracked data as part of the AI-supported system. Technical reporting of AI methods was often limited. Seven studies [20,21,23,27-30] provided only limited, conceptual, or partial descriptions of AI logic or architecture, whereas 6 [17-19,22,24,25] provided at least moderate detail about system workflow, personalization logic, or model type. One study [21] did not evaluate a live AI system but instead assessed attitudes toward a proposed future chatbot.

Theory, Implementation, and Outcome Findings

Theoretical frameworks were identified in most studies (Table 5), including Social Cognitive Theory [19]; the capability, opportunity, motivation, and behavior (COM-B) model; the Theoretical Domains Framework [23]; the Health Action Process Approach; the Elaboration Likelihood Model; Persuasive Systems Design [25]; Self-Determination Theory [27,29]; the Health Promotion Model; the Technology Acceptance Model [21], and the Multi-Process Action Control (M-PAC) model [28]. Other studies referenced broader approaches such as cognitive-behavioral principles, family-centered care, or user-centered design, whereas Aydemir [17] and Oh et al [24] did not report an explicit theoretical framework.

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Table . Theoretical foundations, implementation outcomes, and behavioral/health outcomes.

Study and year	Theoretical framework	Feasibility/acceptability/usability/engagement	Primary PA[a] outcomes	Secondary outcomes	Key findings/effect Size
Aydemir (2025) [17]	NR[b]	High parent satisfaction; 92% participated in WhatsApp (Meta) discussions	Leisure Time Exercise Questionnaire (LTEQ)	Parent feasibility feedback	LTEQ increased from 6.69 to 34.00 in intervention versus 7.46-7.23 in control; interaction F=353.07; P<.001; ηp^2=.936
de Arriba Muñoz et al (2026) [18]	Cognitive-behavioral principles	SUS[c] score 72; exploratory trends between higher engagement and better fat loss	Wearable-recorded PA/biometric metrics collected, but main reported outcomes were clinical obesity measures	BMI, weight, body fat %, muscle mass %, waist circumference, usability, and engagement	At Day 150: BMI –4.51 kg/m²; weight –11.42 kg; body fat –5.63%; waist –8.69 cm; muscle mass 4.47% (all P<.001)
Emerson et al (2026) [30]	Family-centered care- or user-centered adaptation	Qualitative evidence of interest and need; branching logic and family support emphasized	NR	Feasibility, acceptability, accessibility needs, and adaptation recommendations	No efficacy outcomes; key themes were ASD[d] variability, perceived value of mHealth[e], family-centered care, and interdisciplinary support
Heerman et al (2024) [19]	Social Cognitive Theory; health literacy-informed design	High retention: 86.3% primary outcome at 24 months	No direct PA primary outcome; PA support behaviors embedded in program	Weight-for-length trajectory; BMI z score; overweight/obesity prevalence	Weight-for-length at 24 mo was lower by –0.33 kg/m (95% CI –0.57 to –0.09); BMI z score −0.19; obesity 7.4% versus 12.7% (aRR[f] 0.56)
Larizza et al (2023) [22]	Psychological/behavioral change theories; goal-based behavioral intervention	Overall friendliness 85%; perceived utility 100%; chatbot acceptable to 69%; all average scores >3/5	No quantitative PA outcome reported in pilot	Usability, acceptability, friendliness, and utility	High usability and perceived utility; chatbot section scored lower than other features but remained >3/5
Moore et al (2024) [23]	COM-B[g]; Theoretical domains framework; behavior change techniques; theory of planned behavior for confidence module	61 conversations; positive UX[h]; 73% definite intention to use; F_1-score about 80%	Perceived confidence and motivation to engage in PA	Acceptability, usability, recommendation likelihood, and barrier coverage	Significant increase in self-reported confidence and motivation after interacting with Phyllis (Sheffield Hallam University); 73% would use future version
Oh et al (2022) [24]	NR	Postquestionnaire on motivation, fun, perceived exercise effectiveness	Calorie expenditure; VO_2max[i]; 6MWT[j]; RPE[k]; BMI	Motivation, fun, and perceived exercise effectiveness	SUKIA (Funrehab) showed superior calorie consumption, VO_2max, and RPE versus Nintendo Switch (Nintendo Co, Ltd); authors report better cardiopulmonary function and energy expenditure

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Study and year	Theoretical framework	Feasibility/acceptability/usability/engagement	Primary PA[a] outcomes	Secondary outcomes	Key findings/effect Size
Peuters et al (2024) [25]	Health action process approach; elaboration likelihood model; persuasive systems design	High nonusage attrition: 18% never used app; 30% stopped by week 2; interviews highlighted rewards and self-regulation as helpful	PA (ENMO[l]/MV-PA[m]) and sedentary behavior from accelerometers	HRQoL[n], mood, peer support, sleep quality, sleep routine, and breakfast	Beneficial effects for PA (χ^2=4.36; *P*=.04), sedentary behavior (χ^2=6.44; *P*=.01), sleep quality (χ^2=6.11; *P*=.01), and mood (*P*=.02); effects moderated by COVID restrictions
Stasinaki et al (2021) [26]	Behavior change techniques; obesity counseling framework (no single explicit theory emphasized)	Average daily app usage 71.5%; no side effects observed	Physical capacities (strength, agility, and endurance) via modified Dordel-Koch test	BMI-SDS[o], fat mass, muscle mass, waist-to-height ratio, BP[p], pulse, and stress markers	BMI-SDS decreased significantly in controls at 5.5 months, not in PathMate2 (PathMate Technologies GmbH); both groups improved muscle mass, strength, and agility by 12 months; PathMate2 reduced fat mass at T1/T2
Tan et al (2026) [27]	Self-Determination Theory; Self-Regulation Theory	Mean 8.9 behavior entries, 30 reflections, 33.5 AI feedback messages; 63.8% of daily goals achieved	Self-reported PA hours	Screen time, fruit/vegetable intake, sleep, engagement, and sentiment	PA did not significantly change (2.5-2.4 h/day; *P*=.20); screen time decreased by 0.93 h/day (*P*<.001); fruit/veg intake decreased by 0.50 servings (*P*=.02); sleep unchanged
Zarkogianni et al (2023) [29]	Self-Determination Theory	Adherence tracked by usage frequency; activity tracker use correlated with BMI improvement	Activity tracker usage / PA patterns (minutes of activity; steps/day)	BMI *z* score, diet quality, screen time, sleep duration, and usability/adherence	Mean BMI *z* score reduction –0.21 (SD 0.26); *P*<.001; tracker usage correlated with BMI *z* score improvement (*r*=−0.355; *P*=.02)
Kim et al (2025) [20]	MASUN[q] framework/user-centered design methodology	Students/parents prioritized PA and sleep tracking; reward systems rated promising; teachers rated effectiveness/usefulness/usability highly	NR	User needs, usability ratings, and preferred features	No efficacy outcomes; stakeholders favored PA measurement, rewards, and integrated monitoring across student-parent-teacher interfaces

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Study and year	Theoretical framework	Feasibility/acceptability/usability/engagement	Primary PA[a] outcomes	Secondary outcomes	Key findings/effect Size
Kang et al (2026) [21]	Health Promotion Model and Technology Acceptance Model	Positive perceptions of chatbot use in both groups; mean A-uC[r] scores were above 4/5 overall, with parents showing higher intention to use	No intervention PA outcome; PA was one healthy lifestyle subdomain and a commonly reported unmet need	Overall healthy lifestyle score and subdomains; awareness of chatbot use (perceived usefulness/ease, value, empathy, reliability, professionalism, intention to use); topic-modeled unmet needs	No significant group differences in overall healthy lifestyle score (CACSs[s] mean 3.16, SD 0.80 vs parents mean 3.18, SD 0.36; *P*=.74) or PA subscale (mean 2.55, SD 0.89 vs mean 2.53, SD 0.81, *P*=.91). Parents had higher intention to use chatbots (mean 4.21, SD 0.68 vs mean 3.94; SD 0.90; *P*=.03). Common unmet areas were exercise, healthy diet, and regular lifestyle.
Willms and Liu (2024) [28]	Multi-Process Action Control (M-PAC)	Researchers found ChatGPT acceptable and easy to use for producing 13 lessons	NR	Feasibility, acceptability, and ease of use of AI-generated content process	ChatGPT (OpenAI) was judged acceptable and easy to use for creating 13 PA JITAI[t] lessons, but expert review remained essential due to the risk of inaccurate references/content

[a]PA: physical activity.
[b]NR: Not Reported
[c]SUS: system usability scale.
[d]ASD: autism spectrum disorder.
[e]mHealth: mobile health.
[f]aRR: adjusted risk ratio.
[g]COM-B: capability, opportunity, motivation, and behavior.
[h]UX: user experience.
[i]VO_2 max: maximal oxygen uptake.
[j]6MWT: 6-minute walk test.
[k]RPE: rating of perceived exertion.
[l]ENMO: Euclidean norm minus one.
[m]MVPA: moderate to vigorous physical activity.
[n]HRQoL: Health-related quality of life.
[o]BMI-SDS: body mass index standard deviation score.
[p]BP: blood pressure.
[q]MASUN: Method of App Selection based on User Needs.
[r]A-uC: Awareness of the Use of Chatbots.
[s]CACS: childhood or adolescent cancer survivor.
[t]JITAI: Just-in-Time Adaptive Intervention.

Outcome assessment approaches varied across studies (Table 5). Six studies [18,19,24,25,27,29] included an objective or performance-based PA-related measure, such as accelerometer-assessed activity, Fitbit-derived metrics, step counts, calorie expenditure, physical fitness testing, or device-recorded movement patterns. Four studies [17,21,23,26] relied primarily on self-report or parent-report PA-related measures, including exercise questionnaires, activity hours, or perceived confidence and motivation for PA. The remaining 4

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studies [20,22,28,30] did not directly assess intervention-related PA outcomes.

The studies frequently examined outcomes beyond PA alone. Anthropometric or weight-related outcomes, including BMI, BMI *z* score, body fat, waist circumference, or obesity-related indicators, were reported in 6 studies [18,19,22,24,26,29]. Diet- or nutrition-related outcomes were reported in 4 studies [18,19,21,29], screen time or sedentary behavior in 3 studies [19,25,27], and sleep-related outcomes in 3 studies [19,21,25]. Psychosocial, motivational, quality-of-life, and usability-related outcomes were also commonly reported, suggesting that many AI-supported family-based interventions were conceptualized as broader healthy lifestyle or obesity-management programs rather than narrowly focused PA interventions.

Among the 8 studies that reported direct PA-, exercise-, movement-, or fitness-related outcomes, 4 [17,23-25] reported significant improvements in PA participation, exercise performance, movement-related behavior, or fitness-related indicators. Two studies [26,27] reported little or no statistically significant improvement in PA despite favorable findings for engagement or other health outcomes. One study [18] collected wearable-based PA data but reported stronger clinical obesity-related effects than PA-specific effects, and one additional study [19] described PA-related findings as part of a broader multibehavior framework without demonstrating a clearly significant PA effect.

All 14 original studies reported at least one feasibility-, acceptability-, usability-, or engagement-related outcome (Table 5). Five studies [20,21,23,28,30] were primarily qualitative, developmental, survey-based, or case-based in design and therefore emphasized user preferences, accessibility needs, perceived usefulness, desired features, implementation barriers, or design priorities rather than behavioral efficacy. These studies generally reported favorable perceptions of AI-supported tools, particularly when interventions were viewed as personalized, interactive, and supportive of family routines or youth autonomy.

Among the intervention-oriented studies, quantitative implementation indicators were commonly reported. Examples included high parent satisfaction and 92% participation in WhatsApp discussions in one parent-mediated ChatGPT study [17]; a System Usability Scale score of 72 in one obesity-management intervention [18]; 86.3% retention at 24 months in the large primary care trial; 85% friendliness, 100% perceived utility, and 69% acceptability in one pediatric obesity app pilot [22]; 61 total chatbot conversations and 73% definite intention to use in one conversational-agent co-design study [23]; average daily app usage of 71.5% in one obesity management trial [26]; and a mean of 8.9 (SD 7.6) behavior entries, 30 reflections, and 33.5 AI feedback interactions in one school-based chatbot study [27]. One quasi-randomized trial reported substantial nonuse attrition, with 18% of participants never using the app and 30% stopping use by week 2 [25].

Discussion

Principal Findings

This scoping review explored the emerging evidence on AI and chatbot-supported interventions targeting PA and obesity-related lifestyle behaviors among children and adolescents, with attention to family involvement. Across the 14 studies included, the evidence indicates that AI-supported interventions are being used in increasingly diverse ways to support PA, obesity management, and related health behaviors in pediatric populations, but the literature remains varied in terms of intervention design, AI capabilities, family involvement, and outcome measurement.

Complex AI Features Across Studies

Across the included studies, AI features span a continuum of complexity, from rule-based scripted chatbots and automated tailoring systems (eg, structured coaching or tailored text messaging) to hybrid systems that incorporated limited natural language understanding or personalization. AI was most commonly used to support personalization, user interaction, and ongoing behavioral support, rather than for diagnostic, predictive, or decision-making purposes. Many studies provided only high-level or conceptual descriptions of system functionality, with limited detail on model architecture, training data, validation procedures, or performance across subgroups. This lack of transparency makes it difficult to assess reproducibility, evaluate potential bias, or determine whether AI-driven personalization meaningfully contributes to outcomes beyond standard digital tailoring approaches. These gaps are particularly important given the increasing integration of more complex AI systems, which introduce additional concerns related to accuracy, safety, and algorithmic bias. Future research should adopt AI-specific reporting standards and explicitly document how AI outputs are validated, monitored, and updated over time across diverse populations.

Delivery Platforms and Intervention Components

Regarding the delivery platform and intervention components, most interventions embed common behavior change functions, including self-monitoring, goal setting, education, feedback, and rewards, within various platforms. These platforms range from low-burden text messaging and web dashboards to multiapp family–clinician ecosystems, wearable-linked systems, higher-complexity immersive environments, and sensor-rich exercise apps. Engagement strategies also include gamification, relational dialogue, narrative content, and school- or family-embedded routines. Within this structure, AI primarily serves as a delivery and personalization mechanism that shaped how these components were implemented. AI enabled more dynamic forms of support, such as routine coaches, on-demand assistants, and interactive educational or motivational agents [23,25,28]. In this sense, AI modifies the timing, intensity, and responsiveness of intervention delivery rather than fundamentally changing its core behavioral content.

Extent and Operationalization of Family Engagement

A central contribution to this review is the characterization of family involvement, which was important but inconsistently

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operationalized. In some studies, parents were critical to implementation, such as delivering activities at home, receiving caregiver education, or interacting with the digital system directly [17-19,29]. In others, youth were the primary users and family influence was acknowledged but not fully integrated into the intervention structure [23,24,27]. This variability suggests that the field has not yet converged on a clear definition of what constitutes a "family-based" AI intervention. Importantly, most studies do not measure family engagement systematically enough to test whether caregiver involvement mediates or moderates intervention effects. More precise conceptualization of whether caregivers are intended as co-users, facilitators, role models, or targets of behavior change may improve both intervention design and interpretation of outcomes.

Limited Cultural Tailoring and Bilingual Intervention

With respect to cultural tailoring and bilingual delivery, evidence remains limited. One large randomized clinical trial embedded bilingual delivery (English/Spanish) and cultural appropriateness processes in a racially and ethnically diverse population [19]. Although all studies could be situated within identifiable linguistic or contextual settings, specific cultural adaptation was rare, and the evidence base was entirely in middle- and high-income countries. This limits the transferability of current findings to lower-resource contexts and to culturally diverse family populations whose routines, values, digital access, and barriers to health behavior change may differ substantially. The lack of consistent reporting on cultural tailoring, bilingual adaptation, and structural access issues also limits understanding of how well current interventions align with the realities of underserved families. These limitations introduce broader concerns in digital health that technologies may inadvertently reinforce inequities if they are developed primarily in well-resourced settings without sufficient adaptation for different social and cultural contexts [31].

Exploratory Feasibility and Efficacy Findings

Consistent with the aims of this review, PA emerged as the most prominent target behavior, either as a primary intervention focus or as part of broader multibehavior lifestyle and obesity-management programs. Several studies focused directly on PA promotion, home exercise, or movement-related confidence and performance [17,23,24,27], whereas others addressed PA within broader interventions targeting obesity prevention, rehabilitation, or healthy lifestyle routines [18,19,25,26,29]. This pattern likely reflects both the importance of PA in pediatric health promotion and the broader reality that children's movement behaviors are closely associated with diet, sleep, sedentary behavior, and family routines. Rather than treating PA as an isolated outcome, many of the included studies positioned it within a more comprehensive family lifestyle framework.

The reviewed studies also indicate that AI-supported interventions were generally more consistent in demonstrating feasibility, acceptability, and engagement than in behavioral efficacy. These findings align with previous youth-focused syntheses emphasizing that chatbots and AI-supported tools are often perceived as appealing and acceptable when they are interactive, personalized, and low burden [12]. However, the current review also found that favorable usability does not necessarily translate into sustained engagement or robust changes in PA participation, exercise performance, calorie expenditure, cardiopulmonary function, or confidence and motivation for PA [17,23-25], and some broader obesity-management or prevention interventions also showed favorable changes in clinical or anthropometric outcomes [18,19,29]. At the same time, findings were not uniform across studies. Tan et al [27] did not detect significant changes in PA, and Stasinaki et al [26] did not show clear superiority of the conversational-agent intervention over the comparison condition for BMI-SD score (BMI-SDS). Moreover, many included studies were feasibility, pilot, or developmental studies rather than adequately powered effectiveness trials. These findings suggest that while AI-supported interventions show promise, the current evidence remains stronger for feasibility and acceptability than for clinically meaningful and sustained improvements in PA and related outcomes.

Implications for Practice and Research

This review highlights several implications for intervention design, implementation, and future research. In practice, AI-supported family interventions may be most useful when integrated into broader family-based, school-based, or clinical programs rather than positioned as isolated tools. Their strengths appear to lie in delivering tailored education, self-monitoring support, reminders, coaching, and feedback in ways that are flexible, scalable, and responsive to daily family routines. However, the findings also indicate that intervention success likely depends on more than the presence of AI alone. Additional attention to developmental appropriateness, caregiver roles, response quality, burden of use, and contextual relevance will be essential to sustaining engagement and producing meaningful behavior change.

Future research and program development should prioritize family-centered co-design, more rigorous comparative and longitudinal study designs, and greater consistency and transparency in reporting AI features, personalization logic, and behavior change techniques. More culturally and linguistically responsive adaptation is also needed, particularly for diverse and underserved family populations. Additional work should examine implementation outcomes such as reach, adoption, maintenance, scalability, and cost, alongside behavioral and clinical outcomes. Emerging approaches such as generative AI, wearable-integrated personalization, and adaptive feedback systems may offer added value, but their safety, accuracy, transparency, and practical benefit require more careful evaluation in pediatric settings. Continued interdisciplinary collaboration will play an important role in ensuring that AI-supported family interventions are not only innovative but also ethical, accessible, and equitable.

Limitations

Several limitations should be acknowledged. First, the number of included studies was small, and the evidence base was highly heterogeneous. Further, the included studies varied widely in population, intervention modality, duration, AI sophistication, and measured outcomes, which limits comparability. In addition, many studies were pilots, feasibility studies, or usability-focused

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investigations rather than adequately powered trials. Further, reporting of demographic, contextual, and technical AI details was often incomplete, making it difficult to assess generalizability or identify active intervention ingredients. The search was limited to English-language publications; therefore, relevant studies published in other languages may not have been captured, which may have introduced selection bias. Further, the search was limited to peer-reviewed publications indexed in the selected databases and did not include a formal gray-literature search or supplementary citation tracking. Therefore, relevant evidence reported in theses, reports, conference materials, policy documents, unpublished sources, or publications not indexed in the selected databases may not have been captured. A formal critical appraisal or methodological quality assessment was not conducted; therefore, the methodological rigor of the included studies was not evaluated.

Conclusion

In conclusion, this scoping review found that AI and chatbot-supported interventions for pediatric PA and obesity-related lifestyle behaviors are a rapidly emerging but still early-stage field. The existing literature suggests that these interventions are generally feasible, acceptable, and promising as scalable tools for supporting healthy behavior change among children and families. However, evidence for effectiveness, particularly for PA outcomes, remains mixed and limited by methodological heterogeneity, short follow-up, and inconsistent outcomes. The review also highlights important gaps in family-based design, cultural tailoring, equity, and evaluation of advanced AI capabilities. Future research should prioritize rigorous trials, clearer conceptualization of family engagement, objective outcome measurement, and culturally responsive development to ensure that AI-supported interventions are not only innovative but also effective, equitable, and meaningful for diverse families.

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Declaration of Generative AI and AI-Assisted Technologies in the Manuscript Preparation Process.

During the preparation of this manuscript, the authors used ChatGPT (OpenAI) for proofreading, language editing, and reformatting of author-written text. Generative AI was not used to generate original manuscript content or to conduct the literature search, study screening, data extraction, analysis, or interpretation. The authors reviewed and approved all revisions and take full responsibility for the content of the manuscript.

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Data Availability

The data extracted for this scoping review are available from the corresponding author upon reasonable request.

Authors' Contributions

Conceptualization: QJ, XSC
Data curation: DP, SA
Formal analysis: QJ
Funding acquisition: QJ
Investigation: DP, SA
Methodology: QJ, XSC
Project administration: QJ
Supervision: QJ, KB
Writing – original draft: QJ, XSC
Writing – review & editing: QJ, XSC, DP, SA, KB
All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search terms by databases.
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Checklist 1

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PRISMA-ScR checklist.
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Abbreviations

BMI-SDS: BMI-SD score
COM-B: capability, opportunity, motivation, and behavior
M-PAC: Multi-Process Action Control
PA: physical activity
PICOS: population, intervention, comparator, outcomes, and study design
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews
WHO: World Health Organization

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Original Paper

Febrile Seizures in an App-Based Children's Fever Registry: Mixed Methods Study

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Abstract

Background: Febrile seizures, although typically benign, can cause significant emotional distress for parents. Their diverse etiological risk factors underscore the need for further research. Ecological momentary assessment (EMA) offers a cost-effective and timely method for real-time data collection. The FeverApp, an EMA-based registry for fever management, enables parents to document febrile seizures as they occur.

Objective: This study systematically investigates febrile seizure records from the FeverApp registry to assess their characteristics and explore the clinical implications of the findings. By providing real-world data on seizure management, this research demonstrates the potential of app-based EMA in pediatric care. Additionally, it offers insights for targeted interventions and improved febrile seizure management.

Methods: We used a mixed methods approach. A descriptive qualitative analysis of parental descriptions of 226 seizures belonging to 161 children was conducted. Additionally, a comparative quantitative analysis of group differences was assessed through matched-pair sampling, comparing 114 children. Statistical methods were tailored to the nature of the respective variables, which included prevalence, age, gender, health and febrile history, fever management, temperature, well-being, and parental confidence.

Results: Qualitative analyses provided detailed descriptions of seizure symptoms, seizure duration, and seizure management practices. Additionally, the data revealed a high rate of emergency consultations related to febrile seizures. However, there was underreporting of febrile seizures within the FeverApp, with a reported incidence of only 0.4% among febrile children. In a matched sample controlled for gender and age, significant differences were observed between febrile children with and those without febrile seizures in several parameters, including maximum recorded temperature (P<.001), prevalence of chronic diseases (P=.004), parental confidence (P=.01), and frequency of emergency consultations (P<.001).

Conclusions: This study offers valuable insights into the characteristics, temporal dynamics, management strategies, and parental responses to febrile seizures in children. Despite the limitation of potential underreporting in an EMA-based registry, the findings highlight the critical importance of parental education and support in managing febrile seizures. Enhancing these areas has the potential to reduce unnecessary medical consultations and improve the overall care of affected children. Furthermore, integrating improvements in the FeverApp's education and documentation system regarding febrile seizures could facilitate better management and support future research efforts.

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KEYWORDS

children; fever; seizure; ecological momentary assessment; registry; mHealth

Introduction

Theoretical Background

Febrile Seizures

Febrile seizures are among the most common pediatric neurological events, affecting 2%-5% of children aged 6 months to 5 years, with a peak at 18 months [1-5]. They occur in the context of febrile illness and are not caused by intracranial infection or central nervous system damage [6,7]. Diagnostic criteria, as defined by the World Health Organization (WHO) *ICD-11* (*International Classification of Diseases, 11th Revision*), are detailed in Multimedia Appendix 1 [8,9]. They are classified as either simple or complex, with the majority being simple (75%-80%) [7,10]. Seizures typically resolve spontaneously, with children recovering within 24 hours, especially in simple cases [4]. They usually occur within the first day of fever, are more frequent in the early evening, and peak in fall and winter [1,7].

The prognosis for children with febrile seizures is generally favorable, with brain damage or death being extremely rare [11,12]. While most children recover without complications, those with complex seizures, a family history of seizures, or younger age have a slightly higher risk of afebrile seizures or later epilepsy [13-15]. Febrile seizures recur in 30%-50% of cases, with recurrence risk increasing with additional risk factors such as lower fever or early onset after fever [7,15,16]. Despite their benign nature, febrile seizures are clinically significant due to their prevalence and potential for recurrence or later epilepsy [4].

Febrile seizures cannot be prevented with antipyretics [17]. Acute seizures can often be stopped with rectal diazepam or buccal/intranasal midazolam [1], while paracetamol and ibuprofen may relieve discomfort but are not recommended solely to reduce fever [18]. Long-term anticonvulsant therapy does not prevent recurrences or later epilepsy [1].

The exact mechanisms underlying febrile seizures remain unclear. Risk factors include a positive family history, certain genetic predispositions, young age (6 months-5 years, peak 12-18 months), developmental delay, neurological abnormalities, prolonged neonatal hospitalization, and maternal smoking [1,4,19,20]. Boys are slightly more affected [6,13,20-22]. Febrile seizures are often associated with infections and may rarely follow vaccinations [4,23-26]. Seizures are typically triggered by elevated body temperature, frequently above 39 °C, though even mild fever can provoke them. It remains unclear whether absolute temperature or the rate of increase is more critical, and seizures can sometimes occur before or after the fever spike [1].

Parental Experience and Alleviation

Febrile seizures, though generally benign, are often frightening and distressing for parents, who may fear their child is dying [5,27,28]. Reactions can include psychosomatic symptoms (eg, sleep disruption and dyspepsia) and psychological stress such as anxiety, fear of recurrence, and excessive worry. This can disrupt family life and contribute to "vulnerable child syndrome," where parents perceive their child as unusually susceptible to problems [5,29]. Despite these fears, children with febrile seizures do not use more medical resources than peers [5]. Studies indicate that many parents lack prior knowledge: in Germany, around 50% had not informed themselves, only 32% recognized a seizure during the episode, and 63% administered antipyretics at lower-than-recommended temperatures [30].

Early recognition, education, and guidance are key to alleviating parental anxiety and improving outcomes. Multimedia educational interventions about the benign nature and management of febrile seizures can further support parents [13]. Health care providers should address misconceptions, fears, and coping strategies to empower parents effectively [5].

This highlights the potential of digital health applications, which can provide real-time guidance, educational support, and data collection to assist families in managing febrile illnesses safely.

About the FeverApp

The FeverApp is one of 6 model registries funded by the Federal Ministry of Education and Research (BMBF) and launched in 2019 [31]. It serves as an ecological momentary assessment (EMA) for fever management in families, where parents can document febrile illnesses in real time and receive evidence-based information on fever management [31,32]. Initially, access to the FeverApp was only possible via codes provided by pediatricians. This approach ensured data reliability and accuracy, fostered parental trust, and secured acceptance among treating pediatricians. Since August 2022, the app has been accessible without a code as well.

It is primarily a research tool rather than a certified medical device. Its main purpose is observational, collecting longitudinal data on fever and parental management. At the same time, by monitoring their child's illness and accessing evidence-based guidance, parents learn about fever, are supported in their care decisions, and may experience reduced anxiety. Its EMA-based design provides clinicians with structured, high-resolution data that can support diagnosis and management, even though the app itself does not make medical decisions.

Technically, the app operates as a client–server system: anonymized data are stored locally in an open-source database (PouchDB) and synchronized with central CouchDB and transferred to MongoDB servers at the University of Witten/Herdecke. The app is available for iOS and Android. It is also possible to extend the functions of the app by implementing additional modules to document specific diseases. In the current app version, it is possible to document febrile seizures separately. Previous studies show that the backend reliably captures real-time data and complements outpatient care [33,34]. A comparison between different fever apps was presented in Joosen et al [35]. The authors reviewed pediatric

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fever apps for quality and guideline adherence. Out of 878 apps, 3 were fully assessed: Kinsa and FeverApp scored highest in quality, while FeverFriend best adhered to the National Institute for Health and Care Excellence (NICE) guidelines [36]. FeverApp was originally based on the NICE Guidelines until the first author of the present publication and inventor of the FeverApp initiated and coordinated the new German S3 national guideline on fever management in children and youth [37]. The study shows few evidence-based apps exist, including the FeverApp, and highlights their potential for parental support.

Goal of the Study

Febrile seizures represent a common, most benign yet complex pediatric neurological condition with unknown, probably multifactorial etiology and can be frightening for parents. Understanding these theoretical aspects is critical for developing targeted interventions and providing comprehensive care for affected children and their families.

The quality of data collected is often limited due to reporting and recall bias. Therefore, immediate records are preferred in medical research. EMA is a modern method that enables timely, direct, and cost-effective data collection by allowing repeated sampling of participants' behavior in real-time environments, thus minimizing recall bias and increasing external validity [38-40].

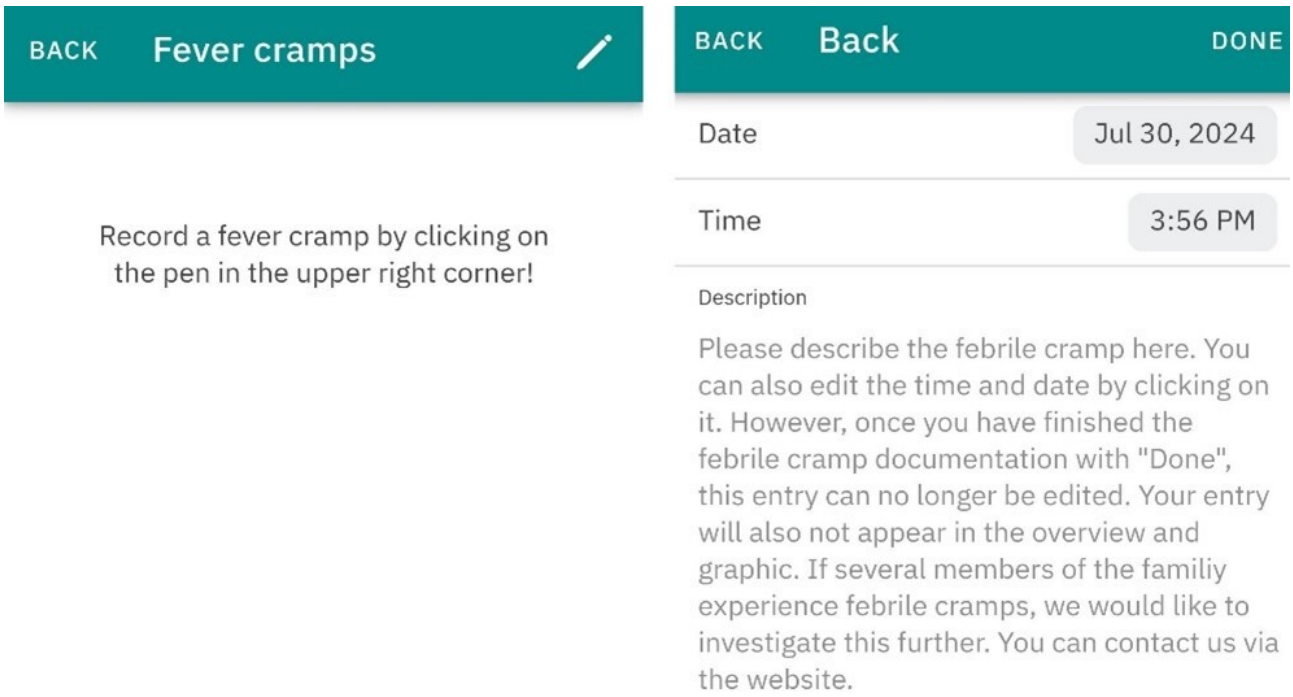
The primary objective of this study is to investigate the FeverApp as an EMA-based registry for febrile illnesses, with a particular focus on differentiating specific conditions such as febrile seizures. Additionally, the study aims to examine febrile seizure records for their conformity with current research, assess the potential for expanding existing studies, and identify areas for improvement in EMA-based registries.

Methods

Data Source

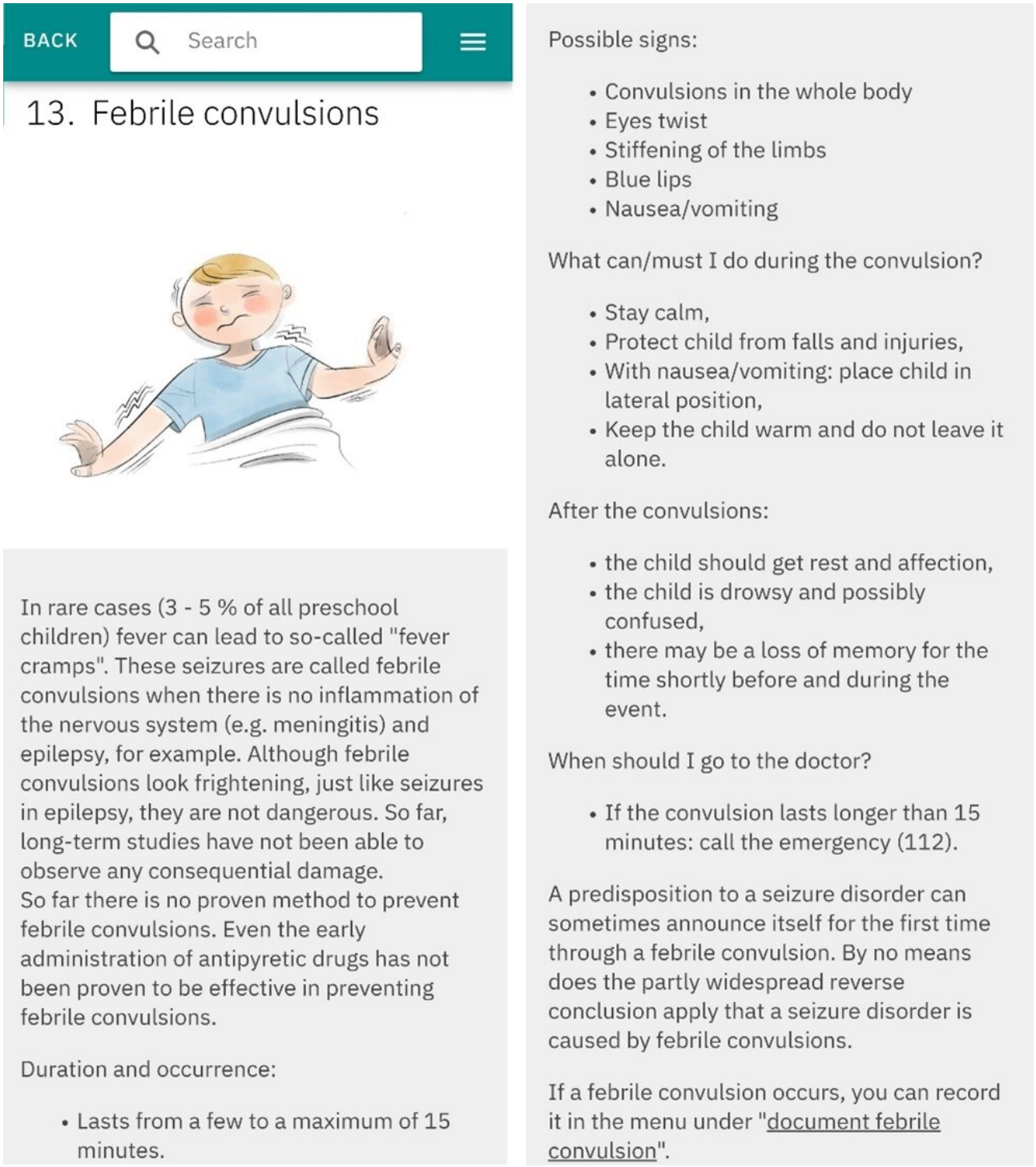
The FeverApp serves as an EMA-based registry for fever management, enabling parents to record febrile illnesses and receive advice on managing their child's fever at home [31]. Since its launch in September 2019, the app has recorded approximately 54,300 fever episodes from around 46,600 children as of November 2024. Data are securely stored on university servers at Witten/Herdecke for scientific research purposes. The app supports various caregiver roles and allows for the creation of multiple profiles and episodes per child. A fever episode concludes either when the parent selects the "child is healthy" option within the app or, during data cleaning, when no further entries are recorded within a 48-hour period. The app collects comprehensive data, including sociodemographic details, medical history, and acute fever-related information such as parental confidence in dealing with their children's fever, the child's temperature, symptoms, well-being, and medication usage [32]. Febrile seizures are documented separately, with automatic timestamps and the option for manual adjustments to the date and free-text seizure descriptions (Figure 1). As a continuously updated registry, the completeness of the data varies. Additionally, users have access to educational resources on childhood fever, including a video and a multimedia, guideline-oriented information library with 23 chapters, one of which is dedicated to febrile seizures (Figure 2).

Figure 1. Febrile seizure module within the FeverApp.



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Figure 2. Chapter about febrile seizures in the Info Library of the FeverApp.



Recruitment and Sampling

The FeverApp registry constitutes at the beginning a convenience sample of parents who voluntarily use the app to document their child's fever episodes. Initially, access to the app was provided exclusively through pediatric offices, where physicians distributed access codes to families, ensuring reliability and authenticity of user data. Over time, the app has become publicly available, allowing any interested caregiver to participate voluntarily. Thus, data originates from a naturalistic sample of parents documenting fever episodes in real-life settings.

For this study, no additional recruitment was performed. Instead, a purposive subsample was extracted from the existing FeverApp database, consisting of all cases in which parents documented at least one febrile seizure episode. Entries were included if the seizure documentation appeared reliable, while duplicates or clearly false entries excluded (15 cases). For comparative analysis, a convenience sample of all existing fever episodes were used. In both analyses, children aged 18 years or older, parents who deleted their account, or parents aged 14 years or younger were filtered out. No further exclusion criteria, such as family history of seizures or previous seizures of the

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child, were applied, as such information was not systematically available.

Data Analysis

The study followed 2 separate analyses: a descriptive qualitative analysis of parental descriptions regarding febrile seizures and a comparative quantitative analysis between children with and those without a febrile seizure.

Two datasets were used for analysis. Continuous EMA data for each entry were stored in a single large dataset, while a separate dataset was created specifically for time-lagged febrile seizure documentation. Data were subsequently cleaned, processed, and analyzed using IBM SPSS (version 28; IBM Corp).

Initial qualitative analyses focused on entries within the "seizures" dataset. A quantitative analysis of sample characteristics was performed, examining variables such as gender, age, number of febrile seizures recorded, prevalence of chronic disease, febrile disease in the past 12 months, tendency for high fever, typical fever duration, behavior during fever rise, antipyretic use in the past 12 months, time of febrile seizure, and difference between seizure date and seizure record. Some variables (age, febrile disease in the past 12 months, tendency for high fever, typical fever duration, time of the febrile seizure, and difference between seizure date and seizure record) were categorized or dichotomized. Detailed categories are provided in Table 1. Parents' free-text descriptions of seizure events were manually analyzed following an inductive thematic approach as described by Braun and Clarke [41], aiming to identify recurring patterns, words, and themes that reflected parents' observations and experiences during febrile seizures to develop categories. To support the interpretation of the qualitative themes, limited frequency indications are provided to show how often specific symptoms or parental descriptions occur. In addition, a quantitative overview of these categories was generated, indicating, for example, the frequency of specific observations such as blue lips or the involvement of emergency services. These descriptive patterns were then interpreted to highlight clinically and behaviorally relevant features of febrile seizures as perceived by parents, such as common symptom clusters, typical parental responses, and indicators of perceived severity, providing insights into both the objective and subjective aspects of seizure events as recorded in a naturalistic setting.

Quantitative analyses within the "seizure" dataset examined variables such as age, gender, number of seizures, health and febrile history (eg, previous fevers, tendency for high fever, typical fever duration, and chronic diseases), fever management strategies (eg, cooling/warming methods and use of antipyretics), timing of seizures, and the time interval between seizure occurrence and documentation.

In the subsequent step, both datasets were merged to incorporate missing variables from the seizure dataset and enable comparisons between febrile children with and those without febrile seizures. As febrile seizures can be recorded some time after they occur, data from fever episodes are not always directly connected. Therefore, seizures in which the timestamp of the entry and the reported seizure differed by more than 48 hours were excluded from the comparison. Since a single child can have multiple fever episodes, comparing children is challenging due to dependency in some entries (multiple episodes for one child) and independence in others (single episode per child). To address this, only the first fever episode for each child was selected for analysis, and in cases of children with seizures, only their first recorded seizure was considered. To control for significant differences in age and gender distribution between the 2 groups, children were randomly matched based on these variables. The analyses examined children with and those without a febrile seizure and compared variables such as age, sex, febrile history (eg, previous fevers, tendency for high fever, and typical fever duration), fever management strategies (eg, cooling/warming methods and use of antipyretics), temperature, parental confidence in dealing with their children's fever (5-point Likert scale from "thumbs down" to "thumbs up"), medical consultations, and children's well-being (5-point Likert scale from "sad face" to "happy face"). Some Variables (fever in the past 12 months, tendency for high fever, typical fever duration, and management during fever rise) were categorized or dichotomized. Statistical tests were applied as follows: the *t* test for normally distributed metric data, the Mann-Whitney *U* test for nonnormally distributed metric data (including Likert scale variables, per scale [42]), and chi-square tests for ordinal and nominal data. For 2×2 contingency tables or when cell frequencies were below 5, Fisher exact test was reported. Effect sizes were calculated for all applicable tests to quantify the magnitude of observed differences.

Reporting of this study followed the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology; for quantitative analyses) and SRQR (Standards for Reporting Qualitative Research; for qualitative analyses) guidelines [43,44]. Completed checklists are available in Multimedia Appendices 2 and 3 [43]. While the study includes qualitative analysis of parental free-text entries regarding febrile seizures, it does not follow traditional qualitative research design (eg, interviews or ethnography). Therefore, some items from the SRQR checklist are not applicable. The analysis was limited to the content of entries collected in the naturalistic, real-world setting of the FeverApp.

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Table 1. Descriptive analyses of seizure dataset.

Characteristic	Value, n (%)
Gender (n=161)	
Male	81 (50.3)
Female	80 (49.7)
Age (n=161)	
0–12 months	24 (14.9)
13–24 months	51 (31.7)
2-5 years	72 (44.7)
>5 years	14 (8.7)
Number of febrile seizures recorded (n=161)	
1	128 (79.5)
2	20 (12.4)
3	4 (2.5)
4	4 (2.5)
5	1 (0.6)
6	3 (1.9)
7	1 (0.6)
Chronic disease present (n=161)	17 (10.9)
Fever in the past 12 months (n=145)	
0	27 (18.6)
1-5	96 (66.2)
>5	22 (15.2)
Tendency for high fever (n=142)	
“Never” to “few times”	102 (71.8)
“Most” to “always”	40 (28.1)
Typical fever duration (n=44)	
≤3 days	43 (97.7)
>3 days	1 (2.3)
Behavior during fever rise (n=95)	
Cooling	30 (31.6)
Warming	20 (21.1)
Neither	29 (30.5)
Don’t know	16 (16.8)
Antipyretics in the past 12 months (n=140)	114 (81.4)
Time of the febrile seizure (n=226)	
5 AM-10 AM	43 (19.0)
11 AM-4 PM	81 (35.8)
5 PM-11 PM	83 (36.7)
12 AM-4 AM	19 (8.4)
Interval between seizure date and record (n=226)	
<24 hours	127 (56.2)
<1 week	34 (15.0)
<1 month	14 (6.2)

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Characteristic	Value, n (%)
>1 month	28 (12.4)
>6 months	23 (10.2)

Ethical Considerations

Ethical approval for the FeverApp registry has been granted by the ethics committee of the University of Witten/Herdecke (proposal number: 139/2018).

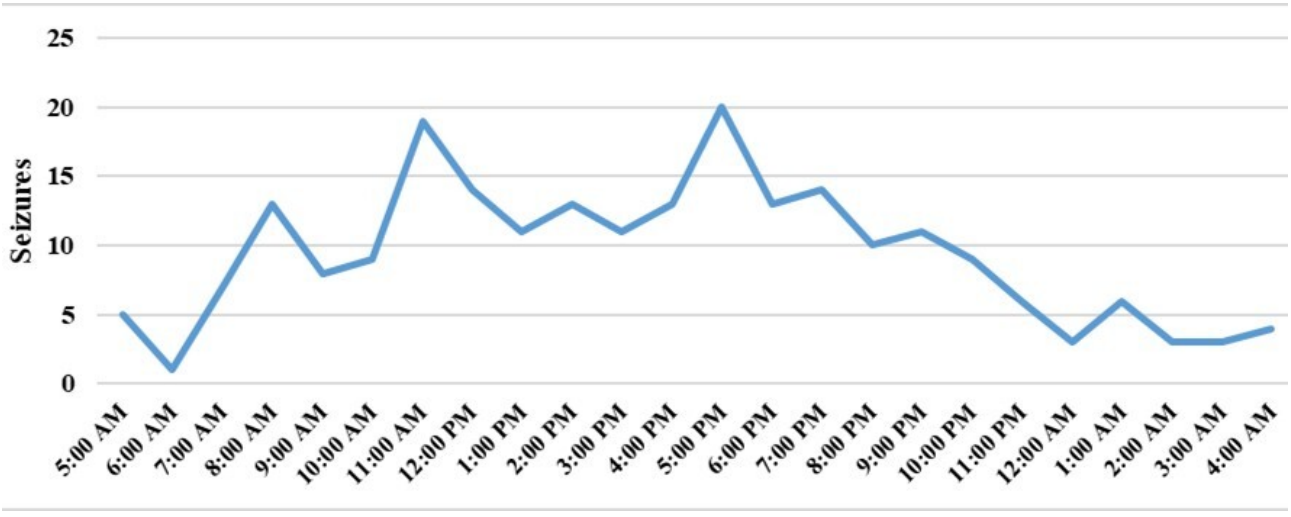
The FeverApp Registry is registered in the German Clinical Trials Register (DRKS-ID: DRKS00016591). The registry follows the Declaration of Helsinki. Informed consent was obtained from all participants involved in the study. After installing the app, users must confirm a data privacy statement where they accept that their data are being recorded and used for scientific reasons. The FeverApp ensures privacy and confidentiality through data anonymization. Each family is assigned a randomly generated 8-character code, and all users and children are identified only by these codes. Data can be deleted at any time either via the app or by contacting the study team by email to request data removal. No compensation was provided to participants, as the study was based on data collected through the FeverApp and did not involve direct participation or intervention.

Results

Dataset of Febrile Seizures

Over a data collection period of 5 years, there were 226 registrations of febrile seizures. These belonged to 161 children, of whom 128 (79%) had only 1 febrile seizure and 33 (21%) had 2 or more febrile seizures. From 226 registered febrile seizures, 125 (60%) included detailed descriptions. Children's gender was evenly distributed. A chronic disease was present in 10% (17/156) of the children. Regarding fever history, around 81% (118/145) of children had experienced a febrile illness in the past 12 months. Most children (102/142, 72%) rarely or never have high fever, and nearly all (43/44, 98%) have a typical fever duration of up to 3 days. Parents' responses varied regarding their actions during a fever rise, with 21% (20/95 children) warming, 31% (30/95 children) cooling, and 31% (29/95 children) doing neither. In 81% (114/140) of children, antipyretics were administered within the past 12 months. Approximately 15% (24/161) of the children were aged 12 months or younger, while about one-third (51/161, 32%) were aged between 12 and 24 months. Nearly half (72/161, 45%) of the children were aged between 2 and 5 years, and approximately 8% (14/161) were aged 5 years or older. Most records of febrile seizures were between 8 AM and 8 PM (168/226, 74%), with peaks at 11 AM and 5 PM (Figure 3). In most cases (127/226, 56% records), the time between the seizure and its recording was less than 24 hours, although in around 10% (23/226 records) of cases, parents recorded the seizure more than 6 months after it happened. Additional results are provided in Table 1.

Figure 3. Seizure frequencies at different times.



Descriptive Qualitative Analysis of Parental Descriptions of Febrile Seizures

A total of 70 children had 1 detailed description, and 17 children had 2-6 descriptions of their seizures. They are reported separately because of their possible different seizure profile.

Children With 1 Seizure Report

High fever was reported in 13 of 70 cases, with temperatures ranging from 39.1 °C to 40.2 °C. Some described it as "sudden fever," "fast rising," or "from 0 to 100." Two of 70 parents reported lower temperatures from 38.0 °C to 38.8 °C. The duration of the seizures ranged from 30 seconds to 10 minutes (40/70), with the majority lasting less than 3 minutes (26/70). One parent reported that the seizure lasted for about half an hour.

Out of 70 descriptions, some parents described their child as whiny (3 cases) or restless, lethargic, clingy, and tired (2 cases each) before the seizure. During the seizure, parents frequently

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reported “rolling eyes,” that is, upward gaze deviation (29 cases), cramping (25 cases), twitching (24 cases), tension or stiffness (15 cases), blue lips (15 cases), unresponsiveness (15 cases), and salivating (9 cases). Additional symptoms included a staring gaze (6 cases) and blue (5 cases) or pale (3 cases) skin color. Some parents reported rhythmic movements (5 cases) and others a limp child (4 cases). Children whimpered or cried (4 cases), screamed (4 cases), vomited (4 cases), and clenched or ground their teeth (3 cases) during the seizure. Breathing was described as gasping for air (6 cases), wheezing (3 cases), or flat breathing (2 cases). Tachycardia was infrequently reported (2 cases). In 3 cases, the seizures were described as uncomplicated and quickly resolved. One mother reported that she was “scared” and “thought he was dying.”

After the seizure, 5 out of 70 cases reported that the child was not responsive for a period or that they fell asleep immediately. In 3 cases, the child vomited afterward. Five of 70 parents reported that their child seemed very limp afterward.

In 19 out of 70 cases, an ambulance or emergency doctor was called. One parent waited and then went to the doctor the next morning. In 13 out of 70 cases, the child was taken to the hospital for overnight monitoring or a few days of observation. Diagnoses reported included kidney inflammation, tonsillitis or throat infection, ear infection, and 3-day fever.

Various measures were taken before, during, or after the seizures. In 2 out of 70 cases, antipyretics were given directly before the seizures, and in 5 of 70 cases, they were given afterward. During the seizures, diazepam was administered once, buccolam once, an “antispasmodic medication” once. Additionally, antipyretics (4/70 cases) were administered during the seizure. Other measures included calf wraps, cooling of the forehead and legs (2 cases), removing clothes (1 case), and placing the child in a stable side position (3 cases).

Overall, these reports illustrate the range and frequency of symptoms, postictal behaviors, and parental responses during single febrile seizure events, highlighting commonly observed patterns such as high fever, eye rolling, cramping, cyanosis, and emergency interventions.

Children With More Than 1 Seizure Report

The temperature ranged from 38 °C to 40.1 °C. Many cases (10/56) had a higher fever than 39 °C. Two reports described low or no fever. A fast fever rise was noted in 2 cases. The duration of the seizure ranged from 50 seconds to 30 minutes. Most seizures (20/56 cases) lasted up to 2 minutes. In 9 cases, a duration of 5 to 10 minutes was reported, and in 3 cases, a duration of 20 to 30 minutes was reported.

In some cases (6/56), parents described that their child was “not really responsive” or “not quite himself” before the seizure even started. Parents described their child as very sleepy (4 cases) and that the child had fever throughout the day (3 cases). Twitching, lots of crying, being shaky on the legs, and screaming (2 cases each), as well as restlessness and stretching (1 case each), were also reported before the seizure. One parent noted that there were no signs of fever or an infection before the seizure.

Among the 56 documented seizures, common clinical manifestations included tonic-clonic activity (cramping, 27 cases), oculogyric crisis (fixed gaze, 18 cases), perioral cyanosis (blue lips, 14 cases), postictal state or loss of consciousness (13 cases), and myoclonus or clonus (twitching, 11 cases). Additionally, a tonic gaze or ictal fear was noted in 11 cases. Less frequent findings included ictal vocalizations (screaming, 9 cases), acrocyanosis or pallor (blue or pale skin, 6 cases), and emesis (vomiting, 4 cases). Some children exhibited opisthotonos (abnormal posturing, 3 cases), rigidity or hypertonia (increased muscle tone, 2 cases), hypotonia or flaccidity (decreased muscle tone, 2 cases), or automatisms (stereotyped rhythmic movements, 1 case). Respiratory compromise was observed in several cases: apnea (cessation of breathing) or dyspnea (difficulty breathing) was reported in 3 instances, and expiratory stridor (wheezing) in another 3. One case involved significant oxygen desaturation requiring supplemental oxygen therapy. Normal respiration was explicitly documented in only 1 case. Regarding seizure characteristics, 2 episodes were described as uncomplicated (simple febrile seizures), while 3 were noted to resemble prior seizures (recurring febrile seizures). One parent expressed acute psychological distress, describing the event as “the horror.”

In 10 out of 56 cases parents reported that their child remained not responsive and required 20 to 30 minutes to be “back to himself/herself.” In 1 case it took over 45 minutes and sleep for the child to become responsive again. Two cases reported that the child was not able to talk for a while. In many cases (n=17), children were very sleepy or lethargic afterward. Parents reported that their child was vomiting (2 cases), salivating (1 case), screaming (1 case), and twitching (1 case) afterward. One noted that she had “the feeling the seizure continued.”

In 16 out of 56 cases, an ambulance was called, or they drove to the emergency room, and in 15 cases, they stayed at the hospital for observation for up to 2 days. One parent was going to a neurologist the next day. Influenza A (2 cases), a side effect of the measles vaccination (1 case), and a mild blood infection (1 case) were diagnosed in the hospital.

Paracetamol was given before the seizure in 1 case, and in 2 cases, paracetamol and ibuprofen were administered. In many cases (16/56 cases), diazepam was given during the seizure. In 2 cases, a double dose of diazepam or diazepam and additionally buccolam was administered. In 1 case it was a combination of diazepam and an antipyretic. Some children (3 cases) received paracetamol or ibuprofen afterward as well. In contrast to children with only 1 seizure or their first seizure, children with more seizures received diazepam as an anticonvulsive medication more frequently.

Overall, these reports illustrate the range and frequency of symptoms, postictal behaviors, and parental responses during multiple febrile seizure events, highlighting recurring patterns such as tonic-clonic activity, blue lips, postictal unresponsiveness, and the frequent involvement of emergency services or administration of diazepam.

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Comparative Quantitative Analysis of Febrile Children With or Without a Febrile Seizure

Overview

Only 0.4% of all children in the FeverApp had a febrile seizure documented. Although most children with a fever were male (14,298/27,342, 52.3%), febrile seizures were evenly distributed (57 female, 57 male; total 114) around gender. The median age of children with a febrile seizure was 30 months (IQR 13-42) and without a febrile seizure was 21 months (IQR 7-36). The age distribution between the groups differed significantly in the 2-tailed *t* test (t_{27237}=–2.41, *P*=.02). After matching, each group consisted of 114 children with an identical distribution of age (mean 31.68, SD 24 months) and gender (57 male and 57 female children in each group).

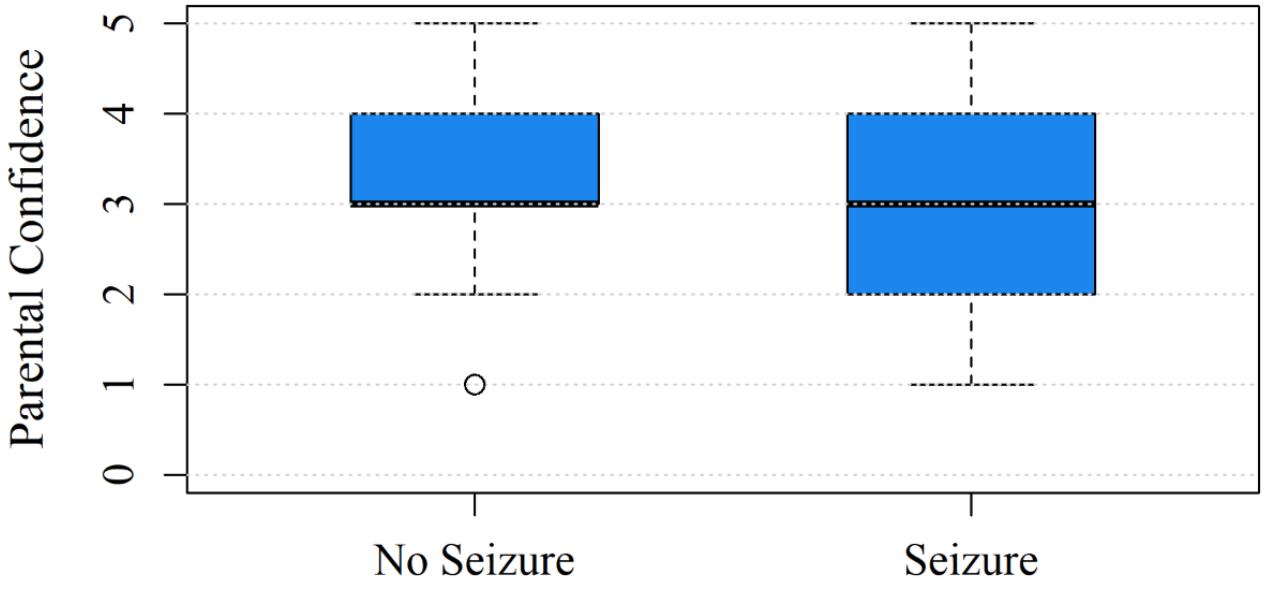
Temperature

Children's mean temperature without a febrile seizure was 38.6 °C and ranged within an episode from 38.0 °C to 39.0 °C. The mean temperature with a febrile seizure was 38.7 °C and ranged from 37.9 °C to 39.5 °C. The difference was significant in the Mann-Whitney *U* test between the highest reported temperature during an episode, with a moderate effect (*U*=2915; *z*=–4.25; *P*<.001; *r*=–0.25).

Parental Confidence

A Mann-Whitney *U* test was conducted to compare the minimum and maximum reported parental confidence during an episode between parents of children with and those without a febrile seizure. Although the medians were identical in both groups (minimum median 3, IQR 3-4; maximum median 4, IQR 3-5), the average lowest reported confidence differed: parents of children with a febrile seizure reported an average minimum confidence level of 2.9, while parents of children without a febrile seizure reported an average of 3.5. The test revealed a significant difference in the distribution of minimum parental confidence with a small effect size (*U*=3657; *z*=–2.45; *P*=.01; *r*=–0.18). As illustrated in the boxplot in Figure 4, this difference may be explained by the greater spread toward lower values among parents of children with febrile seizures compared with those without.

Figure 4. Boxplot comparing the minimum parental confidence levels between the group of children with and without a seizure.



Children's Well-Being

A Mann-Whitney *U* test was conducted to compare the minimum and maximum reported children's well-being during an episode between the group of parents with children with and those without a febrile seizure. The medians for both groups ranged between 2 and 3 (low to moderate well-being) within an episode, with no significant differences. Further information is provided in Table 2.

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Table 2. Results from the comparison of children with and those without a seizure.

Variable	No seizure	Seizure	*P* value	*t* test (df)	Mann-Whitney *U* value	*z* value	Effect size	
							Cohen *d*	Pearson *r*
Temperature (n=196)								
Mean in episode, mean	38.6 °C	38.7 °C	.28	–1.09 (194)	—[a]	—	0.77	—
Minimum in episode, mean	38.0 °C	37.9 °C	.28	1.09 (168)	—	—	0.99	—
Maximum in episode, mean	39.0 °C	39.5 °C	<.001	—	2915	–4.25	—	0.25
Parental confidence (n=192)								
Minimum in episode, median (IQR)	3 (IQR 3-4)	3 (IQR 2-4)	.01	—	3657	–2.45	—	–0.18
Maximum in episode, median (IQR)	4 (IQR 3-5)	4 (IQR 3-5)	.93	—	4527	–0.09	—	–0.01
Children's well-being (n=199)								
Minimum in episode, median (IQR)	2 (IQR 1-2)	2 (IQR 1-2)	.26	—	4501	–1.13	—	–0.08
Maximum in episode, median (IQR)	3 (IQR 2-4)	3 (IQR 2-4)	.09	—	5584	–1.66	—	–0.12

[a]Not applicable.

Contact With a Doctor

In 59% (64/196) of cases, parents had no contact with a doctor when their child did not have a febrile seizure, whereas in the group of children with a febrile seizure, only 34% (30/196) had no contact with a doctor. In this group, 35% (31/196) had contact with an emergency service. Parents who did not have a child with febrile seizure only contacted an emergency service in around 5% (5/196) of cases. The difference was significant in the Fisher exact test, with a moderate effect (*P*<.001; Cramer V=0.401).

Vaccination in the Past 2 Weeks

About 14% (14/179) of children with no febrile seizure had a vaccination in the past 2 weeks. There was a lower percentage of recent vaccination (8/179, 11%) in the group of children with a febrile seizure, although this difference was not significant in Fisher exact test between the 2 groups.

Chronic Diseases

In the group of children with a seizure, 14% (16/203) had a chronic disease, whereas only 3 % (3/203 cases) in the group with no seizure had a chronic disease. Fisher exact test indicated that the difference was statistically significant at the conventional alpha level, with a weak effect (*P*=.004; Cramer V=0.196). Most children had asthma (5 cases), epilepsy (2 cases), or neurodermatitis (2 cases).

Fever in the Past 12 Months

Around one-third of children in the group without a seizure (31/101, 31%) and around one-fourth in the group with a seizure (24/101, 24%) had no fever in the past 12 months. Around two-thirds of children in both groups (61/101, 60% vs 62/101, 63%) had fever 1-5 times in the past 12 months. There was no significant difference in the chi-square test.

Tendency for High Fever

Almost all children in both groups (83/194, 85% vs 75/194, 78%) had a tendency for high fever "never" to "few times." There was no significant difference in the chi-square test.

Typical Fever Duration

Almost all children in both groups (24/56, 92% vs 29/56, 97%) had a normal fever duration of up to 3 days. There was no significant difference in the Fisher exact test.

Antipyretics in the Past 12 Months

Most children in both groups got antipyretics in the past 12 months (79/188, 82% vs 73/188, 79%). There was no significant difference in the chi-square test.

Cooling/Warming During Fever Rise

More parents in the group of children with a febrile seizure would cool their child during fever rise (22/106, 42%) than in the group of children with no febrile seizure (15/106, 28%). Around one-quarter of parents in both groups would warm their child during fever rise (15/106, 28% each). Around 30% (16/106) of parents in the group of children with a febrile seizure would neither cool nor warm their child, whereas 43% (23/106) of parents in the group of children without a febrile seizure would do neither. Even though there was a relevant difference in percent between the groups, these differences were not significant in the chi-square test. Table 3 shows further results from the comparison of children with and those without a seizure.

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Table 3. Results from the comparison of children with and those without a seizure.

Variable	No seizure, n (%)	Seizure, n (%)	*P* value	Chi-square (*df*)	Effect size[a]
Doctors contact (n=196)			<.001[b]	—[c]	0.40
No contact	64 (59)	30 (34)			
Yes, with their doctor	36 (33)	25 (28)			
Yes, with a substitute	3 (3)	2 (2)			
Yes, with the emergency service	5 (5)	31 (35)			
Vaccination in the past 2 weeks (n=179)			.57[b]	—	0.04
Yes	14 (13.5)	8 (10.7)			
No	90 (86.5)	67 (89.3)			
Chronic diseases (n=203)			.004[b]	—	0.2
Yes	3 (2.8)	16 (13.8)			
No	103 (97.2)	100 (86.2)			
Fever in the past 12 months (n=101)			.45[d]	1.61 (2)	0.90
0	31 (30.7)	24 (24.2)			
1-5	61 (60.4)	62 (62.6)			
Over 5	9 (8.9)	13 (13.1)			
Tendency for high fever (n=194)			.24[d]	1.39 (1)	0.08
“Most” to “always”	15 (15.3)	21 (21.9)			
“Never” to “few times”	83 (84.7)	75 (78.1)			
Typical fever duration (n=56)			.59[d]	—	0.1
Up to 3 days	24 (92.3)	29 (96.7)			
More than 3 days	2 (7.7)	1 (3.3)			
Antipyretics in the past 12 months (n=188)			.60[d]	0.26 (1)	0.04
Yes	79 (82.3)	73 (79.3)			
No	17 (17.7)	19 (20.7)			
Management during fever rise (n=106)			.28[d]	2.58 (2)	0.16
Warming	15 (28.3)	15 (28.3)			
Cooling	15 (28.3)	22 (41.5)			
Neither	23 (43.4)	16 (30.2)			

[a]Cramer V.

[b]Fisher exact test.

[c]Not applicable.

[d]Chi-square test.

Discussion

Overview

The primary aim of this study was to assess the effectiveness of the FeverApp as an EMA registry for febrile illnesses, specifically in relation to febrile seizures. Additionally, the study sought to expand existing research and identify improvements for associated EMA registries. Our results provide valuable insights into the characteristics and management of febrile illnesses in children.

Descriptive Qualitative Analysis of Parental Descriptions of Febrile Seizures

The detailed descriptions of febrile seizures provided by parents offer critical insights into the nature and management of these events. Of 226 reported febrile seizures, a significant portion (60%) included comprehensive reports, revealing common patterns in symptoms and parental actions during these distressing episodes. These included temperature, duration, description of the seizure itself, measures that were taken, and contact with a doctor. Some parents even recorded the seizure years after it occurred, which highlights the importance in their

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perception. The febrile seizure module itself is not in the normal backend of the FeverApp but in a different menu, so users must invest extra cognitive effort to record febrile seizures. This finding likewise emphasizes the importance of precise documentation and longitudinal analyses to better understand the lasting effect of febrile seizures.

Among children with a single seizure (13 out of 70 cases) and those with multiple seizures (10 out of 17 cases), many parents reported a high fever of 39.0 °C or higher immediately preceding the seizure. This observation aligns with current research indicating that 75% of seizures in children occur at body temperatures exceeding 39 °C [1]. Descriptions of the fever as "fast rising" or "from 0 to 100" in children with a single seizure (2 cases) and in those with multiple seizures (2 cases) suggest that rapid increases in body temperature may act as a trigger as well. This observation is consistent with existing literature on febrile seizure [1].

The duration of seizures varied between both groups, with most episodes lasting less than 3 minutes. This finding is congruent with related research, where seizures were reported to typically last 1-1.5 minutes. In both groups, however, seizures extended up to 10 minutes, and in 3 cases even up to 20-30 minutes. This may be due to a temporal overestimation on the part of the parents, or as an indicator that the episode constitutes a more complex seizure. Due to the highly emotional nature of seizures, especially during a child's first episode, parents' subjective time perception may often overestimate the actual duration [1,45], that is, this deviation may constitute a systematic time perception bias that warrants further investigation. It should be noted that parents who reported a longer duration consistently described the seizure with additional symptoms (ie, "teeth grinding" and "muscle cramping"). These symptoms were not halted by diazepam, which is indicative of a more complex seizure (prevalence estimated to be 20%-25%) [7,10].

Parents frequently noted a period of postictal unresponsiveness, with some children taking up to 20-30 minutes to recover (in some cases, the child fell asleep). This observation aligns with the typical postictal phase seen in febrile seizures, where children may appear disoriented or lethargic following the event [1].

The symptoms reported by parents, such as rolling eyes, blue lips (cyanosis of the lips), unresponsiveness (altered consciousness or unresponsiveness), twitching, and cramping, are characteristic of febrile seizures and are well-documented in the pertinent clinical literature [46]. The variety of symptoms like smacking, teeth clenching, and vomiting, demonstrates that febrile seizures can manifest in a wide range of symptoms.

In terms of emergency response, the descriptions show parental concern in both groups, with an ambulance or emergency doctor being called in 35 cases. The fact that 28 children were admitted to the hospital for observation can be an indicator either for medical evaluation following a febrile seizure or parent's anxiety [1]. An inpatient admission is considered depending on the age, the complexity of the seizure, the result of the clinical examination and parents' anxiety [1]. A further factor is that some hospitals encourage high admission rates for financial reasons.

Antipyretics were administered both prophylactically and reactively, reflecting their widespread use in fever management. It should be emphasized that empirical data indicate that lowering fever does not prevent the occurrence of febrile seizures [17]. In the group of children with more than 1 seizure diazepam was frequently administered. Most febrile seizures are short, typically resolve on their own, and thus do not need immediate pharmacological intervention. However, when a seizure lasts longer than 5 minutes, it may require medical treatment [47]. It is also recommended to prescribe diazepam after the first seizure in case of a relapse, but also for the feeling of security of parents [1]. However, children are often very strongly affected by diazepam, and such pharmaceutical drugs are not for parents "emotional safety." Benzodiazepines have side-effects (especially in neurosensitive children) and should only be prescribed to children as an ultima ratio [48]. Studies have shown that exposure to benzodiazepines can lead to neuronal apoptosis in the developing brain. For instance, research on neonatal macaques demonstrated that short-term exposure to these drugs resulted not only in neuronal apoptosis but also in oligodendroglial apoptosis, impaired synaptogenesis, inhibited neurogenesis, and subsequent long-term neurocognitive deficits [49]. Our understanding of how benzodiazepines affect the neurosensitive developing brain remains very limited. Research into the GABAergic and opioid systems is evolving, and the interplay between neurochemistry and cognitive development (consciousness) represents a cutting-edge area of study. It cannot be prima facie excluded that benzodiazepines may have longitudinal, and potentially epigenetic, effects on neuronal development [50,51]. This possibility underscores the importance of caution in their use and the exploration of safer and less controversial alternatives. There is a growing awareness of the risks associated with benzodiazepine use in children. The US Food and Drug Administration has updated boxed warnings for all benzodiazepine medicines to highlight the risks of abuse, misuse, addiction, physical dependence, and withdrawal reactions consistently across all drugs in this class [52].

Comparative Quantitative Analysis of Febrile Children With or Without a Febrile Seizure

The quantitative analysis showed that febrile seizures were reported in only 0.4% of cases in the FeverApp, which is likely an underreporting compared to the 2%-5% incidence documented in the literature [2-4]. While app-based registries can capture certain diseases, recording serious events seems to remain a challenge. The relevant module is in a separate menu of the FeverApp, located along with technical settings and information about the app, rather than being integrated into the main backend. Enhancing the accessibility of this module could lead to more accurate records. Additionally, the app should encourage users to distinguish more precisely between simple and complex convulsions and to note subsequent events and preperceptions which could enhance the understanding of febrile seizures. Lastly, including a video about febrile seizures in the information library could both improve the module's visibility and provide educational support, increasing user confidence in this area.

Several medical studies and resources document that the risk of febrile seizures is higher in males [13,20-22]. However, the

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FeverApp shows a slight predominance of female children with febrile seizures, which may also indicate the underreporting within the app. The majority of the children in the study had only 1 recorded seizure, which speaks for a simple nature of the seizure and aligns with reports in the literature [5].

For a better comparison of the 2 groups (viz, children with and those without a febrile seizure), they were matched regarding age and gender. One of the key findings is the significant difference in the highest reported temperatures between children with and those without febrile seizures. This suggests that higher temperatures might trigger a febrile seizure, which is in alignment with current research [1]. On the other hand, children who experienced febrile seizures had a wider range of temperatures, indicating that even a relatively low fever can potentially trigger a seizure. This supports the idea that individual susceptibility plays a role in the occurrence of febrile seizures and that seizure thresholds can vary among children [1]. It has been stated that recurrent febrile seizures and a family history of febrile seizures have a lower threshold in temperature as well [4].

In managing fever, a notable difference was observed in how parents responded to the onset of fever. Parents of children with a history of febrile seizures were more likely to report cooling their child during a fever rise. In contrast, parents of children without such a history were more inclined to take no action or to warm their child during a fever rise. This disparity highlights the heightened concern among parents regarding febrile seizures and their proactive efforts to manage them through cooling. It also emphasizes the importance of providing proper education on febrile seizures and their management strategies. It is to date unclear whether cooling decreases or increases the probability of developing a febrile seizure. Tumor necrosis factor and other cytokines may lower the seizure threshold. Given that their increase in fever can, to a certain extent, be neutralized by warming the child, it has been proposed that warming in the phase of a rising fever may prevent febrile seizures [53,54].

Children with a febrile seizure were more likely to have a chronic disease (notably asthma and neurodermatitis) which is found in other studies as well. A relevant study in Taiwan found a risk of subsequent asthma in children with febrile seizures [55], and a study in Iran found that febrile seizures are associated with the number of comorbid allergic diseases in children [56]. A Turkish study found that children have a higher risk for febrile seizures when they have a chronic illness that requires continuous medication [57].

Despite the differences in temperature, the reported well-being of the children did not significantly differ between the groups. This suggests that while febrile seizures are distressing, they do not necessarily correlate with a perceived decrease in the overall well-being of the child, as assessed by the parents. This finding is important as it may help reassure parents that febrile seizures, while emotionally alarming, are generally not indicative of a more serious underlying condition affecting the child's health.

Interestingly, no significant differences were found between the groups regarding vaccination history in the past 2 weeks, despite the potential for an increased risk of febrile seizures following certain childhood vaccines, such as the diphtheria, tetanus, and pertussis vaccine, as well as the measles-mumps-rubella vaccine [4]. Similarly, there were no notable differences between the groups in terms of fever frequency, duration, or antipyretic use over the past 12 months.

The study also highlighted significant differences in health care use between the 2 groups. Parents of children who experienced a febrile seizure were more likely to seek medical attention, particularly from emergency services. This is consistent with the high level of concern febrile seizures generate, often prompting immediate medical consultation. They usually occur in the evening and thus lead to emergency consultations. In contrast, parents of children without febrile seizures were less likely to contact a doctor, reflecting greater confidence in managing routine fevers at home. This is also shown in the significant difference in confidence levels between the 2 groups. Parents of children who had experienced a febrile seizure reported lower confidence levels. This is also reported in the descriptions, where one parent noted that "it was the horror" and one parent said she was "scared" and "thought he was dying." The lower confidence and higher emergency consultations among these parents highlight the need for better education and support to help them manage future febrile episodes more effectively.

Strengths, Limitations, and Future Research

This study has limitations. First, all data were self-reported by parents through manual entry rather than automated measurement or clinical verification, which may introduce recall bias, subjectivity, or incomplete reporting, particularly regarding seizure duration and symptoms. While some physiological parameters (eg, temperature or heart rate) could potentially be captured with automated devices, febrile seizures themselves are complex, short-lived events that are initially observed by parents. Seizures are more standardized in clinical settings, but often occur at home and are initially described by caregivers, which limits full automation of data collection in real-world environments. Second, although we used a purposive sample, the relatively small number of detailed seizure descriptions (73 out of 121 cases) and general underreporting of febrile seizures among febrile children (0.4%), limits the generalizability of the findings and formal statistical inference for the broader population. Finally, early pandemic restrictions and later increases during the Omicron wave influenced app use [32,58], but these effects likely evened out across the full dataset collected through 2023.

Despite its limitations, one of the primary strengths of this study lies in the comprehensive data collected from a large cohort of children using the FeverApp, providing valuable insights into febrile seizures and their management in a real-world setting. The matching of the sample led to a more valid comparison of the 2 groups, with age and gender differences being controlled as well as accounting for underreporting in the FeverApp. The detailed parental descriptions of febrile seizures offer a unique perspective on the symptoms, duration, and immediate responses, which are often difficult to capture in clinical settings. Additionally, the study highlights the variability in fever patterns

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and seizure characteristics, contributing to a more nuanced understanding of febrile seizures.

Future research could aim to further enhance the data quality of the FeverApp and clinical relevance through partial integration of automated measurements from validated medical devices (eg, temperature or heart rate sensors). Such integration could help to more precisely determine temporal relationships between fever onset, physiological changes, and the occurrence of seizures. In addition, the findings from this study could serve as a basis for developing a structured febrile seizure module with standardized questions reflecting the most frequently reported and relevant anamnestic parameters.

Conclusions

This study offers valuable insights into the characteristics, management, and parental responses to febrile seizures in children, as documented in the FeverApp registry. Its strengths include detailed parental descriptions and real-world data on fever management practices, contributing to a deeper understanding of febrile seizures. However, the findings also highlight the need for further research into the psychological impact on parents. Despite limitations such as reliance on self-reported data and the lack of clinical verification, the study underscores the critical importance of parental education and support in managing febrile seizures. Enhancing these areas could reduce unnecessary medical consultations and improve the care of febrile children. Future research should investigate the effectiveness of parental education in managing febrile seizures and evaluate whether targeted interventions can reduce reliance on emergency medical services. Additionally, improving the reporting mechanism within the FeverApp to better capture febrile seizure data is warranted, as this could address underreporting and support further research. Although video documentation was omitted due to data safety concerns, the registry-based data provides an excellent foundation for future trials on this important topic.

Acknowledgments

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Data Availability

The datasets analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

DM and RM contributed to the conceptualization of the study. The methodology was developed by RM and EJ, while the software was handled by DM and EJ. Validation was carried out by EJ and DM, and formal analysis was performed by RM and EJ. The investigation involved contributions from DM, EJ, MG, and SS. Resources were provided by DM, and data curation was conducted by EJ. The original draft of the manuscript was prepared by DM, RM, CBG, MG, SS, and EJ, while writing, review, and editing were undertaken by DM, RM, CBG, and EJ. Project administration was managed by SS, and funding acquisition was carried out by DM and EJ. All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Febrile seizures: World Health Organization (WHO) International Classification of Diseases, 11th Revision (ICD-11) classification and clinical characteristics.
[DOCX File , 20 KB - pediatrics_v9i1e74933_app1.docx]

Multimedia Appendix 2
STROBE checklist for quantitative analysis.
[PDF File (Adobe PDF File), 194 KB - pediatrics_v9i1e74933_app2.pdf]

Multimedia Appendix 3
SRQR checklist regarding qualitative analysis.
[PDF File (Adobe PDF File), 165 KB - pediatrics_v9i1e74933_app3.pdf]

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Abbreviations

BMBF: Federal Ministry of Education and Research
EMA: ecological momentary assessment
ICD-11: International Classification of Diseases, 11th Revision
NICE: National Institute for Health and Care Excellence
SRQR: Standards for Reporting Qualitative Research
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology
WHO: World Health Organization

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Original Paper

Evaluating the Picterus Jaundice Pro App for Neonatal Jaundice Screening by Parents: Prospective Mixed Methods Study

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Abstract

Background: Neonatal jaundice is a very common condition in the first week of life requiring timely recognition of the small subset of neonates at risk of developing severe neonatal hyperbilirubinemia (SNH). Total serum bilirubin, as quantified through blood testing, remains the gold standard for diagnosis, whereas screening based on visual inspection has been proven unreliable in identifying which jaundiced neonates require total serum bilirubin. Picterus Jaundice Pro (JP) is a mobile health app developed for use by health care professionals and parents to screen for imminent SNH. However, parental user experiences with Picterus JP remain largely unexplored.

Objective: This study aimed to evaluate the usability and user-friendliness of Picterus JP when used and evaluated by parents.

Methods: Between August 2023 and January 2025, we conducted a prospective mixed methods study at 3 maternity care settings: the maternity wards of 2 hospitals in the Netherlands and 1 hospital in Israel. Parents were invited to participate if their infant was near term born (gestational age of ≥35 weeks) and at least 12 hours old but still in the first week of life. Parents used Picterus JP once according to the manufacturer's instructions. Immediately afterward, usability was evaluated using the validated mHealth App Usability Questionnaire, an instrument measured on a 7-point Likert scale ranging from 1 ("strongly disagree") to 7 ("strongly agree"), and open-ended questions. A subset of parents and nurses participated in semistructured interviews and focus groups.

Results: In total, 123 parents completed the questionnaire. The median mHealth App Usability Questionnaire score was 6 (IQR 5-7) out of 7. A total of 87.7% (100/114) of the parents indicated that they would use Picterus JP at home. Parents reported that they found the app easy, quick, and convenient, although 55.8% (67/120) reported a failure on the first try. Some parents struggled to find or interpret the instructions, but most of those who tried again (79/105, 75.2%) obtained a bilirubin estimate. Additionally, 12 nurses from 2 participating maternity wards provided their observations on parents' use of Picterus JP in 2 focus groups. Thematic analysis of all combined data identified 3 themes that were considered important for the usability of Picterus JP: intention to use Picterus JP, infant well-being, and instruction and guidance.

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Conclusions: Parents rated Picterus JP highly in terms of usability despite encountering difficulties during initial use. Technical improvements and more proactive guidance seem important to support successful parental use. Nonetheless, both parents and nurses were positive about the potential of Picterus JP for home screening for SNH.

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KEYWORDS

bilirubin screening; clinical decision support; digital health; hyperbilirubinemia; jaundice detection; mobile health; neonatal jaundice

Introduction

Neonatal jaundice, a yellowish discoloration of the skin and sclerae, occurs in the first days of life due to excessive levels of total serum bilirubin (TSB) [1]. Neonatal jaundice affects over 80% of neonates and is generally self-limiting [2]. However, in 4% to 9% of near-term neonates, treatment is necessary to prevent neonatal jaundice from progressing to severe neonatal hyperbilirubinemia (SNH) [3,4]. Undiagnosed and untreated SNH can lead to irreversible brain damage (ie, kernicterus). Kernicterus is a preventable condition that leads to sensorineural hearing loss, vertical gaze paralysis, dystonia, or more subtle forms of kernicterus spectrum disorders [5]. Therefore, within the large group of jaundiced infants, it is paramount to detect those who develop potentially dangerous levels of TSB.

The gold standard for diagnosing hyperbilirubinemia is quantification of TSB levels through blood sampling [6]. Screening via transcutaneous bilirubin (TcB) is a reliable method to facilitate early recognition of SNH, but the costly TcB devices are not accessible to everyone everywhere every day [7]. As such, visual inspection is widely used by health care professionals (HCPs) to assess the severity of jaundice, although this has shown to be unreliable and inaccurate [8,9].

In some countries, a predischarge TSB or TcB screening is performed to ensure appropriate follow-up of neonatal jaundice [4]. However, this often occurs before the physiological peak in TSB levels, which is typically around the fourth day of life. Other strategies encompass the use of risk factors to predict the risk of developing SNH [10-12]. However, HCP home visits are typically scheduled once or a few times during the first week of life but do not occur daily. As a result, jaundiced neonates may continue to develop SNH unnoticed, placing them at risk of kernicterus and the need for intensive treatment once diagnosed [13].

To support timely diagnosis and treatment, several novel devices to screen for SNH have been developed [7,14-18]. Only a subset of these approaches uses smartphone apps, allowing for bilirubin screening using widely available smartphones rather than dedicated devices.

One of these apps is the Picterus Jaundice Pro (JP), a mobile health (mHealth) app developed to estimate bilirubin levels noninvasively. Picterus JP showed high sensitivity (94%) in detecting SNH and has obtained European CE marking [19-21]. Parents increasingly use mHealth tools for monitoring in the neonatal period [22]. However, the usability of existing apps varies widely, and usability influences use in real-world settings [22,23]. By empowering parents to use the app at home, Picterus JP could facilitate frequent screening for imminent SNH at any time. However, parental experiences with Picterus JP remain largely unexplored.

Therefore, this study aimed to determine the usability and user-friendliness of Picterus JP when used and evaluated by parents.

Methods

Study Design

We evaluated the usability and user-friendliness of Picterus JP through a prospective mixed methods study using the validated mHealth App Usability Questionnaire (MAUQ), open-ended questions, interviews, and focus groups.

Setting and Participants

This study was part of the Jaundice@Home project conducted under the Transforming Health and Care Systems program (project number: 1477) [24]. Participants were recruited from 3 distinct real-world newborn care settings: the maternity wards of 2 hospitals in the Netherlands (Frisius Medical Center, Leeuwarden, and University Medical Center Groningen [UMCG]) and 1 in Israel (Shamir Medical Center). This study was initially conducted in the Netherlands from August 2023 to December 2023 (period 1) and extended to Israel from October 2024 to January 2025 (period 2). To ensure comparability, this study was also repeated at UMCG in the Netherlands in the second period.

Parents and/or caregivers were invited to participate if their neonates were healthy, with a gestational age of 35 or more weeks and between the age of 12 hours and 7 days. At least one parent was required to have sufficient proficiency in Dutch (in the Netherlands) or Arabic or Hebrew (in Israel).

Intervention

Parents were asked to use Picterus JP at least once during their hospital stay. Immediately afterward, parents completed a paper questionnaire about their experiences, which was collected within 24 hours. The app could only be used by parents during their hospital stay for practical and safety considerations. All participating neonates received standard care to ensure safe practice. This included visual inspection for signs of jaundice and TcB and/or TSB measurements as deemed necessary by the attending physicians or midwives. The use of the Picterus JP app did not affect standard care.

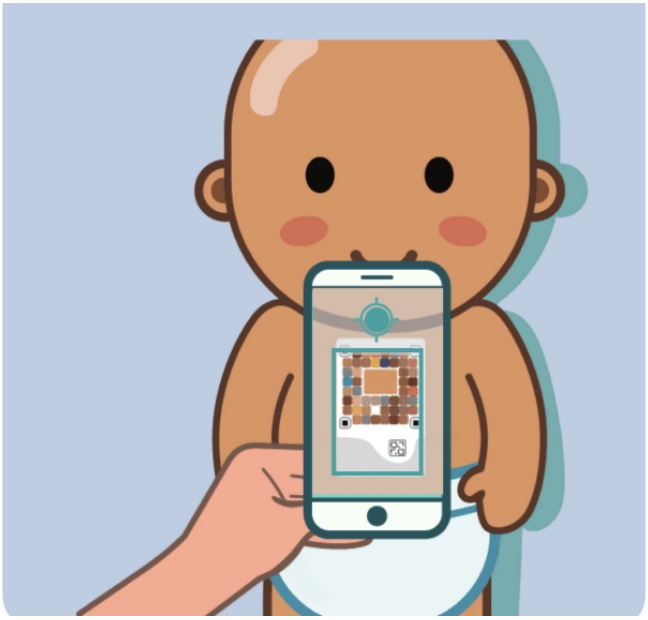
All parents received a Picterus calibration card, a download link, and the same instructions for using Picterus JP at their

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convenience. The instructions consisted of a brief verbal explanation; textual instructions (via the patient information letter or app); and pictograms, which were included in the app and printed out [25]. The study team did not provide explicit demonstrations or guidance before and during app use. Nurses received a demonstration of the app at the beginning of the study period. The study team and nurses were encouraged to leave the room while parents used the app but would sometimes remain as silent bystanders. Parents either installed the app on their own smartphones (the Netherlands) or used a Samsung Galaxy A50 smartphone provided by the researchers (Israel).

When starting Picterus JP, users were instructed to place the square, colorful Picterus calibration card on the infants' bare chest (Figure 1). Picterus JP then guided users on-screen on how to correctly position their smartphone (ie, angle and distance). Once the app detected that the conditions were appropriate (ie, correct placement of the calibration card and positioning of the smartphone and sufficient ambient light), it would then automatically proceed to take 6 photos: 3 with flash and 3 without.

Figure 1. Intended use of Picterus Jaundice Pro. Figure used with permission from Picterus AS.



After capturing the images, the app either displayed a bilirubin value (in µmol/L or mg/dL depending on the setting) or issued an error message. If an error occurred, the app either stated that the measurement was unsuccessful or, if possible, provided a reason (eg, insufficient ambient light or shadows rendering the photo unsuitable for analysis). During the photo-taking phase, the app attempted to correct suboptimal conditions by offering simple on-screen instructions to the user. If image quality remained insufficient, Picterus JP stopped the standard 6-image count and either continued attempting automatic image capture or temporarily paused image capture. Image counting resumed only once image quality improved following user adjustment. If adequate image quality could not be achieved, the measurement attempt was eventually aborted and an error message was displayed, when available.

Data Collection

Quantitative Data Collection

The MAUQ was used to evaluate Picterus JP usability. This is a validated instrument specifically designed to evaluate the usability of mHealth apps [26].

The MAUQ consists of 18 statements divided into 3 subscales: ease of use, interface and satisfaction, and usefulness (Table S1 in Multimedia Appendix 1). One statement (number 17) from the original MAUQ version was omitted because it assessed offline functionality, which did not apply. The MAUQ was scored from 1 ("strongly disagree") to 7 ("strongly agree") on statements in favor of the device. Statements were translated from English into Arabic, Dutch, and Hebrew and verified via independent back translation.

Qualitative Data Collection

All parents were asked to answer 4 open-ended questions about their experiences with the app to elaborate on topics such as their general experience, child comfort, and possible malfunctioning of the app and provide additional comments.

Semistructured interviews and focus groups were conducted using a topic list covering 4 categories: general experience, instruction and guidance, possible app malfunctions, and perceived future use and suggestions for improvement. The topics encompassed 2 to 5 questions that the researcher could use to elicit further responses if participants provided limited information. The topic list can be found in Multimedia Appendix 2.

A subset of 5 participants per center was invited to take part in the semistructured interviews at the midpoint of the study period. Participants were initially approached consecutively at that time point. After the first 2 interviews, additional participants were selected to ensure representation across a broad range of MAUQ scores. The interviews lasted between 5 and 15 minutes and were conducted either in person or over the phone by local members of the study team. The interviews were generally audio

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recorded and transcribed, whereas phone interviews were documented through detailed notes. Data saturation was considered to have been reached when no new codes or themes emerged from the available data.

Registered nurses in the Netherlands were invited to share their observations in focus groups held at the end of a regular work shift near the end of the study period. The number of focus groups was determined pragmatically rather than through data saturation: one in each center where nurses had observed parents using Picterus JP. Focus groups were led by 2 researchers (FT and TdV) and were recorded and transcribed. Each session lasted between 15 and 25 minutes.

Definition of Participant Characteristic Variables

Parental educational level was classified into three categories according to the self-reported highest level attained: (1) basic education (elementary school), (2) intermediate education (high school and vocational training), and (3) advanced education (college or university degree).

Postnatal age was recorded in 24-hour intervals (eg, 24-48 hours and 48-72 hours) based on the time of birth. Daily check-ins were conducted by the study team to confirm whether parents had used the app within the previous 24 hours. Exact age in hours was not documented. Infants younger than 12 hours were not enrolled due to the informed consent reflection period.

Additional demographic and clinical variables collected from infants and parents were neonatal sex, birth weight, gestational age, maternal parity, and country and hospital of recruitment. These variables were collected as per standard clinical documentation.

Limited information on health care providers was collected, including age, years of work experience, and the number of times they observed the use of the app.

Ethical Considerations

This study was conducted in accordance with the Declaration of Helsinki. In the Netherlands, the study was approved by the Central Ethical Review Committee of UMCG (research register number 10763). This study was classified as falling outside the scope of the Medical Research Involving Human Subjects Act. Local feasibility was confirmed by the Regional Ethics Review Committee at Frisius Medical Center (reference: RTPO 1160). In Israel, the study was approved by Shamir Medical Center Helsinki Committee (approval number 264-23-ASF). Informed consent was obtained from the parents of all participating neonates.

Data Analysis

Sample Size

A convenience sample of 120 participants was targeted across 2 study periods, with 30 participants per participating center in each period. This sample size was chosen to ensure sufficient variation in user experiences for a usability study while remaining feasible within the available study duration and recruitment capacity of the participating sites. No formal power calculation was applicable as this study did not aim to detect statistical differences but to explore usability and user perceptions.

Quantitative Data Analysis

The Likert-scale data of the MAUQ were summarized using medians and IQRs given the skewed data distribution as visually assessed via histograms. Other categorical data were represented as relative distribution (frequencies and percentages) per item. Demographic variables were assessed for normality and reported as means with SDs, medians with IQRs, or ranges depending on distribution. No formal hypothesis testing was performed; all analyses were descriptive. Microsoft Excel and SPSS Statistics for Windows (version 28; IBM Corp) were used for all analyses.

Qualitative Data Analysis

Qualitative data from focus groups, in-depth interviews, and the 4 open-ended survey questions were analyzed and systematically coded using thematic analysis [27]. Participant responses were summarized as codes (ie, keywords). Codes with similar meanings were grouped into overarching topics. These topics were either facilitators of or barriers to the use of Picterus JP.

Topics (ie, barriers and facilitators) were subsequently organized into themes. These themes could follow the structure of the open-ended questions (deductive) or emerge from the data themselves (inductive). This approach allowed for a comprehensive and integrated analysis of all qualitative sources.

Coding was independently performed by country by local researchers. Additionally, one author (FT) coded all datasets of both countries to ensure consistency across contexts and maintained a manual codebook in Microsoft Excel that was iteratively refined. Another author (TdV) reviewed a sample of the coded data and confirmed agreement with the chosen topics and thematic structure.

Quantitative MAUQ results are presented first, followed by qualitative findings that provide additional context to these results.

Results

Participants

In total, 123 parents completed the MAUQ and open-ended questions. Table 1 shows participant characteristics. The sample included both first-time and experienced parents, with a relatively high proportion (78/123, 63.4%) of participating parents having completed higher education. In total, 16 parents were approached for in-depth interviews: 12 (75%) participated after 2 reminders across the 3 centers. Data saturation was reached after approximately 5 interviews.

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Table 1. Participant characteristics: neonate and parent dyads.

Variable	The Netherlands (n=93)	Israel (n=30)
Hospitals, n	2	1
Parents per period, n (%)		
2023	62 (66.7)	0 (0)
2024 and 2025	31 (33.3)	30 (100)
Interviews with parents, n	6	6
Gestational age (wk), median (IQR)	39 (38-40)	39 (38-40)
Postnatal age category (h), most common category (range of reported ages)	24-48 (12-144)	24-48 (12-120)
Birth weight (g), mean (SD)	3466 (570)	3552 (339)
Female sex, n (%)	44 (47.3)	14 (46.7)
Maternal parity, n (%)		
First	14 (15.1)	11 (36.7)
Second	48 (51.6)	7 (23.3)
Third or higher	31 (33.3)	12 (40)
Parent educational level, n (%)		
Basic education	1 (1.1)	0 (0)
Intermediate education	25 (26.9)	4 (13.3)
Advanced education	56 (60.2)	22 (73.3)
Unknown	11 (11.8)	4 (13.3)

The 2 focus groups included 12 nurses, all Dutch and female. Nurses had sometimes observed when parents used the app as they had been caring for mother and infant or had heard parents discuss app use afterward. Table 2 shows nurse characteristics. Overall, the nurses were relatively young and had few years of work experience.

Table 2. Characteristics of the registered nurses who participated in 1 of the 2 focus groups.

Variable	Focus group 1 (n=5)	Focus group 2 (n=7)
Location	Frisius Medical Center, Leeuwarden, the Netherlands	University Medical Center Groningen, the Netherlands
Female sex, n (%)	5 (100)	7 (100)
Age (y), median (IQR)	24 (24-26)	27 (23-34)
Work experience (y), median (range)	0.5 (0.3-15)	5 (0-12.5)
Frequency of witnessing Picterus app being used by parents, n		
1 time	1	4
1-5 times	2	3
5-10 times	1	0
≥10 times	1	0

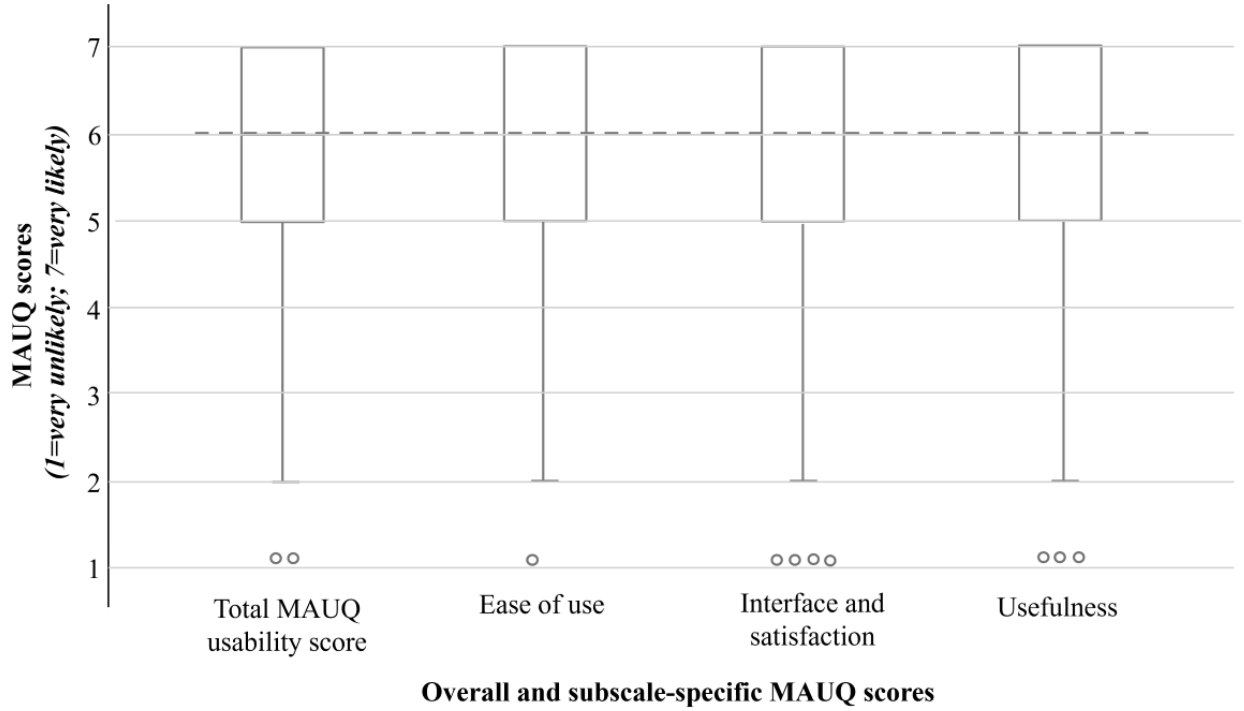
Quantitative Usability: MAUQ

Figure 2 shows the median MAUQ usability score of 6 (IQR 5-7) on a scale from 1 to 7 on the MAUQ. Similarly, the median scores for the subscales of ease of use, interface and satisfaction, and usefulness were 6 (IQR 5-7). There were no differences in overall median MAUQ scores or MAUQ scores per subscale between the 2 countries, among the 3 hospitals, or between both study periods.

Parents expressed the most positive attitudes toward the statements that Picterus JP was easy to learn and improved their access to health care, with a median MAUQ score of 7 (IQR 6-7). All other statements had a median MAUQ score of 6. Table S1 in Multimedia Appendix 1 shows all 17 MAUQ statements and their corresponding median scores.

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Figure 2. Total parental mHealth App Usability Questionnaire (MAUQ) scores and scores on the 3 subscales. The median is marked by the horizontal dotted line. The boxes are limited by the 25th and 75th percentiles. The whiskers (⊥) represent the lowest and highest irradiance within 1.5 times the interquartile distance below the box. Extreme outliers (◯) indicate participants who gave the lowest possible rating (ie, a score of 1) on the statements.



Qualitative Usability: Thematic Analysis

Themes, Facilitators, and Barriers

Table 3 shows the results of the thematic analysis. Three themes were identified: "intention to use Picterus JP," "neonatal well-being," and "guidance and instructions." The first 2 themes were deductive, corresponding to 2 open-ended questions, whereas the last theme was inductive and emerged from the interviews and focus groups but was also supported by the responses to the open-ended survey questions. Within these themes, 13 facilitators and 10 barriers were identified.

Table 3. Facilitators of and barriers to using the Picterus Jaundice Pro (JP) app: insights from parents and nurses[a].

Theme	Facilitators	Barriers
Intention to use Picterus JP	• Easy and simple to use (P[b], I[c], and N[d]) • Home access (P and I) • Feeling in control (P, I, and N) • Reassuring for extra monitoring (P and I)	• Difficulties obtaining measurements (P, I, and N) • Doubts about relevance (I and N) • Doubts about reliability (P and I) • Reminders needed (I and N)
Infant well-being[e]	• Quick (P and N) • Comfortable (P) • Safe (P) • Minimally intrusive (P) • Usable at own convenience (P and I)	• Prolonged undress (P and I) • Neonate too upset (P and I) • Camera flash (P and I)
Guidance and instructions	• Easy to understand (P, I, and N) • Self-explanatory (P, I, and N) • Quick to explain (P and N) • In-person explanation (I and N)	• Unclear for parents what to do when a problem occurs (P, I, and N) • Uncertainty among parents regarding what to do with results (P, I, and N) • In-app guidance easy to miss (P, I, and N)

[a]This table presents perceived topics divided into either facilitators of or barriers to using the Picterus JP app. Topics were grouped into 3 themes. Within themes, topics were ordered from most to least frequently mentioned.

[b]P: parents (responses from the survey; n=123).

[c]I: interviewed parents (n=12).

[d]N: nurses who participated in the focus groups (n=12).

[e]The theme "infant well-being" reflected factors related to the infant's comfort and safety as perceived by parents but did not indicate actual clinical risk that was reported during the study.

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Open-Ended Questionnaire Responses From Parents

Table 4 presents the 4 open-ended questions for parents. A total of 87.7% (100/114) of the parents responded affirmatively to the first question ("Would you use the app?"). For the second question, 81.7% (98/120) of the parents reported no concerns about their infants' comfort while using the app. A common facilitator in both questions was that Picterus JP was "easy, simple, and quick to use." Common barriers included difficulty obtaining a valid measurement and specific concerns about their baby, particularly when using the app took longer than expected. Parents worried that prolonged undressing might result in hypothermia or cause the neonate to become upset. Of the 22 parents who expressed concerns, 20 (87%) reported having encountered difficulties using the app.

Table 4. Open-ended questions[a].

Question	Yes, n (%)	No, n (%)
Would you use the app? (n=114)	100 (87.7)	14 (12.3)
Concerned about neonates comfort? (n=120)	22 (18.3)	98 (81.7)
Did you encounter any difficulties using the app? (n=120)	67 (55.8)	53 (44.2)
Do you have any other comments? (n=123)	50 (40.7)	73 (59.3)

[a]Missing data were excluded from the analysis.

For the third question ("Did you encounter any difficulties using the app?"), 55.8% (67/120) of the parents reported having experienced an issue. Textbox 1 shows the reasons for difficulties, which varied between study periods and countries and were either device-related or user-related issues. Device-related difficulties referred to issues in which parents reported having received an error message. For example, when the photo quality was insufficient for analysis, Picterus JP could display a message such as "ambient light insufficient" or "difficulty focusing."

Textbox 1. Parental difficulties when using the Picterus Jaundice Pro app for the first time organized from most to least frequent.

Device-related difficulties

- Issue with focusing and/or ambient light
- Miscellaneous error messages (ie, freezing or calibration card not recognized)
- Unknown error
- Phone not compatible

User-related difficulties

- Baby factors (ie, upset or moving)
- Finding the instructions unclear
- Using the calibration card incorrectly
- Miscellaneous parental factors (ie, hand tremors)

User-related difficulties included cases in which the infant was too "uncooperative" to obtain sufficient photos or parents acknowledged incorrect use of Picterus JP (eg, displacing the calibration card).

During the first study period in the Netherlands (2023), 58.1% (36/62) of the parents primarily encountered device-related difficulties for various reasons. During the second period in the Netherlands (2024), 32.3% (10/31) of the parents reported difficulties, which were primarily user related, whereas in Israel (2025), 76.7% (23/30) of the parents reported difficulties, and these were mostly device related. In Israel, 30.4% (7/23) of these parents indicated an issue in which ambient light was insufficient. Multiple attempts were made to improve ambient light. Retrospective analysis of these photos indicated that the issues in these cases were often related to the quality of the camera and the saved file format of the specific phone model being used.

Of the 105 parents who attempted the measurement again, even though this was not required within the scope of the study, 79 (75.2%) reported that they were able to obtain a bilirubin estimate. Similarly, 70% (21/30) of the Israeli parents reported a successful measurement after further attempts.

The fourth question ("Do you have any additional comments?") resulted in 50 responses that were integrated into the thematic analysis (Table 3). Some comments addressed misunderstandings and suggestions regarding the instructions and in-app guidance (ie, correct use of the calibration card), whereas others expressed uncertainty about interpreting the results. Additionally, satisfaction with Picterus JP was expressed. All emerging topics were closely aligned with findings from the other survey questions, interviews, and focus groups.

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Findings From Focus Groups With Nurses and Interviews With Parents

Because themes and topics overlapped, results from parents and nurses are presented together. The identified topics in focus groups with nurses and in-depth interviews with parents supported and further contextualized the topics previously reported by parents in the questionnaires. This led to the identification of 3 additional topics (Table 3).

An additional identified facilitator was the perceived value of receiving an in-person explanation or demonstration of the app. There were 2 additional barriers. First, parents needed reminders to use the Picterus JP app. Another issue was that in-app guidance could easily be missed, which delayed or disrupted the process. All 3 of these topics were mentioned by both nurses and parents. Table S1 in Multimedia Appendix 3 presents supporting quotes from nurses.

Theme 1: Intention to Use Picterus JP

Consistent with questionnaire findings, ease of use was frequently mentioned as a facilitator by parents and nurses (quote 1: Multimedia Appendix 3). However, more unique to this part of the data collection, both nurses and parents noted that reminders to use Picterus JP were often necessary (quote 2).

Parents appreciated the ability to monitor their neonate for jaundice themselves but questioned its added relevance alongside regular health care visits. Parents stated that it had to be very clear for them what they had to do with the results. In the interviews, they emphasized the need for clear guidance. Nurses acknowledged the relevance as well, noting that their clinical experience and recognition of early signs of jaundice served as important reminders for parents (quote 3).

Theme 2: Neonatal Well-Being

Similarly to the answers from parents, nurses mentioned that taking a photo using Picterus JP was perceived as quick and nondistressing for the neonate. Similarly to the questionnaire, parents expressed a preference for additional warnings about the camera flash to remind them to cover their neonates' eyes (quote 4). Nurses expressed no concerns about infant well-being during the use of Picterus JP when asked about disadvantages or improvements that could be made.

Theme 3: User Guidance and Instructions

User guidance and instructions were most prominently discussed during interviews and focus groups. Oral explanations were preferred over written instructions even though, in general, the latter were considered clear (quote 5). Nurses found the instructions easy to explain, and often parents agreed that understanding what to do was straightforward (quote 6).

Interestingly, as was often reported in the survey and also shown in Textbox 1, when parents were unsuccessful in obtaining a measurement, it was not always clear to them what had gone wrong (quote 7). Some parents admitted in hindsight that they had not fully paid attention to the in-app guidance or that they had misunderstood the instructions (quote 8). Some nurses reported that, at times, they were unsure why a measurement had failed. In contrast, other nurses stated that the cause of failure was often clear to them as observers, whereas parents appeared to have overlooked the in-app guidance (quote 9).

Overall, nurses in the focus groups were positive about the potential parental use of Picterus JP in the home setting (quote 10).

Discussion

Principal Results

We determined how parents perceived the usability and user-friendliness of Picterus JP, a novel smartphone app to allow for early detection of imminent SNH. Our results show that parents rated Picterus JP highly on usability, supported by a median MAUQ score of 6 (IQR 5-7) out of 7. Parents described Picterus JP as easy, simple, and quick to use.

A considerable number of parents reported either technical difficulties or movement of their baby as reasons for failing to obtain a result on the first use of Picterus JP.

Technical difficulties reported by users may be partly explained by the variation in smartphone devices used across study sites despite the fact that these devices passed Picterus JP's compatibility check. However, some phones (eg, budget models) may still be more sensitive to ambient lighting conditions. In Israel, all parents used the same midrange phone provided by the study team, whereas in the Netherlands, varied personal devices were used. This difference may explain the lower incidence of technical difficulties in the Netherlands than in Israel. Furthermore, within the Dutch sites, technical difficulties decreased in the second study period, possibly due to ongoing software improvements of Picterus JP.

In addition to technical difficulties, some parents (22/120, 18.3%) expressed concerns regarding neonatal well-being during app use. Frequent topics were concerns about the infant becoming cold or upset. Most of these parents (20/23, 87%) reported having encountered difficulty using Picterus JP on their first attempt. This may suggest a possible connection between prolonged attempts and parental concerns, but this was not formally studied.

Although parents and nurses found the Picterus JP instructions clear, they reported that instructions could be overlooked or misunderstood. It is possible that, in some cases, unsuccessful attempts were related to skipped or misunderstood instructions rather than technical failure alone. Picterus JP offers multiple instructions: symbols on calibration cards and the app launch screen, online text, and in-app pop-ups. It is tempting to speculate that passive instructional methods may not fully support parents in busy postpartum settings.

Nonetheless, most parents (100/114, 87.7%), even among those who encountered technical difficulties or had concerns, stated that they would use the app at home. This implies that, despite initial barriers, overall acceptability and perceived usefulness of Picterus JP in a home setting are high, which are both essential prerequisites for its implementation. Given the near-universal smartphone use in our study population, eventual barriers to implementation are unlikely to stem from limited access to or lack of experience with smartphones [28].

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Notably, the nurses participating in focus groups were young and had limited work experience, reflecting the composition of junior and senior staff typically present during shifts. Demographic characteristics, with younger nurses potentially being more technologically savvy, may influence generalizability but also improve comparability with similarly aged parents.

Nevertheless, all nurses had experience with SNH screening and regarded Picterus JP as relevant and useful. They emphasized that parents engaged more with Picterus JP when its relevance was clear to them too. Moreover, insights from nurses helped contextualize parental responses as they frequently observed parents during the use of Picterus JP. This underlines the importance of incorporating multiple perspectives in usability studies.

Comparison With Prior Work

While many SNH screening applications have been developed over the years, our findings align with broader digital health literature showing that the main challenges of home-based screening tools lie in usability [29]. Despite the widely recognized need for accessible screening tools to detect SNH, still few clinically validated alternatives currently exist. Although noninvasive screening can be performed using TcB devices, these devices are rather costly and currently not available in home settings [7]. To save costs, 2-color and multicolor icterometers (ie, the BiliStrip and Bili-Ruler, respectively) have been developed with rather acceptable screening performances and interrater reliability [14,17]. In parallel with these icterometers, other smartphone apps to optically estimate hyperbilirubinemia have been developed and studied over the past years [7,15,16]. Except for Picterus JP, to our knowledge, none have currently published usability results or reached a clinical implementation phase and obtained a CE mark or Food and Drug Administration certification.

Our findings on the usability of Picterus JP are consistent with those of the 2 prior studies to date in which the use of Picterus JP was assessed by HCPs. HCPs perceived Picterus JP as an easy-to-use, useful, and time-saving tool in the management of neonatal jaundice [30,31]. Our study builds on previous work by including the perspectives of both HCPs and parents in high-income countries.

Usability studies are a relevant step for implementation given that apps that are considered easy to use have yielded higher acceptability and satisfaction ratings [32]. However, studies linking app usability to clinical outcomes in pediatrics remain scarce and are mainly focused on chronic disease management [33,34]. The MAUQ is a validated and reliable instrument specifically developed to evaluate mHealth apps used by patients and HCPs, unlike more general instruments such as the System Usability Scale and the Post-Study System Usability Questionnaire [26].

The MAUQ has increasingly been adopted in recent years and used for studies across diverse health care settings worldwide [35]. High MAUQ scores have been associated with proper test performance in another mHealth screening app [36] This suggests that high usability scores as measured using the MAUQ could be a relevant indicator for evaluating the feasibility of successful implementation of a screening mHealth tool such as Picterus JP.

Limitations

This study has several limitations. First, we used convenience sampling, which may limit representativeness, although saturation was observed in the open-ended responses, interviews, and focus groups. The design may have led to selection bias: participants were motivated to take part, comfortable with smartphone use, less frequently first-time parents, and noticeably highly educated on average. We did not observe a clear association between educational level and MAUQ score or between educational level and parental experience (ie, failure to obtain a measurement). This does not eliminate the concern that less technologically savvy or lower-literacy parents may have been systematically underrepresented. Future studies should, therefore, specifically evaluate usability and feasibility in more diverse populations and care settings, including lower-income countries.

Second, the observational nature of our study design limited us to reporting descriptive findings rather than statistical cross-site comparisons or adjusting for potential confounders.

Third, MAUQ scores were generally high (median 6, IQR 5-7 on a 7-point scale) but with no complete concentration at the maximum score, suggesting no clear evidence of a ceiling effect.

Finally, the app was typically used for only 1 measurement in a hospital setting, with limited instruction with the purpose of generalizing the outcomes. One in-hospital measurement with either the study team or an HCP nearby may introduce performance bias and limit ecological validity. Although the study team was not always directly present during measurements, the potential influence of supervision was not systematically assessed. It is important to note that, in real-world settings, parents are also likely to use the app in interaction with HCPs such as maternity care assistants, who provide daily postpartum care in the Netherlands, or during telehealth consultations. The intended repeated daily use of Picterus JP in variable settings might influence user experience differently. Although repeated use might expose the user to other user- and device-related difficulties, familiarity through guidance and practice may also enhance perceived parental usability of the app.

Strengths

To the best of our knowledge, this is the first study to assess the usability of a smartphone-based bilirubin screening tool from the perspective of both parents and HCPs. Furthermore, the multicenter and multicultural setting spanning 2 countries and 3 hospitals adds to the potential generalizability of the results to different health and care systems as similar usability patterns emerged across diverse user groups. In addition, we used a validated instrument (MAUQ) to evaluate usability, which enhances the reliability and comparability of our findings.

Conclusions

Our findings show that parents and nurses highly appreciated the Picterus JP app despite some device- and user-related

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difficulties. Our findings highlight the importance of ongoing technological improvements, clear user guidance, and proactive support to improve usability and user experience to successfully facilitate the implementation of parental use of Picterus JP in neonatal jaundice management.

If future studies confirm the clinical accuracy and reliability of parental use of Picterus JP in different populations and health and care systems, daily noninvasive home screening could become feasible. As such, the use of Picterus JP may enable earlier detection of imminent SNH, allowing for timely intervention for at-risk neonates, reducing the emotional and logistical burden on families, and supporting clinical decision-making by HCPs.

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Data Availability

The datasets generated and analyzed during this study are not publicly available due to participant privacy and ethical restrictions but are available from the corresponding author on reasonable request. Data can be shared in fully anonymized form for noncommercial research purposes.

Authors' Contributions

Conceptualization: FT, TdV, PD, CH
Data curation: FT, AH, EK
Formal analysis: FT, AH, EK
Investigation: FT, AH, EK
Methodology: FT, TdV, PD, CH
Project administration: FT
Supervision: TdV, PD, CH
Validation: TdV, CH
Visualization: FT
Writing—original draft: FT
Writing—review and editing: FT, AH, EK, MB, TdV, JB, PD, CH
All authors contributed to the interpretation of the findings and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Statements and results of the mHealth App Usability Questionnaire.
[DOCX File , 17 KB - pediatrics_v9i1e83077_app1.docx]

Multimedia Appendix 2
The topic list used for interviews and focus groups.
[DOCX File , 18 KB - pediatrics_v9i1e83077_app2.docx]

Multimedia Appendix 3
Quotes from interviews and focus groups.
[DOCX File , 15 KB - pediatrics_v9i1e83077_app3.docx]

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Abbreviations

HCP: health care professional
JP: Jaundice Pro
MAUQ: mHealth App Usability Questionnaire
mHealth: mobile health
SNH: severe neonatal hyperbilirubinemia
TcB: transcutaneous bilirubin
TSB: total serum bilirubin
UMCG: University Medical Center Groningen

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Agreement and Screening Performance of an App-Based Cranial Shape Assessment Tool Compared With a 3D Scanner in Municipal Child Health Checkups in Japan: Instrument Validation Study

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Abstract

Background: Positional cranial deformities are common in infancy. Smartphone-based apps are increasingly used to assess infant head shape, but evidence comparing these tools with 3D scanners across age groups in community-based settings remains limited.

Objective: This study evaluated age-stratified agreement and screening performance of a mobile app for estimating Cranial Vault Asymmetry Index (CVAI) and Cephalic Index, compared with a 3D scanner, when used by a trained examiner during routine municipal health checkups in Japan.

Methods: We conducted a cross-sectional study in Goto City, Japan, between May 2023 and March 2025. Independent, age-specific cohorts of children attending municipal health checkups at 4, 18, and 42 months were included. Paired cranial measurements were obtained by a trained examiner using a VECTRA H2 3D scanner (Canfield Scientific Inc) and the mobile app. Agreement was assessed using mean differences, 95% limits of agreement (LoA), and intraclass correlation coefficients (ICCs), with device-stratified sensitivity analyses. Screening performance was evaluated using sensitivity and specificity based on prespecified clinical thresholds. Receiver operating characteristic (ROC) analyses were secondary exploratory analyses. The primary outcome was app-based CVAI for detecting scanner-defined moderate-or-worse plagiocephaly (CVAI≥7%). Secondary outcomes were app-based Cephalic Index for detecting brachycephaly (Cephalic Index>94%) and dolichocephaly (Cephalic Index<79%).

Results: The final analytic samples comprised 262 children at 4 months, 171 at 18 months, and 216 at 42 months. Agreement for continuous CVAI was highest at 4 months (mean difference 0.14, 95% LoA −4.18 to 4.46; ICC 0.76, 95% CI 0.71 - 0.81) and lower at 18 months (ICC 0.42, 95% CI 0.29 - 0.54) and 42 months (ICC 0.49, 95% CI 0.38 - 0.59). For Cephalic Index, the app consistently overestimated values relative to the scanner, with mean differences of 3.83 SD 3.42, 3.24 SD 3.07, and 2.61 SD 3.33 points at 4, 18, and 42 months, respectively. For detecting scanner-defined moderate-or-worse plagiocephaly, app sensitivity and specificity were 84.8% and 88.0% at 4 months, 50.0% and 88.4% at 18 months, and 53.3% and 89.6% at 42 months, respectively. Device-stratified analyses showed some variation in measurement agreement and screening performance across devices.

Conclusions: Under municipal health checkup conditions with a trained examiner, app-based CVAI showed the strongest performance at 4 months and may be useful for early screening. However, performance was weaker at 18 and 42 months. App-based Cephalic Index was systematically higher than scanner-based Cephalic Index, potentially increasing false-positive classifications for brachycephaly when identical thresholds are applied. Performance varied somewhat between devices, although device effects

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could not be separated from study period and accumulated examiner experience. Positive findings, particularly at later ages or for Cephalic Index–based measures, should be interpreted in the context of the child's age and broader clinical findings, with further evaluation or referral considered only when clinically indicated.

Trial Registration: UMIN Clinical Trials Registry UMIN000052342; https://center6.umin.ac.jp/cgi-open-bin/ctr_e/ctr_his_list.cgi?recptno=R000059748

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KEYWORDS

plagiocephaly; infants; mobile apps; 3D imaging; cranial vault asymmetry index; cephalic index; screening performance; reproducibility; sensitivity; specificity

Introduction

Positional cranial deformities, including plagiocephaly, brachycephaly, and dolichocephaly, are common conditions observed during infancy. Although some cases may resolve spontaneously over time, moderate-to-severe deformities may warrant early evaluation and, when appropriate, timely consideration of cranial orthotic therapy within a critical age window during which treatment effectiveness is expected to be greater [1-3]. In Japan, parental awareness and concern regarding infant head deformities have increased, and the number of head-shape consultations has risen in recent years [4,5]. In this context, the availability of accessible and reliable tools to support timely assessment and appropriate referral decisions has become increasingly important.

Cranial shape is commonly quantified using standardized indices. For plagiocephaly, the Cranial Vault Asymmetry Index (CVAI) is widely used to quantify cranial asymmetry, whereas the Cephalic Index is used to describe head width-to-length proportions relevant to the classification of brachycephaly and dolichocephaly. In Japan, threshold-based classification systems derived from these indices are routinely applied in clinical and community settings, including the identification of moderate-or-worse deformities that may prompt specialist referral or closer clinical follow-up [6,7]. However, the application of index-based thresholds depends on the availability of measurements that demonstrate sufficient reliability and consistency under real-world conditions, particularly in nonspecialist, community-based settings.

Smartphone- and tablet-based apps that estimate cranial indices from photographs are increasingly available and widely accessible. Such apps have the potential to serve as practical screening tools; however, their accuracy may be influenced by real-world image capture conditions and may vary across different age groups [8-10]. 3D scanners are generally regarded as the reference standard for cranial shape assessment, as they reconstruct head morphology in three dimensions and derive indices in a standardized and reproducible manner [7]. Nevertheless, empirical evidence directly comparing app-based measurements with 3D scanner-derived indices in real-world populations of infants and young children—particularly across different ages and within community-based settings—remains limited.

In Japan, municipal child health checkups provide a near-universal platform for early childhood health assessment and monitoring. The 18-month checkup and the checkup for children aged 3 years to younger 4 years are mandated by law, and a 3 - to 5-month infant checkup is also widely implemented across municipalities. Recent national data indicate attendance rates of approximately 96% for the 3 - to 5-month, 18-month, and 3-year checkups [11]. Accordingly, these settings provide opportunities not only for early identification of cranial deformities during infancy but also for follow-up, parental reassurance, and guidance regarding residual head shape asymmetry in early childhood.

Therefore, this study aimed to evaluate whether this mobile app could serve as a practical screening aid under municipal health checkup conditions by (1) quantifying age-stratified agreement in continuous CVAI and Cephalic Index measurements between a 3D scanner and the mobile app and (2) assessing its screening performance relative to 3D-scanner–based reference classifications for deformational plagiocephaly, brachycephaly, and dolichocephaly.

Methods

Study Design and Setting

This cross-sectional study included infants and young children attending municipal health checkups in Goto City, Nagasaki Prefecture, Japan. The 4-, 18-, and 42-month assessments were treated as independent cross-sectional samples, with no child contributing to more than one age group. A formal a priori sample size calculation for diagnostic accuracy estimates was not conducted because all eligible participants attending the age-specific checkups during the study period were targeted for enrollment.

All measurements were obtained within routine municipal health checkup workflows under standardized conditions. The 4-month checkups were conducted at the obstetrics and gynecology outpatient clinic of Goto Central Hospital, whereas the 18- and 42-month checkups were conducted at the Fukue Comprehensive Welfare and Health Center. Reporting was guided by the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) statement for observational studies and the STARD (Standards for Reporting Diagnostic Accuracy Studies) 2015 guideline [12,13]. Completed checklists are provided in Checklist 1 (STROBE checklist) and Checklist 2 (STARD checklist).

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Participants

Eligible participants were infants and young children, along with their parents or guardians, who attended the 4-, 18-, or 42-month municipal health checkups organized by Goto City between May 2023 and March 2025. Children were excluded if they had a diagnosed congenital cranial disorder or an obvious structural abnormality (eg, craniosynostosis).

These age-specific municipal health checkups have high population coverage, with nearly all eligible children in the target age groups attending. After routine clinical examination and anthropometric measurements, a research nurse or midwife approached parents or guardians to invite participation and obtained written informed consent prior to study-specific measurements.

Data Collection Procedures

Parents or guardians completed a self-administered questionnaire on obstetric history, the child's medical history, and daily positioning and care practices. Additional variables collected for descriptive and comparative purposes included the child's sex, mode of delivery, gestational age at birth, birth weight, and anthropometric measurements at the time of the health checkup (ie, weight, length or height [as appropriate], and head circumference), as well as the presence of muscular torticollis or limitation of hip abduction as assessed by physicians and documented in health checkup records. Information on birth-related and anthropometric variables was extracted from the Maternal and Child Health Handbook and health checkup records. The handbook is a nationally standardized, home-based record system used in Japan to document pregnancy, birth, and child health information, and is routinely referenced during municipal health checkups [14-16].

Cranial measurements were performed after fitting a standardized measurement cap and were obtained using both the mobile app and the 3D scanner during the same visit. All measurements were performed by a trained examiner following a predefined protocol. To minimize burden on children and parents and disruption to routine health checkup procedures, measurements were performed as efficiently as possible and were omitted if the child was excessively distressed or uncooperative.

Reference Standard: 3D Scanner

3D scanners are widely used as the clinical reference method for quantitative cranial shape assessment; however, they do not represent a pathological gold standard independent of measurement. We used the VECTRA H2 3D scanner (Canfield Scientific Inc), which has been used clinically for cranial shape assessment [17,18]. Each child wore a dedicated grid-pattern measurement cap to reduce interference from hair and facilitate 3D surface reconstruction. Children aged 4 and 18 months were imaged while seated on their caregiver's lap, whereas children aged 42 months were seated in a chair. Imaging was conducted by a single trained examiner with assistance from one staff member. All scans were performed throughout the study period by the same examiner, who received prestudy training using a head model.

Cranial images were captured from 7 directions for construction of a 3D cranial model. Subsequent processing and quantitative analysis of the 3D scanner data were performed by Japan Medical Company (JPMC) technical staff according to previously reported methods [7,19,20]. 3D image reconstruction was performed primarily using dedicated software, with manual refinement by technical staff as needed. Subsequent procedures included definition of measurement planes and landmarks, measurement of cranial dimensions, calculation of CVAI and Cephalic Index, and severity classification. A reference plane (0th slice) was defined by connecting the lowest point of the nasal root (ie, the sellion) and the bilateral tragion points, after which the cranium was divided into 10 equal horizontal slices, with the vertex corresponding to the 10th slice. The third slice from the reference plane was used for quantitative analysis. Cranial asymmetry (CA, mm), CVAI using the shorter diagonal as the denominator (CVAI(S), where S indicates the shorter diagonal; %), and Cephalic Index (%) were derived at this slice. CA was defined as the absolute difference between the lengths of the two 30° diagonal lines across the midline. CVAI(S) was calculated as the difference in diagonal lengths divided by the shorter diagonal, expressed as a percentage. Hereafter, CVAI(S) is referred to as CVAI. Cephalic Index was calculated as biparietal width divided by anteroposterior length, expressed as a percentage. Scanner-derived CVAI and Cephalic Index were used as the reference-standard measures for agreement and screening performance analyses.

Index Test: Mobile App

The index test was the "Akachan no Atama no Katachi SOKUTEI (Measurement of Baby's Head Shape)" mobile app, developed by JPMC as a nonmedical, smartphone- or tablet-based tool for assessing infant cranial shape for screening purposes. The app was installed on dedicated tablets. Images captured from May 22, 2023, to June 24, 2024, were obtained using an Apple iPad (sixth generation; iOS 17.5.1), whereas images captured from June 25, 2024, to March 31, 2025, were obtained using a Lenovo Tab M10 Plus (third generation; TB125FU; Android 13). The device change was not preplanned and occurred because the in-app camera function could no longer be launched on the original iPad. The Lenovo tablet was selected as the next available device confirmed to be compatible with the app. For the main analyses, data from both device periods were pooled to evaluate overall performance across the municipal screening program; device-stratified analyses were conducted as sensitivity analyses.

Although the app is intended for use by parents or caregivers as well as health care professionals, all image capture, landmark identification, and contour tracing in this study were performed by a single trained examiner. App-based measurements were performed after 3D scanning by the same examiner using the same measurement cap and positioning, with minimal delay between measurements. The vertex image of the child's head was captured using the tablet's built-in camera. The examiner premarked the positions of both ears and the nose on the measurement cap and, after image capture, identified these landmarks on the two-dimensional image and manually traced the cranial contour according to the in-app instructions (Multimedia Appendix 1). The app outputs 2 indices:

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"Yugami-do" (degree of asymmetry) and "Tantou-do" (degree of brachycephaly). Based on developer information and previous validation work, these indices were operationally defined and analyzed as app-based CVAI and app-based Cephalic Index, respectively [8].

Blinding and Test Interpretation

At the time of app-based image capture and contour tracing, the examiner did not have access to the final, processed quantitative results derived from the 3D scanner. Conversely, JPMC technical staff who processed and analyzed the 3D scanner data were blinded to the app-based measurement results. However, because the same examiner performed both procedures consecutively in a fixed order under a partially shared measurement context, the measurements were not fully independent and may have been subject to measurement bias.

Definitions of Cranial Indices and Clinical Thresholds

Plagiocephaly severity was classified according to the CVAI severity criteria specified in the Japanese package insert for the Michigan-style cranial reshaping orthosis: normal (<5%), mild (5%-<7%), moderate (7%-<10%), severe (10%-<14%), and very severe (≥14%) [21].

For the primary screening accuracy analyses, moderate-or-worse plagiocephaly was defined as scanner-derived CVAI≥7%. This prespecified threshold represents clinically meaningful severity for which cranial orthotic (helmet) therapy may be considered [7].

Brachycephaly was defined as scanner-derived Cephalic Index>94% and dolichocephaly as Cephalic Index<79%, based on reference values for Japanese children and thresholds used in previous Japanese clinical studies [7,22]. These thresholds were selected to align with population-specific normative data and established clinical interpretations in Japan. Because age-specific differences in Cephalic Index have been reported among Japanese children [22], analyses were stratified by age at 4, 18, and 42 months.

Statistical Analysis

All statistical analyses were performed using SPSS Statistics (version 29.0; IBM Corp). Agreement, screening performance, and receiver operating characteristic (ROC) analyses were conducted separately within each age group, using participants with paired measurements from both methods for the relevant index. Participant characteristics were summarized as counts and percentages for categorical variables and means and SDs for continuous variables. Continuous variables were reviewed for distributional plausibility to support the use of parametric summaries.

Primary Analysis: Agreement (Continuous Indices)

Agreement between the 3D scanner and mobile app was assessed for CVAI and Cephalic Index within each age group. Differences were calculated as app−scanner, with the mean difference representing systematic bias. Positive values indicated higher measurements from the app relative to the 3D scanner.

Bland-Altman 95% limits of agreement (LoA) were computed as mean difference ±1.96×SD of the differences, and Bland-Altman plots were generated for visual inspection of agreement and potential trends across the measurement range. Systematic and proportional bias were assessed descriptively from the plots. Heteroscedasticity was assessed using Spearman rank correlations between the absolute method differences and measurement magnitude, defined as the mean of the 2 methods.

Intraclass correlation coefficients (ICCs) were estimated within each age group using a two-way mixed-effects model with absolute agreement for single measurements (ICC [1,3]) and reported with 95% CIs [23]. ICCs were interpreted according to conventional thresholds: <0.50, poor; 0.50 - 0.75, moderate; 0.75 - 0.90, good; >0.90, excellent agreement. ICCs were calculated from paired measurements only, using listwise deletion within each age group and index.

Primary Analysis: Screening Performance (Clinically Anchored Thresholds)

For screening performance analyses, 3D scanner–based classifications were used as the reference standard (plagiocephaly: CVAI≥7%; brachycephaly: Cephalic Index>94%; dolichocephaly: Cephalic Index<79%). App-based results were dichotomized using the same thresholds. For each age group, 2×2 contingency tables were constructed to calculate scanner-defined prevalence, sensitivity, specificity, positive predictive value (PPV), and negative predictive value (NPV). For sensitivity, specificity, PPV, and NPV, 95% CIs were calculated using the Wilson score method.

Secondary Exploratory ROC Analyses

As secondary exploratory analyses, ROC analyses evaluated continuous app-based indices against scanner-defined classifications within each age group. Areas under the curve (AUCs) with 95% CIs were estimated, and optimal cutoffs were identified by maximizing the Youden index (sensitivity + specificity − 1). Sensitivity-prioritized cutoffs were also derived.

For outcomes in which higher app-based values indicated a positive state (CVAI and brachycephaly), the sensitivity-prioritized cutoff was defined as the highest cutoff achieving sensitivity≥0.90 while maximizing specificity; for dolichocephaly, in which lower values indicated a positive state, it was defined as the lowest cutoff meeting the same criterion.

For plagiocephaly, we additionally performed ROC analyses using multiple scanner-defined severity thresholds as the positive definition (CVAI≥5%,≥7%,≥10%, and≥14%). We summarized the AUC, Youden-optimal cutoff values, and the corresponding sensitivity and specificity for each threshold. Age-stratified confusion matrices were also constructed using identical classification boundaries for both methods: 5×5 matrices for plagiocephaly (normal,<5%; mild, 5%-<7%; moderate, 7%-<10%; severe, 10%-<14%; very severe,≥14%) and 3×3 matrices for cephalic shape (dolichocephaly, Cephalic Index<79%; normal, 79% - 94%; brachycephaly, Cephalic Index>94%). For both, the 3D scanner classifications were represented as rows and app classifications as columns, and cell counts, row percentages, exact agreement rates, and directions of discordance (overclassification vs underclassification relative to the 3D scanner reference) were reported.

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Sensitivity Analyses: Device-Stratified Analyses

To assess potential variation associated with the tablet device, sensitivity analyses were stratified by the iPad and Lenovo device periods described above. Within each device period and each age group (4, 18, and 42 months), we repeated the primary agreement analyses (mean difference [app−scanner], Bland-Altman 95% LoA, and ICC [1,3] with 95% CIs) and the threshold-based screening performance analyses (sensitivity and specificity, with 95% CIs).

Ethical Considerations

This study was conducted in accordance with the Declaration of Helsinki and the Japanese Ethical Guidelines for Life Science and Medical Research Involving Human Subjects. The protocol was approved by the Ethics Committee of the Graduate School of Biomedical Sciences, Nagasaki University (approval no. 23020901‐3) and prospectively registered in the University Hospital Medical Information Network (UMIN) Clinical Trials Registry (UMIN000052342). Written informed consent was obtained from all parents or legal guardians after they received a comprehensive explanation of the study aims, procedures, potential risks and benefits, and the voluntary nature of participation, including explicit assurance that refusal or withdrawal would not affect access to health services. When results indicated severe or very severe cranial asymmetry, parents or guardians were offered referral for further clinical assessment and provided with information on specialist services, with referral facilitated as appropriate. Low-dose computed tomography (CT) cranial imaging was considered when clinically indicated.

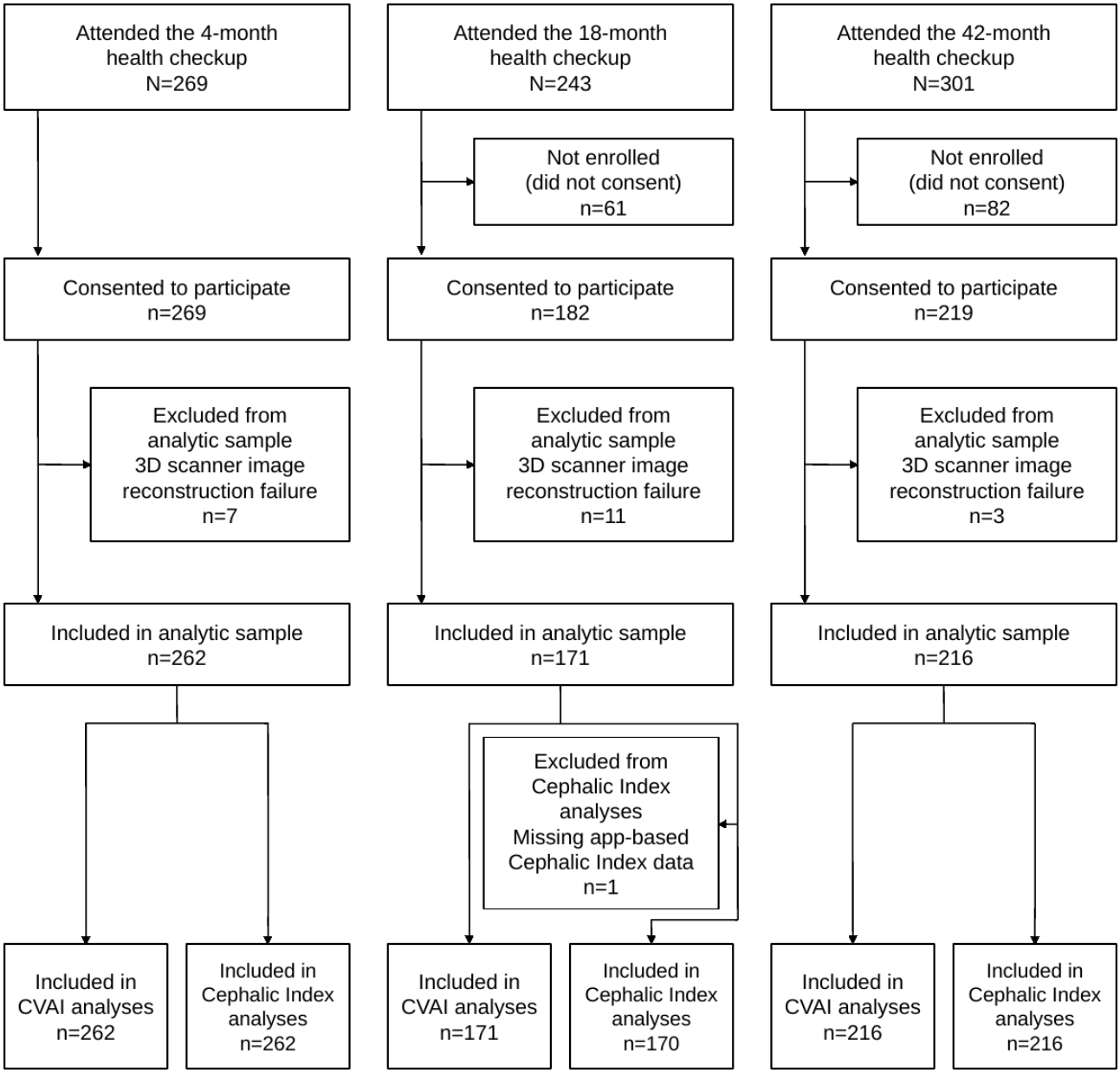
Results

Participant Characteristics

Figure 1 shows the flow of participants through the study. Of the consenting participants, 7 of 269 children at 4 months, 11 of 182 at 18 months, and 3 of 219 at 42 months were excluded because 3D scanner images could not be successfully reconstructed, resulting in final analytic samples of 262, 171, and 216 children, respectively. Agreement and screening performance analyses were performed using paired measurements from both the 3D scanner and the mobile app for each index. At 18 months, 1 participant had missing app-based Cephalic Index data and was therefore excluded from Cephalic Index−based analyses only, while remaining included in CVAI-based analyses.

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Figure 1. Participant flow diagram by age group. CVAI: Cranial Vault Asymmetry Index.



The characteristics of the participants at each assessment time point are shown in Table 1. Across all 3 assessments, the sex distribution was approximately balanced, with boys accounting for 49.6% (130/262) at 4 months, 45.0% (77/171) at 18 months, and 45.1% (97/215) at 42 months. The proportion of children born by cesarean section ranged from 13.5% (29/215) to 18.7% (32/171), indicating that the majority of participants were delivered vaginally. Mean gestational age at birth was consistent with term delivery at all time points (mean 39.1, SD 1.7, 38.9, SD 1.7, and 39.2, SD 1.7, weeks at 4, 18, and 42 months, respectively). Torticollis and limitation of hip abduction were rarely observed, with no more than 1 child affected at any assessment time point (0%-0.5%). Missing data for selected variables were minimal and are indicated in the table footnotes.

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Table . Characteristics of participants at each assessment time point[a].

Characteristics	4 months (n=262)[b]	18 months (n=171)[c]	42 months (n=216)[d]
Sex, n (%)			
Male	130 (49.6)	77 (45.0)	97 (45.1)
Female	132 (50.4)	94 (55.0)	118 (54.9)
Delivery			
Vaginal delivery, n (%)	218 (83.8)	139 (81.3)	186 (86.5)
Cesarean section, n (%)	42 (16.2)	32 (18.7)	29 (13.5)
Gestation, at birth, weeks, mean (SD)	39.1 (1.7)	38.9 (1.7)	39.2 (1.7)
Weight at assessment, kg, mean (SD)	6.9 (0.8)	10.4 (1.0)	14.4 (1.8)
Height at assessment, cm, mean (SD)	62.9 (2.6)	79.5 (2.7)	94.5 (5.5)
Head circumference, cm, mean (SD)	41.6 (1.3)	47.2 (1.3)	49.8 (1.5)
Torticollis, n (%)	0 (0)	0 (0)	1 (0.5)
Limitation of hip abduction, n (%)	1 (0.4)	0 (0)	1 (0.5)

[a]Percentages were calculated using the number of participants with nonmissing data for each variable.

[b]At 4 months, data on mode of delivery were missing for 2 participants.

[c]At 18 months, data on weight and height at assessment were missing for 1 participant each.

[d]At 42 months, data on sex, mode of delivery, torticollis, and limitation of hip abduction were missing for 1 participant each.

Distribution of Cranial Indices by Age Group and Measurement Method

Figure 2 shows the age-stratified distributions of CVAI (%) obtained using the 3D scanner and mobile app. Across age groups, CVAI values were right-skewed and concentrated at lower levels, and the app tended to yield slightly higher values than the 3D scanner. For the 3D scanner, most CVAI values were distributed below the higher severity thresholds, with relatively few observations in the severe and very severe ranges.

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Figure 2. Distribution of CVAI (%) by age group and measurement method (3D scanner vs mobile app). CVAI was calculated using the shorter diagonal as the denominator ([CVAI(S), where S denotes the shorter diagonal]). Vertical reference lines indicate CVAI severity thresholds, marking the cut-offs for moderate (≥7%), severe (≥10%), and very severe (≥14%) categories. CVAI: Cranial Vault Asymmetry Index.

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Figure 3 shows the corresponding distributions of Cephalic Index (%), which were approximately unimodal and centered in the mid-to-high range; the app similarly showed a modest rightward shift (ie, higher Cephalic Index values) relative to the 3D scanner. For the 3D scanner, Cephalic Index values were predominantly distributed within the normal-to-brachycephalic range, whereas values in the dolichocephalic range were relatively infrequent.

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Figure 3. Distribution of Cephalic Index (%) by age group and measurement method (3D scanner vs mobile app). The 2 vertical reference lines indicate the prespecified Cephalic Index cut-off thresholds (79% and 94%), corresponding to the boundaries for dolichocephaly (<79%), normal (79% - 94%), and brachycephaly (>94%).

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Agreement Between the 3D Scanner and the Mobile App

Table 2 shows the agreement between the 3D scanner and the mobile app for CVAI and Cephalic Index at each assessment time point, and the corresponding Bland-Altman plots are presented in Figure 4 (CVAI) and Figure 5 (Cephalic Index).

For CVAI, at 4 months, the mean difference between the app and the scanner was small (0.14, SD 2.20), with 95% LoA from −4.18 to 4.46 and an ICC of 0.76 (95% CI 0.71 - 0.81), indicating good agreement. At 18 months and 42 months, the mean differences for CVAI remained close to zero (0.32 and 0.31, respectively), but the LoAs were wider (−5.60 to 6.23 and −4.63 to 5.25, respectively), and the ICCs decreased to 0.42 (95% CI 0.29 - 0.54) and 0.49 (95% CI 0.38 - 0.59), suggesting poor-to-moderate agreement at these later time points.

For Cephalic Index, the app consistently yielded higher values than the scanner, with mean differences of 3.83, SD 3.42, 3.24, SD 3.07, and 2.61, SD 3.33 at 4, 18, and 42 months, respectively, indicating a systematic positive bias. The 95% LoA were wide at all time points (approximately −2.88 to 10.54 at 4 months, −2.77 to 9.25 at 18 months, and −3.91 to 9.14 at 42 months), indicating substantial individual-level variability. Although ICC point estimates were similar across age groups (0.69 - 0.70), their 95% CI were wide, particularly at 4 and 18 months (4 months: 0.07 - 0.88; 18 months: 0.09 - 0.87; 42 months: 0.31 - 0.84). Therefore, the ICC point estimates should not be overinterpreted as evidence of stable agreement for Cephalic Index. In this context, the Bland-Altman mean differences and LoA, which directly quantify the magnitude and direction of systematic bias and individual-level disagreement, provide a more clinically informative summary (Table 2 and Figure 5).

Table . Agreement between 3D scanner and mobile app-derived measurements of CVAI[a] and Cephalic Index at each assessment time point.

* Measure	4 months (n=262)	18 months (n=171)[b]	42 months (n=216)
CVAI[c]			
Mean difference (app−scanner), mean (SD)	0.14 (2.20)	0.32 (3.02)	0.31 (2.52)
95% limits of agreement[d]	−4.18 to 4.46	−5.60 to 6.23	−4.63 to 5.25
ICC[e] (95% CI)[f]	0.76 (0.71 - 0.81)	0.42 (0.29 - 0.54)	0.49 (0.38 - 0.59)
Cephalic Index			
Mean difference (app−scanner), mean (SD)	3.83 (3.42)	3.24 (3.07)	2.61 (3.33)
95% LoA[d,g]	−2.88 to 10.54	−2.77 to 9.25	−3.91 to 9.14
ICC (95% CI)[f]	0.70 (0.07 - 0.88)	0.69 (0.09 - 0.87)	0.70 (0.31 - 0.84)

[a]CVAI: Cranial Vault Asymmetry Index.

[b]At 18 months, 1 participant was excluded from CI-based analyses because of missing Cephalic Index data (n=170).

[c]CVAI was calculated using the shorter diagonal as the denominator [CVAI(S)].

[d]Limits of agreement were calculated as mean difference±1.96× SD of the differences.

[e]ICC: intraclass correlation coefficients.

[f]Intraclass correlation coefficients were calculated using a two-way mixed-effects model with absolute agreement, single measures.

[g]LoA: limits of agreement.

To assess heteroscedasticity in Bland-Altman differences, we examined Spearman correlations between the absolute method differences and the measurement magnitude (defined as the mean of the two methods). For CVAI, absolute differences increased modestly with increasing measurement magnitude across all ages (ρ=0.18 - 0.29; $P \leq .004$), suggesting mild heteroscedasticity. In contrast, for Cephalic Index, the association was weak and not consistently observed across age groups (ρ=0.06 - 0.18), indicating no clear consistent pattern of heteroscedasticity across age groups.

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Figure 4. Bland-Altman plot of agreement between 3D scanner–derived and mobile app–derived CVAI measurements. CVAI: Cranial Vault Asymmetry Index.

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Figure 5. Bland-Altman plot of agreement between 3D scanner–derived and mobile app–derived Cephalic Index measurements.

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Threshold-Based Screening Performance

Table 3 summarizes scanner-defined prevalence and screening performance, including sensitivity, specificity, PPV, and NPV, when the same clinical thresholds were applied to both the 3D scanner (reference standard) and the mobile app. Specifically, for plagiocephaly (CVAI≥7%), sensitivity was 84.8% (39/46) at 4 months and decreased to 50.0% (12/24) and 53.3% (8/15) at 18 and 42 months, respectively, whereas specificity remained stable at 88.0% (190/216), 88.4% (130/147), and 89.6% (180/201). Scanner-defined prevalence decreased from 17.6% (46/262) at 4 months to 14.0% (24/171) and 6.9% (15/216) at 18 and 42 months, respectively, with PPV decreasing correspondingly from 60.0% (95% CI 47.9 - 71.0) to 41.4% (95% CI 25.5 - 59.3) and 27.6% (95% CI 14.7 - 45.7); NPV remained high at 96.4% (190/197), 91.5% (130/142), and 96.3% (180/187).

Table . Screening performance of the mobile app relative to the 3D scanner reference standard.

Age	Prevalence, n/N (%)	Sensitivity, n/N (%)	95% CI	Specificity, (n/N) %	95% CI	PPV[a], % (95% CI)	NPV[b], % (95% CI)
Plagiocephaly[c]							
4 months	46/262 (17.6)	39/46 (84.8)	71.8 - 92.4	(190/216) 88.0	82.9 - 91.7	60.0 (47.9 - 71.0)	96.4 (92.8 - 98.3)
18 months	24/171 (14.0)	(12/24) 50.0	(31.4 - 68.6)	(130/147) 88.4	82.3 - 92.7	41.4 (25.5 - 59.3)	91.5 (85.8 - 95.1)
42 months	15/216 (6.9)	(8/15) 53.3	(30.1 - 75.2)	(180/201) 89.6	84.6 - 93.1	27.6 (14.7 - 45.7)	96.3 (92.5 - 98.2)
Brachycephaly[d,e]							
4 months	70/262 (26.7)	(64/70) 91.4	(82.5 - 96.0)	(121/192) 63.0	56.0 - 69.5	47.4 (39.2 - 55.8)	95.3 (90.1 - 97.8)
18 months	10/170 (5.9)	(10/10) 100.0	(72.2 - 100.0)	(138/160) 86.3	80.1 - 90.7	31.3 (18.0 - 48.6)	100.0 (97.3 - 100.0)
42 months	6/216 (2.8)	(6/6) 100.0	(61.0 - 100.0)	(184/210) 87.6	82.5 - 91.4	18.8 (8.9 - 35.3)	100.0 (98.0 - 100.0)
Dolichocephaly[d,f]							
4 months	11/262 (4.2)	(2/11) (5.1 - 47.7)	(5.1 - 47.7)	(251/251) 100.0	98.5 - 100.0	100.0 (34.2 - 100.0)	96.5 (93.6 - 98.2)
18 months	13/170 (7.6)	(2/13) 15.4	(4.3 - 42.2)	(157/157) 100.0	97.6 - 100.0	100.0 (34.2 - 100.0)	93.5 (88.7 - 96.3)
42 months	12/216 (5.6)	(5/12) 41.7	(19.3 - 68.0)	(203/204) 99.5	97.3 - 99.9	83.3 (43.6 - 97.0)	96.7 (93.3 - 98.4)

[a]PPV: positive predictive value.

[b]NPV: negative predictive value.

[c]Cranial Vault Asymmetry Index (CVAI) was calculated using the shorter diagonal as the denominator [CVAI(S)]. Plagiocephaly was defined as CVAI≥7% for both the 3D scanner and the mobile app.

[d]At 18 months, 1 participant was excluded from brachycephaly and dolichocephaly analyses because of missing Cephalic Index data (n=170).

[e]Brachycephaly was defined as Cephalic Index>94% for both the 3D scanner and the mobile app.

[f]Dolichocephaly was defined as Cephalic Index<79% for both the 3D scanner and the mobile app.

For brachycephaly (Cephalic Index>94%), sensitivity was high across age groups (64/70, 91.4%, 10/10, 100.0%, and 6/6, 100.0% at 4, 18, and 42 months, respectively), while specificity increased from 63.0% (121/192) at 4 months to 86.3% (138/160) and 87.6% (184/210) at 18 and 42 months. Scanner-defined prevalence decreased from 26.7% (70/262) at 4 months to 5.9% (10/170) and 2.8% (6/216) at 18 and 42 months, respectively, accompanied by a decrease in PPV from 47.4% (64/135; 95% CI 39.2 - 55.8) to 31.3% (10/32; 95% CI 18.0 - 48.6) and 18.8% (6/32; 95% CI 8.9 - 35.3), while NPV remained high at 95.3% (121/127) - 100.0% (184/184).

For dolichocephaly (Cephalic Index<79%), specificity remained≥99.5% across age groups, whereas sensitivity was low overall at 18.2% (2/11), 15.4% (2/13), and 41.7% (5/12) at 4, 18, and 42 months, respectively. PPV was 100.0% (2/2) at 4 and 18 months and 83.3% (5/6) at 42 months, whereas NPV ranged from 93.5% (157/168) to 96.7% (203/210).

As some Cephalic Index–based subgroup estimates were based on small numbers of scanner-positive cases, these sensitivity estimates—particularly those that appear high (eg, 100%)—should be interpreted cautiously. One 18-month participant with missing Cephalic Index data was excluded from the brachycephaly and dolichocephaly analyses only.

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Secondary Exploratory ROC Analyses of Continuous App-Based Indices

These ROC analyses were conducted as secondary exploratory analyses to describe the discriminative characteristics of the continuous app-based indices and should be interpreted as supplementary to the primary clinically anchored same-threshold screening analyses shown in Table 3.

For scanner-defined moderate-or-worse plagiocephaly, ROC analyses showed excellent discrimination at 4 months, with lower discriminative performance at 18 and 42 months. ROC-derived cut-off values varied across age groups, and sensitivity-prioritized cutoffs at older ages required substantial reductions in specificity, reinforcing the primary same-threshold findings that screening performance was most favorable at 4 months.

For brachycephaly, ROC analyses suggested apparently high discriminative performance at 18 and 42 months; however, these estimates were based on very small numbers of scanner-positive cases and should therefore be interpreted with caution as exploratory and potentially unstable. For dolichocephaly, ROC analyses also suggested good discrimination in some age groups, but the limited number of positive cases restricted the precision and interpretability of these estimates. Detailed ROC results, including AUCs, Youden-optimal cut-off values, and sensitivity-prioritized cut-off values, are provided in Multimedia Appendices 2-4.

Agreement in Severity Classification

Additional analyses compared severity classifications derived from the 3D scanner and mobile app. Across age groups, discordance in 5-category CVAI-based plagiocephaly severity classification more often reflected overclassification by the app (App>3D scanner) than underclassification (App<3D scanner), and disagreements often occurred between adjacent severity categories. At 42 months, the observed severity range was more restricted, resulting in a 3×4 classification matrix (Multimedia Appendices 5-7). The overall direction of discordance is summarized in Multimedia Appendix 8, showing that discordance was more often in the direction of higher severity classification by the app.

Similarly, for 3-category Cephalic Index–based head-shape classifications (dolichocephaly, normal, or brachycephaly), discordance was predominantly in the direction of higher Cephalic Index–based classification, particularly toward brachycephaly, with minimal underclassification and no evidence of extreme misclassification across nonadjacent categories (Multimedia Appendices 9-11). The direction of discordance is summarized in Multimedia Appendix 12. At 18 months, 1 participant with missing Cephalic Index data was excluded from these analyses (valid n=170).

Device-Stratified Sensitivity Analyses

Device-stratified analyses showed some variation across devices (Multimedia Appendix 13). For CVAI, the mean difference was small with both devices, but the direction differed at 18 months (iPad: 0.49, SD 3.13 vs Lenovo: −0.55, SD 2.23); the Lenovo subgroup was small (n=28). For Cephalic Index, positive bias was observed with both devices but was larger during the iPad period (eg, at 4 months: 4.24, SD 3.45 vs 3.06, SD 3.25). Device-stratified screening performance also varied by device and age (Multimedia Appendix 14), although the overall pattern of higher plagiocephaly sensitivity at 4 months was observed with both devices. Several subgroup estimates, particularly at later ages, were based on few scanner-positive cases and should be interpreted cautiously.

Discussion

Main Findings

The main finding of this study was that, under standardized, trained-examiner municipal health checkup conditions, app-based CVAI showed the most favorable screening performance for scanner-defined moderate-or-worse plagiocephaly at 4 months, whereas its performance was less favorable and more variable at 18 and 42 months. This age-related pattern was consistent across both agreement and screening performance analyses. Although ICCs provided a global summary index of agreement between methods, the Bland-Altman LoA were more clinically relevant for assessing individual-level disagreement and potential interchangeability between the app and the 3D scanner [24]. However, even at 4 months, the 95% LoA (−4.18 to 4.46) indicate that app-based values could still differ from scanner-based values by several percentage points in either direction. Importantly, small average differences between methods did not necessarily translate into stable classification at clinically relevant thresholds. When values were near the 7% threshold for moderate-or-worse plagiocephaly, even modest between-method differences could shift a child across the classification boundary. Accordingly, the app may be useful as a practical screening aid in structured, examiner-administered settings, but it should not be regarded as a direct substitute for 3D scanner–based classification when making decisions for individual children.

For Cephalic Index, a distinct pattern emerged. Across all ages, the app showed a consistent positive bias (ie, higher Cephalic Index values relative to the 3D scanner) and wide LoA, indicating a tendency toward systematic overestimation with substantial variability at the individual level. This may have contributed to increased false-positive classifications for brachycephaly, particularly at lower specificity levels. In addition, the Cephalic Index–based findings should not be interpreted as establishing robust age-specific screening thresholds, but rather viewed as exploratory signals that require confirmation in larger samples with sufficient numbers of scanner-positive cases. Device-stratified analyses also showed some variation across devices, including a reversal in the small CVAI bias at 18 months and differences in Cephalic Index bias. However, sequential device use was confounded with study period and accumulated examiner experience, precluding attribution to hardware alone.

Comparison With Existing Literature

Prior validation work has largely been conducted under more controlled conditions than routine municipal health checkups. For example, Nakahari et al [8] evaluated the same app used in this study against a reference method using 3D-printed head

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models under highly standardized imaging conditions and proposed ROC-based cutoffs. In contrast, our study assessed Japanese infants and young children in real-world municipal health checkup settings, where unavoidable factors (eg, movement, hair, and variability in landmark visibility and camera-to-head distance) may introduce additional measurement variability. This difference in study context is important when interpreting the observed performance patterns, particularly the finding that agreement and screening performance for CVAI were most favorable at 4 months and declined at later ages in our data.

Given this context, our findings both align with and extend existing evidence in clinically relevant ways. In exploratory ROC analyses, the Youden-optimal cutoff for detecting scanner-defined moderate-or-worse plagiocephaly at 4 months was similar to that reported previously, suggesting convergent validity under comparable age conditions. However, these ROC-derived cutoffs should be interpreted as sample-specific exploratory findings rather than as proposed clinical thresholds for implementation [8]. For Cephalic Index–based outcomes, the ROC-derived cutoffs varied across ages and measurement contexts and should not be interpreted as establishing robust generalizable age-specific screening thresholds, particularly given the small number of scanner-positive cases in some subgroups. In addition, app-based Cephalic Index values consistently exceeded scanner-based values across all ages, indicating a systematic tendency toward overestimation. Correspondingly, ROC-derived app cutoffs to reproduce scanner-defined brachycephaly (Cephalic Index>94%) were substantially higher than those reported in prior studies, suggesting that Cephalic Index thresholds may not be directly transferable across measurement contexts without local calibration. Consistent with the primary same-threshold analyses, at 18 and 42 months, achieving high sensitivity required substantial reductions in specificity, indicating that cutoff adjustment alone may not fully compensate for age-related limitations in measurement agreement beyond early infancy. This study also adds an implementation-oriented perspective by evaluating “same-threshold” use (ie, applying identical clinical thresholds to both the app and the scanner) and by describing the direction and magnitude of discordance in severity classification. These analyses demonstrate how acceptable agreement for continuous indices may not translate directly into consistent threshold-based classification, thereby highlighting the importance of considering both measurement agreement and classification behavior in real-world screening pathways.

Interpretation of Age-Related and Cephalic Index–Related Differences

Plagiocephaly

Agreement and discrimination of CVAI were strongest at 4 months but attenuated at 18 and 42 months, with corresponding reductions in sensitivity for detecting scanner-defined CVAI≥7%. This age-related pattern should be interpreted cautiously as a hypothesis-generating observation rather than a directly tested causal explanation. One possible contributor is a shift in case mix over time: CVAI may peak in early infancy and gradually improve as infants develop gross motor skills, which could shift the population distribution toward milder asymmetry at older ages [10,25,26]. In our study, the number of children with scanner-defined moderate-or-worse plagiocephaly was also smaller at older ages, particularly at 42 months, which increases statistical uncertainty in sensitivity estimates. This interpretation is consistent with the observed concentration of CVAI values in the lower range at older ages and with discordance often occurring between adjacent severity categories.

A second, nonmutually exclusive explanation relates to increased measurement difficulty under real-world image capture conditions. App-based CVAI estimation depends on accurate visualization and manual specification of key anatomical landmarks from a single vertex photograph; the app instructs users to capture an overhead image with the nose and ears visible and to annotate these landmarks, and prior validation work suggests that landmark visibility and positioning conditions can influence screening sensitivity [8]. Moreover, because prior validation studies were conducted using stationary head models without hair, performance in older infants and young children may be more susceptible to real-world capture challenges, including movement, hair coverage, and variable head positioning, which could increase landmark identification error and contour-tracing variability and reduce measurement repeatability in single-image assessments [8,27]. Our data could not determine whether the lower apparent performance at older ages was primarily attributable to changes in case mix (ie, fewer scanner-positive cases and a higher proportion of borderline values near classification thresholds) or to greater measurement difficulty under real-world conditions.

In addition to biological or case-mix differences across ages, part of the apparent age-related pattern may also reflect methodological features inherent to the measurement process. Because the 3D scanner was always used first, followed by app-based measurement by the same examiner with the same cap in place and minimal delay, the index test was performed under a partially shared measurement context with a fixed testing sequence. This design likely enhanced comparability between methods, but it may also have introduced the potential for overestimation of agreement and screening performance compared with fully independent assessments. Therefore, the observed age-related differences should not be interpreted solely as intrinsic differences in app performance across developmental stages, but rather in the context of potentially interacting biological, behavioral, and methodological factors.

Cephalic Index–Related Findings: Brachycephaly and Dolichocephaly

Across all assessment time points, the app tended to yield systematically higher Cephalic Index values than the 3D scanner, indicating a consistent positive bias. This shift may have contributed to the comparatively lower specificity for brachycephaly (scanner-defined Cephalic Index>94%) and to an increased frequency of false-positive classifications. This finding can be considered in relation to a previous smartphone-based validation study [28]. Kocabalkanli et al [28] compared smartphone-based cranial measurements with 3D

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reference measurements in 71 infants and reported minimal Bland-Altman bias for both CVAI (−0.05; 95% LoA, −3.85 to 3.76) and Cephalic Index (0.08; 95% LoA, −4.18 to 4.34). Although differences in the reference systems, study populations, app, and image-capture protocols preclude direct comparison, the CVAI agreement observed in their study was similar to that observed in our 4-month cohort (mean difference, 0.14; 95% LoA, −4.18 to 4.46), whereas our Cephalic Index showed a substantially larger positive bias (mean difference 3.83, 95% LoA −2.88 to 10.54). This index-specific contrast suggests that the positive Cephalic Index bias observed in our study may not be attributable to 2-dimensional image acquisition alone. Kocabalkanli et al [28] noted the importance of positioning the camera orthogonally to the measurement plane for smartphone-based cranial measurements. Potential contributors in our study include deviation of the camera from an orientation orthogonal to the cranial measurement plane, variation in head position during image acquisition, cranial contour extraction, the algorithm used to derive Cephalic Index from the 2-dimensional image, and differences between dimensions derived from a 2-dimensional cranial contour and those measured on a defined cross-section of a 3D model. In particular, differences in the estimation of cranial width or anteroposterior length could systematically affect Cephalic Index because Cephalic Index is calculated as the ratio of these dimensions. However, the app did not output the component cranial width and anteroposterior length measurements, and these potential mechanisms could therefore not be directly evaluated in the present study.

In contrast to brachycephaly, the app showed high specificity but low sensitivity for dolichocephaly (scanner-defined Cephalic Index<79%), indicating that scanner-defined cases of dolichocephaly were frequently missed by the app. This pattern may partly reflect the underlying distribution of Cephalic Index in the study population: because Cephalic Index varies with age in Japanese children, relatively few children fell below the 79% threshold, resulting in few positive cases and limited precision in sensitivity estimates [22]. In addition, the systematic positive bias in app-based Cephalic Index values may have shifted some measurements above the lower Cephalic Index threshold, thereby contributing to the low sensitivity for dolichocephaly.

Taken together, these features also help explain the uncertainty in agreement estimates for Cephalic Index. Although ICCs for Cephalic Index were approximately 0.69 - 0.70, their 95% CIs were relatively wide, likely reflecting restricted between-child variability in Cephalic Index within this community-based sample. Moreover, the systematic positive bias indicates that disagreement between methods was not purely random. Therefore, for Cephalic Index, Bland-Altman mean differences and LoA provide a more transparent summary of the clinically relevant disagreement than ICCs alone.

Clinical Implications

Clinically, the potential role of the app appears to vary by age and clinical context. At 4 months—when early identification can guide timely counseling and referral—the app may be most useful as a screening aid when administered by a trained examiner within a structured health checkup setting. In contrast, at 18 and 42 months, agreement and/or screening performance were reduced, suggesting more limited utility for threshold-based clinical decision-making. At 42 months in particular, assessment should be interpreted as descriptive of residual cranial shape and supportive of parental reassurance and counseling, rather than as determinative of treatment eligibility. In practice, because this app is commonly used in home settings, parents may use its outputs to decide whether to seek specialist evaluation [8]. This timing is clinically important because helmet therapy outcomes are strongly age-dependent: a review recommends initiation before 6 months, reports that treatment is generally effective up to 12 months, and notes that the effect becomes limited after 12 months and poor after 18 months [2]. In addition, the Congress of Neurological Surgeons guideline recommends helmet therapy for infants with persistent moderate-to-severe plagiocephaly after a course of conservative treatment, and also for infants with moderate-to-severe deformity who present at an older age [29]. Consistent with these recommendations, delayed identification and initiation of treatment may reduce the achievable degree of correction, as older infants are less responsive to helmet therapy [7]. Therefore, incorporating app-based CVAI screening into the 4-month municipal health-checkup workflow could be pragmatically valuable, as this represents a near-universal point of contact and may facilitate early identification and timely referral for confirmatory assessment when moderate asymmetry is suspected.

At the same time, the LoA suggest that app-based measurements should not be considered directly interchangeable with 3D scanner–based classifications for individual clinical decision-making. Rather, the app appears more suitable for screening purposes—specifically, **i**dentifying children who may warrant confirmatory assessment**,** particularly when values lie, near clinically relevant thresholds, where classification may change according to the measurement method. For implementation, clear and practical operational guidance is essential to reduce avoidable variability, including maintaining a consistent camera-to-head distance, avoiding head tilt or rotation**,** and ensuring adequate visualization of key landmarks in a vertex-view photograph (ie, the nose and both ears), alongside adherence to the in-app measurement guide [8].

Finally, because app-based Cephalic Index values tended to be systematically higher than scanner-based values across age groups in this study, app-positive brachycephaly findings should be interpreted cautiously. For moderate-or-worse plagiocephaly, PPV decreased from 60.0% (39/65) at 4 months to 27.6% (8/29) at 42 months as scanner-defined prevalence declined; similarly, PPV for brachycephaly decreased from 47.4% (64/135) to 18.8% (6/32). Thus, particularly at later ages, app-positive findings may lead to additional confirmatory assessments for children who would not meet the corresponding 3D scanner–based threshold. Accordingly, positive findings at later ages require cautious interpretation in light of age, clinical context, and, when appropriate, confirmatory evaluation.

Strengths and Limitations

This study has several strengths. First, measurements were obtained during municipal health checkups with broad

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population coverage, supporting the relevance of the findings to community-based screening in Japan. Second, app-based measurements were compared with a clinically used 3D scanner. Third, age-stratified analyses allowed assessment of agreement and screening performance across 3 developmental stages.

Several limitations should also be noted. First, findings may not generalize beyond the devices and OSs evaluated. Because the devices were used sequentially rather than concurrently, device type was confounded with study period and accumulated examiner experience, precluding separation of hardware effects from examiner learning or other temporal factors. Second, some subgroup analyses included very small numbers of scanner-positive cases, particularly in the 18-month Lenovo subgroup and at higher-severity plagiocephaly thresholds (CVAI≥10% and≥14%), resulting in potentially unstable estimates. Third, although JPMC technical staff were blinded to the app-based measurement results, JPMC—the developer of the index app—also performed postacquisition processing and quantitative analysis of the 3D scanner data. Therefore, the reference-standard analysis was not fully independent of the app developer and may have introduced potential bias. Fourth, although the examiner did not have access to the final quantitative results derived from the 3D scanner at the time of app-based measurement, both measurements were performed during the same visit by the same trained examiner in a fixed sequence (3D scanner first, app second) under a partially shared measurement context. This partial nonindependence may have favored agreement, and the observed performance may therefore represent an upper-bound estimate under standardized, trained-examiner conditions. Fifth, the app was not evaluated under its intended unsupervised home-use conditions; performance may differ when measurements are performed by untrained users. Sixth, repeated measurements were not collected, precluding assessment of intra- and interrater reproducibility and repeatability. Finally, ROC-derived cutoffs were sample-based point estimates without CIs, limiting the precision and generalizability of these exploratory findings.

Conclusion

App-based CVAI showed the most favorable agreement and screening performance at 4 months under trained-examiner municipal health-checkup conditions, but performance was lower at 18 and 42 months. App-based Cephalic Index was systematically higher than scanner-based Cephalic Index, potentially increasing false-positive classifications for brachycephaly when identical thresholds are applied. Performance also varied to some extent between devices, although device effects could not be separated from study period and accumulated examiner experience. Overall, positive findings from the app—particularly beyond early infancy and for Cephalic Index-based measures—should be interpreted in light of the child's age and broader clinical findings, with further evaluation or specialist referral considered only when clinically indicated, rather than treated as definitive diagnostic classifications.

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Data Availability

The datasets generated and/or analyzed during this study are not publicly available due to ethical and consent-related restrictions, as participants did not provide consent for public data sharing or secondary use at the time of enrollment. However, the datasets are available from the corresponding author upon reasonable request. Researchers interested in accessing the data may contact Mai Takeshita (takeshita.mai.7f@kyoto-u.ac.jp). Requests will be reviewed and considered on a case-by-case basis in accordance with applicable ethical guidelines and institutional policies.

Authors' Contributions

Conceptualization: YH, YK, HE
Formal analysis: YH, MT, HK, YK, HE
Funding acquisition: HE
Investigation: YH, YK, HE
Methodology: YH, YK, HE
Supervision: HK, SH, HE
Visualization: MT
Writing – original draft: MT
Writing – review & editing: YH, MT, HK, YK, KU, SH, HE

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Conflicts of Interest

HK reports a consulting relationship with Japan Medical Company Inc (JPMC), the developer of the mobile app evaluated in this study. HK has received honoraria, consulting fees, and travel support from JPMC, and holds equity (stock) in the company. JPMC performed the reconstruction and quantitative analysis of the 3D scanner data and provided analytic support for the present study. HK has filed and/or holds patents; however, these patents are not directly related to the work reported in this manuscript. The author's affiliated institutions (Keio University School of Medicine and Baby's Head Reshaping Clinic) do not receive financial benefits from these intellectual properties.

Multimedia Appendix 1
Example screen of the mobile app used for cranial shape assessment. The app outputs "Yugami-do" (degree of asymmetry) and "Tantou-do" (degree of brachycephaly), which were operationally analyzed as app-based CVAI and app-based Cephalic Index, respectively.
[PNG File, 611 KB - pediatrics_v9i1e105473_app1.png]

Multimedia Appendix 2
Receiver operating characteristic (ROC) analysis of app-based CVAI to detect moderate-or-worse plagiocephaly defined by 3D scanner CVAI ≥ 7%, stratified by age group.
[DOCX File, 18 KB - pediatrics_v9i1e105473_app2.docx]

Multimedia Appendix 3
Receiver operating characteristic (ROC) analysis of app-based Cephalic Index to detect brachycephaly (3D scanner Cephalic Index > 94%), stratified by age group.
[DOCX File, 19 KB - pediatrics_v9i1e105473_app3.docx]

Multimedia Appendix 4
Receiver operating characteristic (ROC) analysis of app-based Cephalic Index to detect dolichocephaly (3D scanner Cephalic Index < 79%), stratified by age group.
[DOCX File, 19 KB - pediatrics_v9i1e105473_app4.docx]

Multimedia Appendix 5
Confusion matrix of 5-level plagiocephaly severity classification Cranial Vault Asymmetry Index (CVAI) between the 3D scanner and the mobile app at 4 months (n=262).
[DOCX File, 18 KB - pediatrics_v9i1e105473_app5.docx]

Multimedia Appendix 6
Confusion matrix of 5-level plagiocephaly severity classification Cranial Vault Asymmetry Index (CVAI) between the 3D scanner and the mobile app at 18 months (n=171).
[DOCX File, 18 KB - pediatrics_v9i1e105473_app6.docx]

Multimedia Appendix 7
Confusion matrix of 5-level plagiocephaly severity classification Cranial Vault Asymmetry Index (CVAI) between the 3D scanner and the mobile app at 42 months (n=216).
[DOCX File, 18 KB - pediatrics_v9i1e105473_app7.docx]

Multimedia Appendix 8
Direction of discordance between app- and 3D scanner–based 5-level plagiocephaly severity classifications (App < 3D scanner vs App > 3D scanner), by age group.
[DOCX File, 17 KB - pediatrics_v9i1e105473_app8.docx]

Multimedia Appendix 9
Confusion matrix of 3-category Cephalic Index-based head-shape classification between the 3D scanner and the mobile app at 4 months (n=262).
[DOCX File, 18 KB - pediatrics_v9i1e105473_app9.docx]

Multimedia Appendix 10

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Confusion matrix of 3-category Cephalic Index-based head-shape classification between the 3D scanner and the mobile app at 18 months (valid n=170).
[DOCX File, 18 KB - pediatrics_v9i1e105473_app10.docx]

Multimedia Appendix 11
Confusion matrix of 3-category Cephalic Index-based head-shape classification between the 3D scanner and the mobile app at 42 months (n=216).
[DOCX File, 18 KB - pediatrics_v9i1e105473_app11.docx]

Multimedia Appendix 12
Direction of discordance between app- and 3D scanner–based 3-category Cephalic Index classifications (App < 3D scanner vs App > 3D scanner), by age group.
[DOCX File, 18 KB - pediatrics_v9i1e105473_app12.docx]

Multimedia Appendix 13
Device-stratified agreement between the 3D scanner and mobile app measurements of Cranial Vault Asymmetry Index (CVAI) and Cephalic Index at each assessment time point.
[DOCX File, 20 KB - pediatrics_v9i1e105473_app13.docx]

Multimedia Appendix 14
Device-stratified sensitivity and specificity of the mobile app using the 3D scanner as the reference standard.
[DOCX File, 22 KB - pediatrics_v9i1e105473_app14.docx]

Checklist 1
Completed STROBE checklist for cross-sectional studies.
[PDF File, 142 KB - pediatrics_v9i1e105473_app15.pdf]

Checklist 2
The STARD reporting checklist.
[PDF File, 148 KB - pediatrics_v9i1e105473_app16.pdf]

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Abbreviations

AUC: area under the curve
CA: cranial asymmetry
CT: computed tomography
CVAI: Cranial Vault Asymmetry Index
CVAI(S): Cranial Vault Asymmetry Index-Shorter Diagonal
ICC: intraclass correlation coefficient
JPMC: Japan Medical Company
LoA: limits of agreement
NPV: negative predictive value
PPV: positive predictive value
ROC: receiver operating characteristic

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STARD: Standards for Reporting Diagnostic Accuracy Studies
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology
UMIN: University Hospital Medical Information Network

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Original Paper

Millimeter-Wave Imaging for Idiopathic Scoliosis Screening: Diagnostic Accuracy Study

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Abstract

Background: Idiopathic scoliosis is a common 3D spinal deformity with a global prevalence of 2% to 3% in adolescents. Early detection is crucial for timely intervention and preventing curve progression. Although standing full-spine radiography with Cobb angle measurement remains the diagnostic gold standard, its time-consuming nature limits its utility for large-scale screening. Safe, rapid, and noninvasive screening methods are urgently needed to identify high-risk individuals while reserving x-rays for definitive diagnosis.

Objective: This study aimed to evaluate the diagnostic accuracy of a custom-developed millimeter-wave imaging system in patients with suspected scoliosis, with radiographic Cobb angle measurement serving as the reference standard, and explore its potential as a first-line screening tool.

Methods: This prospective diagnostic accuracy study enrolled consecutive outpatients with suspected scoliosis. All participants underwent rapid millimeter-wave imaging scanning (K_a band, 29-40 GHz with no undressing required) followed by standard standing full-spine radiography. Scoliosis was defined as a Cobb angle of 10° or higher. Millimeter-wave images were evaluated using four morphological indicators: (1) shoulder height asymmetry (≥2 cm), (2) trunk lateral shift (≥2 cm), (3) waistline contour asymmetry (≥5°), and (4) lower-limb height difference (≥1 cm). A multiparameter integration strategy classified screening as positive if more than 2 indicators exceeded threshold values. Cobb angle measurements were performed independently by 2 experienced orthopedic surgeons blinded to millimeter-wave image results and each other's assessments. Diagnostic performance metrics (sensitivity, specificity, positive predictive value, negative predictive value, and overall accuracy) were calculated according to the STARD (Standards for Reporting of Diagnostic Accuracy Studies) guidelines. A multivariate logistic regression model incorporating the 4 morphological parameters was constructed for receiver operating characteristic curve analysis.

Results: Ultimately, 132 participants were included. Radiographic evaluation confirmed 98 (74.2%) cases with scoliosis (Cobb angle≥10°) and 34 (25.8%) negative cases. Millimeter-wave imaging achieved an overall accuracy of 86.4% (114/132; 95% CI 76.5%-94.7%), sensitivity of 85.7% (84/98; 95% CI 75.1%-96.5%), specificity of 88.2% (30/34; 95% CI 70.7%-97.6%), positive predictive value of 95.5%, and negative predictive value of 68.2%. Receiver operating characteristic curve analysis of the multivariate logistic regression model exhibited an area under the curve of 0.862 (95% CI 0.802-0.922), with a sensitivity of 92.9% (91/98) and specificity of 38.2% (13/34). Notably, sensitivity was lower for mild curves (Cobb angle=10°-20°) than for moderate or severe curves (≥20°).

Conclusions: Millimeter-wave imaging represents a feasible, rapid, and non-ionizing radiation screening method for scoliosis with good diagnostic accuracy (accuracy=114/132, 86.4%; sensitivity=84/98, 85.7%; specificity=30/34, 88.2%). Its capability to penetrate clothing and rapid scanning time (approximately 2 seconds) make it suitable for large-scale screening applications.

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As a first-line screening tool, this method identifies high-risk individuals for targeted referral and definitive radiography. It follows the “as low as reasonably achievable” principle, optimizing scoliosis screening and reducing unnecessary radiation exposure.

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KEYWORDS

idiopathic scoliosis; early detection; millimeter-wave imaging; diagnostic accuracy; nonionizing radiation

Introduction

Idiopathic scoliosis is a common 3D spinal deformity characterized by coronal plane curvature, vertebral rotation, and alterations in the sagittal plane profile [1,2]. Among its various subtypes, adolescent idiopathic scoliosis constitutes the predominant form affecting children and adolescents, with an estimated global prevalence of 2% to 3% [3-6]. Early detection during the adolescent growth spurt is of paramount importance as timely intervention can delay or halt deformity progression, thereby reducing the risk of progression to severe curves requiring surgical correction [7,8].

Currently, standing full-spine radiography with Cobb angle measurement remains the gold standard for diagnosing and monitoring idiopathic scoliosis. According to guidelines from the Scoliosis Research Society and the International Society on Scoliosis Orthopaedic and Rehabilitation Treatment, scoliosis is defined as a coronal curvature of 10° or more as measured using the Cobb method [7]. Although radiography provides high diagnostic accuracy, repeated exposure to ionizing radiation raises concerns regarding cumulative cancer risk, particularly in pediatric patients who may require long-term follow-up [9,10]. Moreover, the procedure is relatively time-consuming, limiting its practicality for large-scale population screening [11].

Accordingly, there is a growing demand for safe, rapid, and noninvasive screening methods capable of identifying individuals at elevated risk of scoliosis while reserving radiography for confirmatory diagnosis [12]. Several radiation-free approaches, including surface topography [13] and optical scanning [14], have been investigated. However, these techniques are frequently constrained by their sensitivity to clothing and ambient lighting, as well as workflow inefficiencies that limit their applicability in high-throughput screening settings [15,16].

Millimeter-wave imaging has been widely adopted in security screening due to its ability to penetrate clothing and generate high-resolution images without ionizing radiation [17,18]. On the basis of frequency-modulated continuous wave radar [19] and synthetic aperture radar processing principles [20], this technology enables reconstruction of surface topography and subsurface contours. When applied to the human back, millimeter-wave imaging has the potential to capture clinically relevant morphological features associated with spinal deformity in a rapid, objective, and privacy-conscious manner (Multimedia Appendices 1 and 2).

Despite the theoretical advantages of millimeter-wave imaging technology, no studies have evaluated its clinical utility for scoliosis detection. The objective of this study was to evaluate the diagnostic accuracy of a custom-developed millimeter-wave imaging system for detecting scoliosis in patients with suspected spinal deformity using radiographic Cobb angle measurement as the reference standard. We hypothesized that millimeter-wave imaging would demonstrate high sensitivity and acceptable specificity, supporting its potential application as a first-line screening tool consistent with the “as low as reasonably achievable” principle.

Methods

Ethical Considerations

This prospective diagnostic accuracy study was conducted in accordance with the Declaration of Helsinki and approved by the institutional review board of the First Affiliated Hospital of Anhui Medical University (approval PJ 2025-16-05). Written informed consent was obtained from all participants and their legal guardians prior to enrollment.

Study Population

The inclusion criteria were as follows: (1) no prior history of scoliosis diagnosis; (2) suspected scoliosis based on positive physical examination findings, parental concern, or referral from school or community screening programs; and (3) ability to maintain a standing posture during imaging examinations.

The exclusion criteria were as follows: (1) inability to tolerate standing examination due to severe orthostatic intolerance or balance disorders, (2) severe skin conditions or open wounds on the back that might affect imaging quality, or (3) any condition judged by the investigator as potentially compromising patient safety or data integrity.

Millimeter-Wave Imaging System and Acquisition

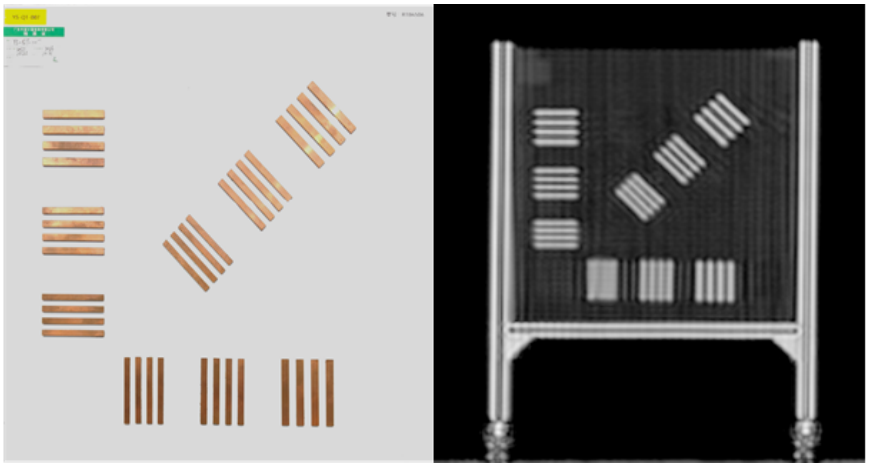
The scoliosis screening system used a custom-developed millimeter-wave scanner operating in the K_a band (29-40 GHz). This frequency range was selected to balance penetration through common clothing materials with spatial resolution sufficient for detailed surface topography mapping [21]. The system integrated frequency-modulated continuous wave radar for precise range resolution [19] and synthetic aperture radar processing via the range migration algorithm [20,22] to generate high-resolution azimuthal imagery. The fusion of these techniques produced a detailed 3D scattering map of the back’s surface and underlying contours.

The reconstructed volume was characterized by a voxel matrix of 192 (width) × 448 (height) × 128 (depth) with spacings of 4.2 mm (horizontal), 3.6 mm (vertical), and 4.0 mm (depth). A maximum intensity projection algorithm was applied for initial visualization and qualitative analysis. The scanning procedure was completed within approximately 2 seconds, and calibration

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was verified using standardized test boards to ensure imaging accuracy. The image of the calibration test board is shown in Figure 1.

Figure 1. Image of the calibration test board and a scan of the board.



Imaging Protocol

Each participant underwent millimeter-wave scanning in 5 standardized standing positions (as illustrated in Figure 2): natural standing position (posture A), palms externally rotated (posture B), hands behind the head (posture C), and single-arm elevation (postures D and E).

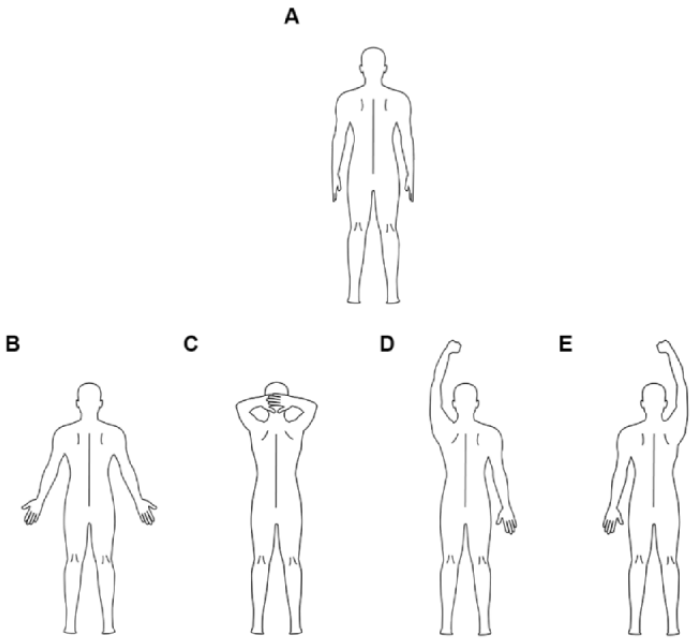
Considering reproducibility and stability, this study used only the natural standing position (posture A) for quantitative analysis, with the remaining 4 postures reserved for qualitative assessment.

Participants were scanned while wearing lightweight clothing (including athletic wear, single-layer garments, or T-shirts) without the need for disrobing, thereby substantially preserving patient privacy and dignity. Metallic items (such as underwire bras) that could potentially interfere with imaging quality were removed when present (Multimedia Appendix 3).

All participants underwent standard standing anteroposterior and lateral full-spine radiography using standardized imaging parameters (85 kV; 20-55 mAs; focus-film distance: 180 cm). Regarding examination sequence, participants first underwent millimeter-wave scanning followed by standard radiographic examination as the definitive diagnostic reference. Both examinations were completed on the same day to minimize potential changes in spinal alignment.

The blinding protocol required millimeter-wave image analysts to be blinded to radiographic results and radiographic assessors to be blinded to millimeter-wave results. Cobb angle measurements were performed independently by 2 experienced orthopedic surgeons, with assessors blinded to each other's results and to millimeter-wave findings. All image identifiers were removed prior to analysis, and an independent data management system was used to prevent unblinding.

Figure 2. Schematic illustration of millimeter-wave image scanning postures.



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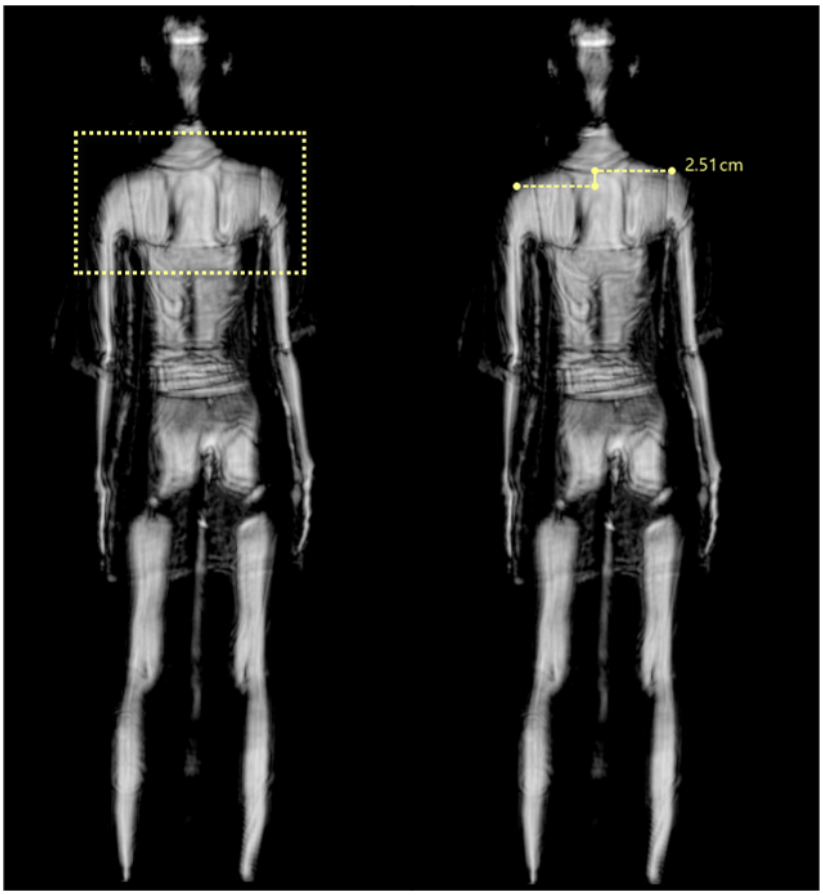
Image Analysis and Screening Criteria

Millimeter-wave images were analyzed using a predefined protocol focusing on 4 clinically relevant morphological indicators [23-29]: shoulder height asymmetry, trunk lateral shift, waistline contour asymmetry, and lower-limb height discrepancy.

Assessment of Shoulder Height Asymmetry

Shoulder balance was evaluated by first interactively selecting the shoulder regions from the millimeter-wave maximum intensity projection image. A least squares fitting algorithm was applied to automatically identify the bilateral acromion points, with submillimeter precision in coordinate extraction. The vertical height difference (ΔH) was calculated as the absolute difference in the z-axis coordinates of the acromion points. The assessment criteria followed those by Lee et al [23] and other clinical standards [24], where ΔH of less than 2 cm was classified as normal and ΔH of 2 cm or more indicated abnormal shoulder imbalance (as illustrated in Figure 3).

Figure 3. Assessment of shoulder balance.

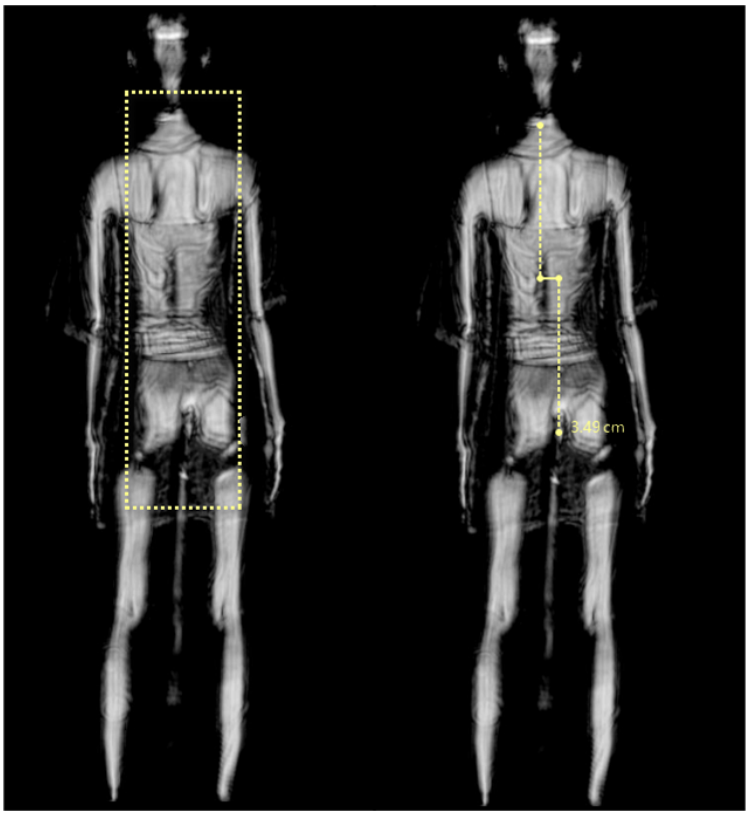


Assessment of Trunk Lateral Shift

Trunk alignment was quantified by measuring the horizontal offset distance (ΔL) between the midpoint of the cervicothoracic junction (C7-T1) and the gluteal cleft. In this study, the assessment of trunk lateral shift was performed by measuring the horizontal distance difference (ΔL) between the medial shoulder midpoint and the gluteal midline point. Following the work by Trobisch et al [25] and related studies on trunk balance [26,27], ΔL of less than 2 cm was classified as normal, and ΔL of 2 cm or more was classified as abnormal (as illustrated in Figure 4).

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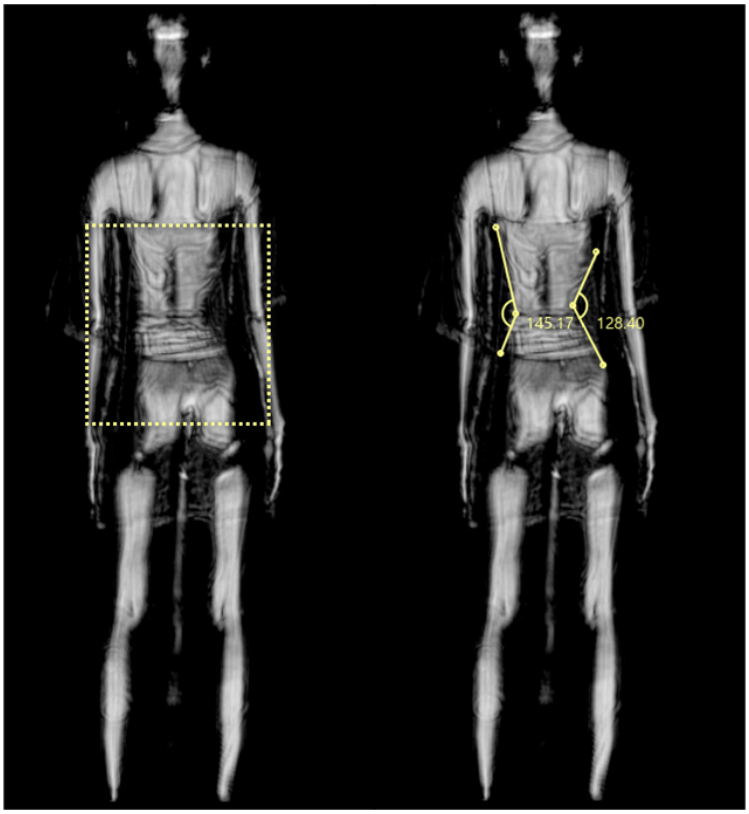
Figure 4. Assessment of trunk lateral shift.



Assessment of Waistline Contour Asymmetry

Waistline symmetry was analyzed by delineating bilateral waistline contours through interactive annotation. Bezier curve fitting technology was used to extract curvature characteristics, and the tangent angle difference (ΔD) at the points of maximum curvature was calculated. Following the work by Qiu et al [28], ΔD of less than 5° was classified as normal, and ΔD of 5° or more indicated abnormal asymmetry (as illustrated in Figure 5).

Figure 5. Assessment of waistline contour asymmetry.

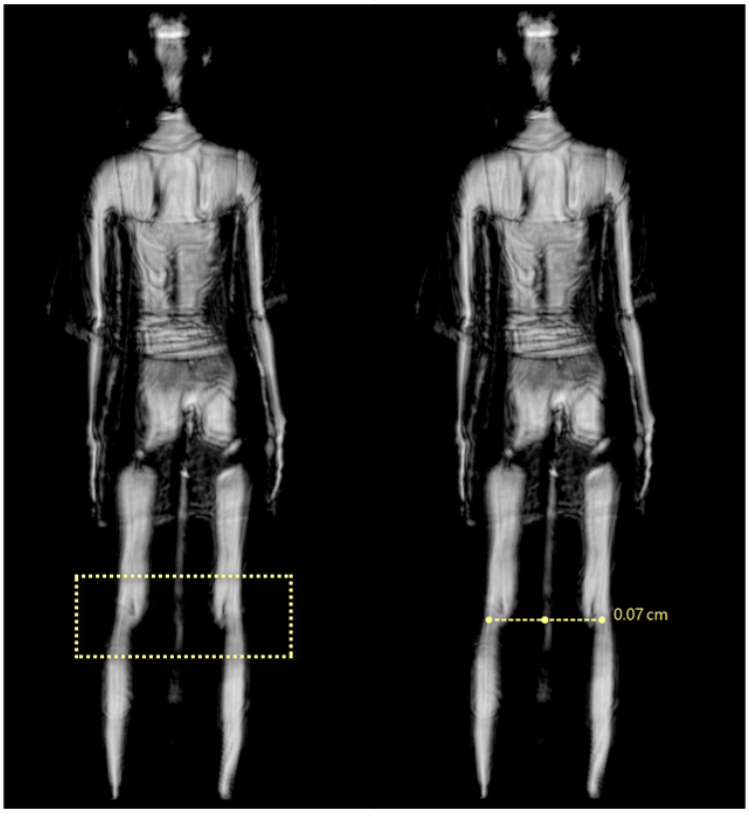


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Assessment of Lower-Limb Height Asymmetry

Lower-limb discrepancy was assessed by interactively annotating the popliteal regions in the millimeter-wave images. The system automatically identified the highest points of the bilateral popliteal fossae with knee extension to standardize measurements. The height difference (ΔH) was computed. Following established clinical criteria [29], a threshold of ΔH of less than 1 cm defined the normal range, whereas ΔH of 1 cm or more indicated abnormality (as illustrated in Figure 6).

Figure 6. Assessment of lower-limb asymmetry.



Judgment Criteria

On the basis of a multiparameter integrated strategy, a scan was categorized as positive for scoliosis screening if 2 or more of the 4 morphological indicators met or exceeded their predefined abnormal thresholds; otherwise, it was classified as negative (Multimedia Appendix 4).

Statistical Analysis

Diagnostic performance was assessed using sensitivity, specificity, positive predictive value, negative predictive value, and overall accuracy in accordance with the STARD (Standards for Reporting of Diagnostic Accuracy Studies) guidelines [30]. Continuous variables with normal distribution were expressed as means and SDs and compared between groups using the independent-sample *t* test (2-tailed), whereas nonnormally distributed data were analyzed using the Mann-Whitney *U* test. All statistical analyses were performed using SPSS (version 22.0; IBM Corp), with statistical significance defined as a 2-tailed *P* value of less than .05.

Results

Patient Characteristics and Group Distribution

Between July 2024 and December 2025, a total of 165 consecutive patients presenting to the spinal surgery outpatient clinic with suspected scoliosis were screened for eligibility. Of these 165 patients, 19 (11.5%) were excluded for failing to meet the inclusion criteria (eg, not first-time presentation). Of the remaining 146 patients, 14 (9.6%) were subsequently excluded based on the exclusion criteria: 9 (64.3%) for inability to undergo radiographic examination (patient refusal or contraindications) and 5 (35.7%) for excessive perspiration on the back compromising image quality. Ultimately, 132 patients were enrolled and completed the study protocol, constituting the final analysis cohort.

Of the 132 patients enrolled in this study, 98 (74.2%) were confirmed to have scoliosis (Cobb angle≥10°) based on x-ray examination, whereas the remaining 34 (25.8%) had measurements of less than 10° and were classified as the nonscoliotic group. The baseline characteristics of the 2 groups are summarized in Table 1. There were no significant differences in age, height, or weight between the 2 groups (P>.05), ensuring the comparability of the study cohorts.

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Table 1. Baseline characteristics of the study participants.

Characteristic	Scoliosis group (n=98)	Nonscoliosis group (n=34)	*P* value
Age (y), mean (SD; range)	15.9 (9.3; 6-23)	14.7 (8.4; 6-22)	.22
Gender, n (%)			.04
Male	32 (32.7)	18 (52.9)	
Female	66 (67.3)	16 (47.1)	
Height (cm), mean (SD; range)	157.2 (9.3; 122.3-184.4)	155.9 (8.4; 120.2-174.3)	.52
Weight (kg), mean (SD; range)	49.1 (7.2; 26.2-78.9)	47.2 (5.8; 26.1-72.1)	.19
Cobb angle (°), mean (SD; range)	28.5 (12.3; 10.5-87.5)	6.2 (2.1; 1.9-9.7)	<.001

Diagnostic Performance of Millimeter-Wave Imaging

The comparative analysis between millimeter-wave assessments and the x-ray reference standard yielded the results shown in Table 2. The overall diagnostic accuracy of the millimeter-wave imaging protocol was 86.4% (114/132). The technology demonstrated a high sensitivity of 85.7% (84/98) and a specificity of 88.2% (30/34). The positive predictive value was 95.5%, and the negative predictive value was 68.2%.

Table 2. Diagnostic performance of millimeter-wave imaging.

Parameter	Value (%; 95% CI)
Accuracy	86.4 (76.5-94.7)
Sensitivity	85.7 (75.1-96.5)
Specificity	88.2 (70.7-97.6)
PPV[a]	95.5 (94.5-96.7)
NPV[b]	68.2 (66.7-72.7)

[a]PPV: positive predictive value.

[b]NPV: negative predictive value.

Analysis of Millimeter-Wave Morphological Parameters

With the exception of lower-limb length discrepancy, the remaining 3 morphological parameters demonstrated higher abnormality rates in the scoliosis group than in the nonscoliosis group as detailed in Table 3. Notably, shoulder height asymmetry and waistline contour asymmetry also exhibited relatively elevated abnormality rates in the nonscoliosis group (13/34, 38.2% and 11/34, 32.4%, respectively).

Table 3. Millimeter-wave imaging morphological parameter analysis.

Parameter	Abnormalities in the scoliosis group (n=98), n (%)	Abnormalities in the nonscoliosis group (n=34), n (%)
Shoulder height asymmetry	75 (76.5)	13 (38.2)
Trunk lateral shift	38 (38.8)	2 (5.9)
Waistline contour asymmetry	78 (79.6)	11 (32.4)
Lower-limb discrepancy	6 (6.1)	1 (2.9)

Multivariate Model Analysis

To further evaluate the integrated diagnostic capability of millimeter-wave imaging, a multivariate logistic regression model was developed incorporating the 4 morphological parameters. The receiver operating characteristic curve analysis of this composite model demonstrated superior performance compared to the individual parameters. The multivariate model achieved an area under the curve of 0.862 (95% CI 0.802-0.922), indicating excellent discriminatory ability (as illustrated in Figure 7).

The detailed performance metrics of the model are shown in the confusion matrix (Figure 8). The model exhibited a sensitivity of 92.9% (91/98 true positives) and a specificity of 38.2% (13/34 true negatives), with an overall accuracy of 78.8% (104/132). This indicates that the methodology aligns with the primary goal of screening protocols, which is to prioritize sensitivity to avoid missed cases, thereby underscoring its value in clinical practice.

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Figure 7. Receiver operating characteristic curve of the multivariate logistic regression model. AUC: area under the curve.

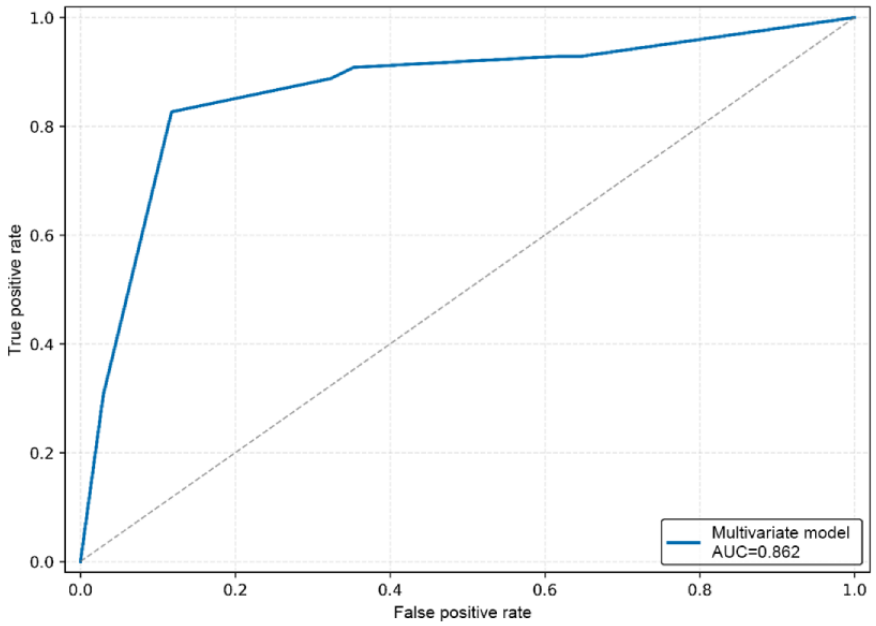
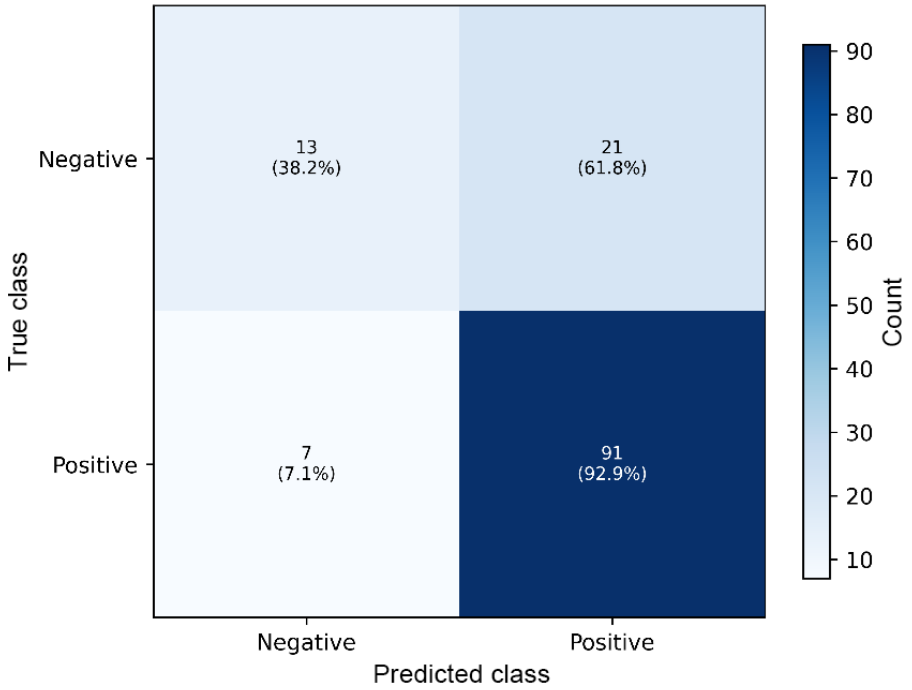


Figure 8. Confusion matrix detailing the performance of the multivariate model.



Subgroup Analysis by Curve Severity

In a subgroup analysis of the 98 patients with scoliosis, the millimeter-wave imaging system demonstrated varying performance across different curve severity groups. The technology demonstrated high diagnostic accuracy in the moderate curve group (Cobb angle=20°-40°) and severe group (≥40°) compared to 75.4% (43/57) in the mild group (10°-20°).

Discussion

Principal Findings

This diagnostic accuracy study evaluated a custom-developed millimeter-wave imaging system in 132 pediatric outpatients with suspected scoliosis. The system demonstrated a sensitivity of 85.7% (84/98), specificity of 88.2% (30/34), and overall accuracy of 86.4% (114/132) for detecting scoliosis (Cobb angle≥10°). Each scan was completed in approximately 2 seconds, effectively minimizing motion artifacts. Notably,

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sensitivity was lower for mild curves (Cobb angle=10°-20°) than for moderate or severe curves.

As a non-ionizing modality, millimeter-wave imaging aligns with the "as low as reasonably achievable" principle and may reduce unnecessary radiation exposure in pediatric populations. The rapid acquisition time (approximately 2 seconds) and ability to scan through light clothing balanced efficiency with privacy preservation, supporting application in large-scale, high-throughput settings such as schools or communities. Moreover, the 3D surface data may enable future assessment of parameters such as vertebral rotation, offering morphological information beyond that provided by conventional 2D radiography.

In summary, this technology is suitable for initial scoliosis screening. Key advantages include (1) absence of ionizing radiation, avoiding cumulative cancer risks from repeated radiographic examinations and supporting longitudinal monitoring; (2) ability to image through everyday clothing, preserving patient dignity and addressing privacy concerns relevant to adolescents; (3) rapid scanning, facilitating efficient large-scale screening; and (4) 3D morphological data that complement planar radiographic findings. Current scoliosis screening techniques based on angular measurement primarily include the use of a scoliometer for assessing the angle of trunk rotation (ATR) and optical surface topography systems. Reported sensitivities for these methods typically range from approximately 70% to 86% [31,32]. In comparison, the millimeter-wave imaging system used in this study achieved a sensitivity of 85.7% (84/98), which is comparable to the performance of existing non–radiation-based screening technologies. The device can be positioned as a triage tool to identify high-risk individuals requiring confirmatory radiographic evaluation. It should be emphasized that this system does not replace Cobb angle measurement, and definitive diagnosis still requires standard radiography.

Limitations

This study has several limitations that should be acknowledged. First, diagnostic accuracy was significantly lower in the mild scoliosis group (Cobb angle=10°-20°) than in the moderate (20°-40°) and severe (≥40°) groups. This difference arose because, under the current diagnostic criteria, some imaging-confirmed mild scoliosis cases were classified as negative during initial screening when at least one quantitative parameter did not meet the predefined threshold, resulting in false-negative outcomes (Multimedia Appendix 5). Moreover, although multi-posture analysis often identifies compensatory asymmetries indicative of scoliosis (eg, scapular asymmetry), these features are not fully captured in single-posture or single-parameter assessments. To preserve the objectivity of this blinded diagnostic accuracy study, qualitative findings from multi-posture observations were not incorporated into the formal statistical analysis, nor were they used to retrospectively revise the initial binary (positive or negative) classification based on the predefined quantitative thresholds.

Second, this was a diagnostic accuracy study conducted in patients with suspected scoliosis referred for clinical evaluation, not a screening study in an asymptomatic population. Future multicenter studies with larger and more diverse populations are needed to further validate the clinical applicability of this technology.

Third, we did not include ATR measurements for direct comparison with existing clinical screening tools. In addition, we did not perform direct comparison between clothed and unclothed measurements or between millimeter-wave imaging and optical surface topography systems. Future studies should incorporate direct comparison among ATR measurements, optical surface topography systems, and millimeter-wave imaging.

Finally, diagnostic accuracy was lower for mild scoliosis (10°-20°) as subtle asymmetries may not always meet quantitative threshold criteria. Future integration of machine learning algorithms for automated analysis may improve detection of mild curves [32-35].

Conclusions

Millimeter-wave imaging represents a promising advancement in scoliosis screening. It provides a rapid, safe, and privacy-preserving approach, achieving a diagnostic performance comparable to initial clinical assessments while offering greater objectivity. As an effective preliminary screening step prior to radiographic evaluation, this technology has the potential to optimize health care resource use. Overall, it shows substantial promise for enabling large-scale, routine scoliosis screening in a safe and practical manner, consistent with recommendations from leading clinical organizations.

Funding

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Data Availability

The data used to support the findings of this study are available from the corresponding author on reasonable request.

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Authors' Contributions

XT was responsible for the acquisition of millimeter-wave image data. QZ performed the formal analysis of the millimeter-wave image data. WL and CL were responsible for reading and reviewing the x-ray data and critically revising the manuscript for important intellectual content. All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

YX and ZZ are affiliated with Anhui Yuanshuo Terahertz Technology Co, Ltd, which is involved in the development of millimeter-wave imaging technologies. The company had no role in the study design, manuscript preparation, or decision to publish. All authors declare no conflicts of interest.

Multimedia Appendix 1
Scanning image method.
[MP4 File (MP4 Video), 5725 KB - pediatrics_v9i1e92125_app1.mp4]

Multimedia Appendix 2
Scanning working principle.
[MP4 File (MP4 Video), 7469 KB - pediatrics_v9i1e92125_app2.mp4]

Multimedia Appendix 3
Scan workflow demonstration.
[MP4 File (MP4 Video), 31132 KB - pediatrics_v9i1e92125_app3.mp4]

Multimedia Appendix 4
Data measure.
[XLSX File (Microsoft Excel File), 44 KB - pediatrics_v9i1e92125_app4.xlsx]

Multimedia Appendix 5
Reinterpretation of false-negative cases through multi-postural millimeter-wave imaging.
[DOCX File , 594 KB - pediatrics_v9i1e92125_app5.docx]

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Abbreviations

ATR: angle of trunk rotation
STARD: Standards for Reporting of Diagnostic Accuracy Studies

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A Stepwise Animated Video Modeling App With Token-Based Reinforcement for Toilet Training in Children With Autism Spectrum Disorder: Pilot Study Using Multiple-Baseline and Single-Case Designs

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Abstract

Background: Toilet training is a major challenge for children with autism spectrum disorder. While mobile health offers accessible support, few apps specifically address the complex chaining required for independent toileting routines.

Objective: This pilot study evaluated the feasibility and preliminary effectiveness of a caregiver-mediated mobile app using stepwise animated video modeling with token-based reinforcement support for toilet training in young children with autism spectrum disorder.

Methods: A multiple-baseline design across participants (urination training) and a single-case AB design (defecation training) were used. Ten children (aged 3 - 6 years) were enrolled, and 4 (40%) were included in the final analyses. The tablet-based intervention guided a 16-step toileting routine using animation and token reinforcement. Primary outcomes were caregiver-recorded in-toilet elimination success (percentage) and routine completion (percentage). Secondary outcomes included standardized adaptive behavior scores (Korean Scales of Independent Behavior–Revised) and social validity.

Results: Four children completed the study, whereas 6 were not included in the final analyses for heterogeneous reasons, including child engagement, caregiver implementation burden, and postenrollment ineligibility. Among completers, in-toilet elimination success improved substantially from baseline, reaching 100% for all participants at the limited 3-day follow-up observation window conducted 3 months after the intervention. Notably, one participant showed marked improvement from a stable 0% at baseline to 93.8% (30/32) of elimination events during the intervention. Routine completion also increased across all participants, suggesting improvements in independence. Caregivers reported favorable treatment adherence and social validity.

Conclusions: The app showed preliminary feasibility and was associated with improvements in toileting outcomes among families who maintained engagement. However, the high attrition rate suggests that successful implementation may depend on child engagement readiness and caregiver resources. Future research should prioritize defining readiness criteria to identify families most likely to benefit from digital toileting interventions.

(JMIR Pediatr Parent 2026;9:e92147) doi:10.2196/92147

KEYWORDS

autism spectrum disorder; toilet training; mobile apps; video modeling; token-based reinforcement; activities of daily living; caregivers; pilot projects

Introduction

Autism spectrum disorder (ASD) is often accompanied by challenges in adaptive functioning and daily living routines, including difficulties with sequencing multistep self-care behaviors [1]. Among daily living skills, toileting is a major developmental milestone, yet many children with ASD experience persistent difficulties across the toileting routine—such as communicating need, clothing management, in-toilet elimination, and completing hygiene steps [2-4]. These difficulties can increase caregiver burden and interfere with participation in everyday routines at home and in early childhood

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settings (eg, day care or preschool), underscoring the need for feasible, family-centered toileting supports [5].

Behavioral toilet training packages—most notably those derived from rapid toilet training approaches—have been widely used for children with developmental disabilities, including ASD [4,6,7]. Although these approaches can increase in-toilet elimination, most published studies remain small sample sizes and report interventions and outcomes heterogeneously, which limits generalizability across children and settings [5]. In addition, many programs emphasize continence and scheduled routines while paying less attention to the broader toileting sequence required for independence (eg, clothing management, wiping, flushing, and handwashing) and to generalization across settings; some packages may also include aversive components that raise acceptability and ethical concerns [4,7,8].

In recent years, mobile health (mHealth) interventions for children with ASD have proliferated, leveraging the portability and accessibility of tablets and smartphones. However, recent systematic reviews indicate that most ASD-related mHealth apps focus on communication, social skills, or parent-mediated support rather than toileting-specific daily living routines [9,10]. Integrated digital tools that combine structured toileting routines, caregiver-mediated implementation, stepwise video modeling, reinforcement support, and home-based toileting data recording remain limited [11].

Video modeling is an evidence-based instructional strategy in which individuals observe a model performing a target behavior and then practice the same behavior, which can reduce verbal demands and leverage visual learning strengths often reported in ASD [12-14]. Meta-analytic and experimental studies support video modeling for teaching functional skills to children with ASD [14-16]. In toileting, video modeling has shown promise for teaching parts of the toileting routine [17,18]. To address challenges in depicting sensitive behaviors (eg, in-toilet urination or defecation), some studies have incorporated animation to visually represent the full toileting sequence [19,20]. However, for multistep routines, video-based instruction can still be constrained by attention demands and prerequisite learning skills when sequences are long or complex; segmented and stepwise formats have therefore been proposed to support acquisition of response chains [21].

Because toileting requires repeated practice over extended periods, sustaining children's participation and caregiver implementation is a practical challenge. In ASD-focused digital interventions, game-related features (eg, simple token collection, visual rewards, or optional mini games) have been used to support engagement and repeated practice, although evidence remains limited and mixed for daily living skills [22,23]. Technology-assisted delivery may also help standardize modeling, provide in-the-moment prompts, and support caregiver-mediated implementation in naturalistic home settings.

Accordingly, this pilot study describes the development and preliminary evaluation of a tablet-based toileting program that delivers brief, stepwise animated video models with simple interactive prompts, caregiver-entered performance feedback, and a token-based reinforcement system (digital stickers exchanged for preferred reinforcers, with optional mini games). Using single-case experimental designs (a multiple-baseline design across participants for urination training and a single-case AB design for defecation training) with 4 preschool-aged children with ASD, we explored feasibility and preliminary patterns of change in toileting routine completion and independent toileting performance over time.

Methods

Study Design

This pilot study used single-case experimental methods. A multiple-baseline design across participants was applied to evaluate the program for urination (participants T06, T09, and T10), and a single-case design with baseline, intervention, and follow-up phases was used for defecation training (participant T05).

Ethical Considerations

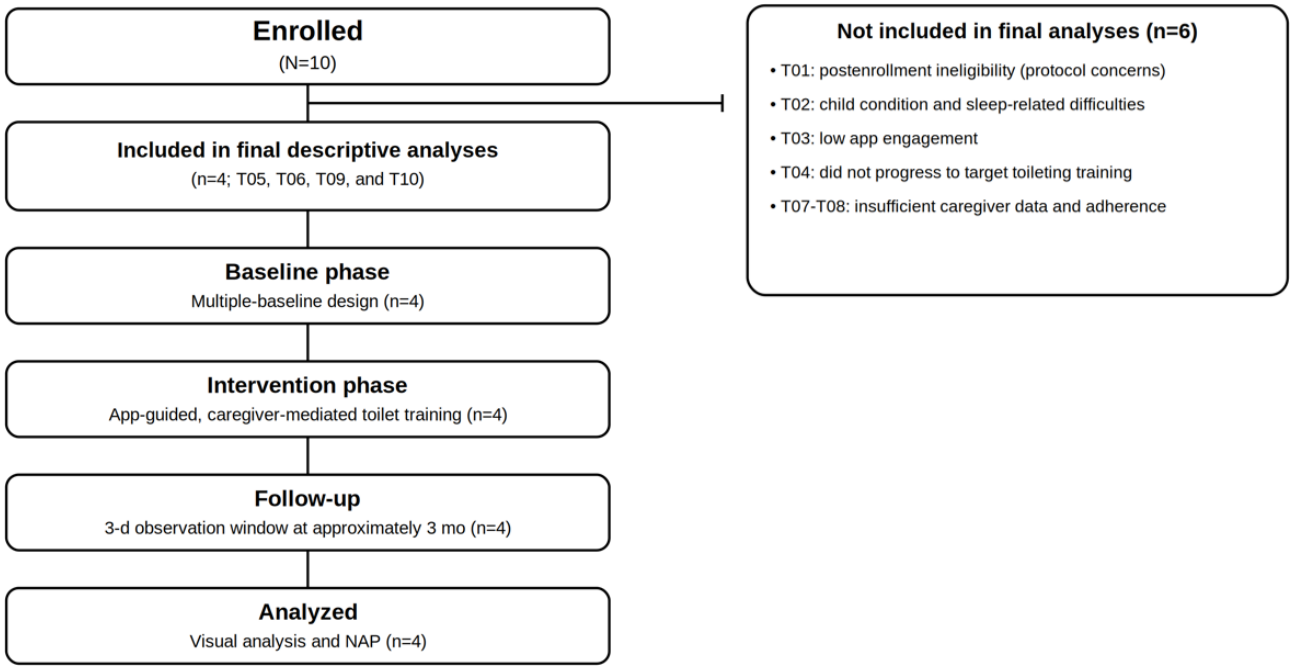
This study was approved by the Public Institutional Review Board designated by the Ministry of Health and Welfare of South Korea (P01-202308-01-056). All procedures were conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained from all parents or legal guardians prior to participation.

Participants and Recruitment

Children were recruited through an online community for caregivers of children with developmental disabilities. Children were eligible if they were aged 3 to 6 years and had either a clinical diagnosis of ASD by a pediatrician or an ongoing diagnostic evaluation for suspected ASD at enrollment. Children were excluded if they were receiving ongoing toilet training outside the study protocol at enrollment. Eligibility additionally required persistent toileting difficulties (eg, elimination outside the toilet, no spontaneous toilet visits, and/or prior attempts with continued problems); no participation in a structured toileting intervention within the 4 weeks prior to enrollment; and the ability to understand simple instructions, with no reported vision or hearing impairments. Formal standardized measures of imitation ability or receptive language were not collected at screening. Withdrawal and discontinuation criteria were defined a priori and applied consistently: participation could be discontinued if (1) unexpected adverse responses or safety concerns arose, (2) repeated refusal or low engagement prevented feasible delivery of the training procedures and/or adequate recording, (3) a new structured toileting intervention was initiated during the study period, or (4) the caregiver withdrew consent. Four children (T05, T06, T09, and T10; n=2 girls) met the prespecified analytic inclusion criterion (≥5 caregiver-reported app-guided training sessions) and were included in the final analyses. Participant flow is shown in Figure 1.

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Figure 1. Participant flow. NAP: nonoverlap of all pairs.



Setting and Materials

The intervention was delivered via a mobile app compatible with smartphones and tablets and was implemented by caregivers in naturalistic settings, primarily the children's home bathrooms. To standardize access and screen size across families, caregivers were provided with a 10.4-inch Samsung Galaxy tablet with the app preinstalled. Caregivers were asked not to introduce new toileting interventions during the study and to keep the children's usual toileting routines and concurrent therapies as consistent as feasible across phases.

App Development and Design Rationale

Overview

The app was developed to support toilet training for young children with ASD by integrating video modeling with applied behavior analytic principles to facilitate chaining of a multistep toileting routine [24,25]. The toileting routine was operationalized as a 16-step task analysis (Textbox 1) developed in consultation with a board-certified behavior analyst at Seoul National University Hospital. Segmenting self-care routines into teachable units was intended to support children who commonly experience difficulty with sequencing and adaptive functioning [1].

Textbox 1. The 16-step toileting routine.

- Step 1: requesting the bathroom
- Step 2: turning on the light
- Step 3: entering the bathroom
- Step 4: checking the toilet lid
- Step 5: pulling down pants
- Step 6: pulling down underwear
- Step 7: sitting on the toilet
- Step 8: eliminating in the toilet (urination and/or defecation)
- Step 9: wiping with toilet paper
- Step 10: putting on underwear
- Step 11: putting on pants
- Step 12: flushing the toilet
- Step 13: washing hands
- Step 14: drying hands with a towel
- Step 15: leaving the bathroom
- Step 16: turning off the light

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Rationale for Animation and Character-Based Modeling

The modeling content was implemented as animation rather than live-action video to reduce potential discomfort and privacy concerns associated with depicting sensitive toileting-related behaviors (eg, wiping) using human actors and to present a child-friendly character that may be easier for young children to attend to and imitate. Video modeling aligns with learning characteristics commonly described in ASD by reducing verbal demands and emphasizing visual information [13,14]. Prior toileting-focused interventions have incorporated animation within video modeling to represent sensitive behaviors while preserving a complete routine sequence [19,20].

Reward Features and Reinforcement

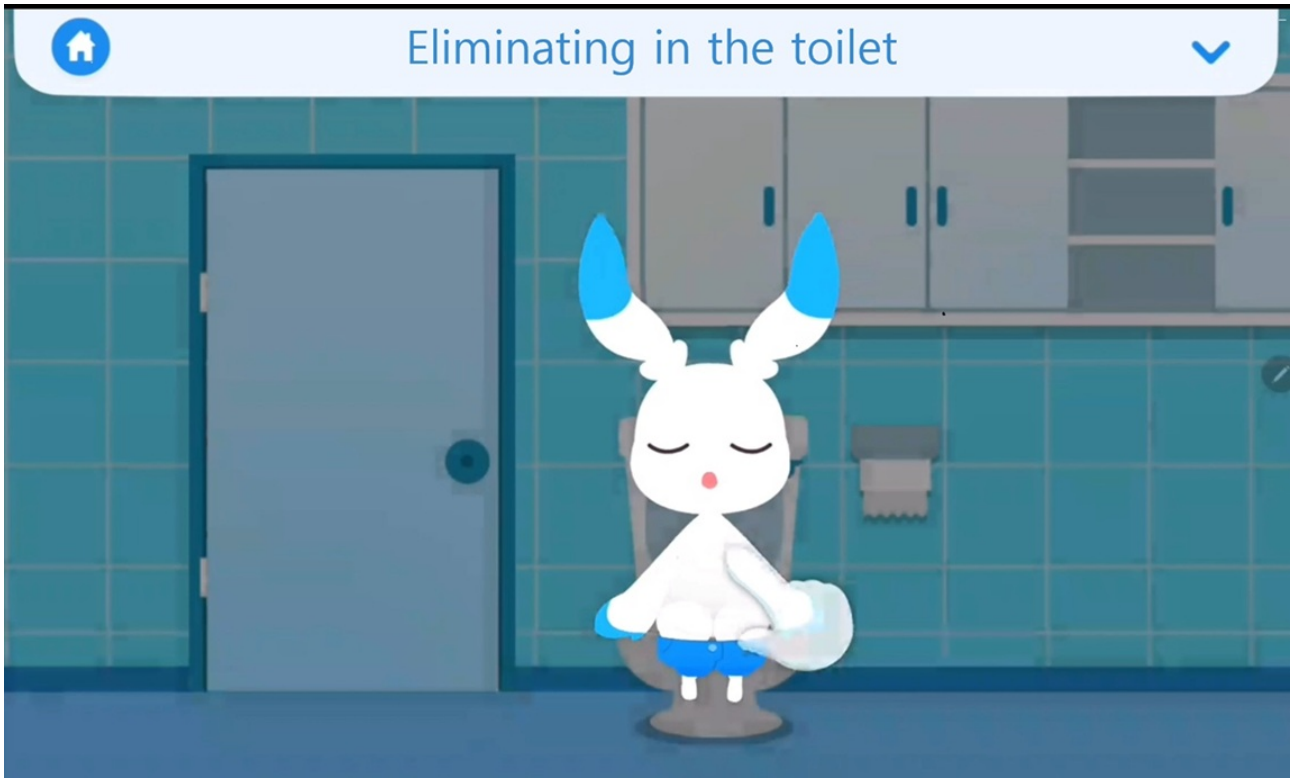
The app incorporated a reward structure consistent with token-based reinforcement [24]. Digital sticker tokens were delivered contingent on successful completion of targeted steps. Tokens were accumulated and exchanged using a fixed rule (10 tokens→immediate reward). Reward options could include in-app content (eg, mini games or customization and decoration features) and/or caregiver-selected preferred items or activities available in the bathroom area, allowing for individualized reinforcement while keeping the exchange rule consistent. No punishment or aversive procedures were used.

Intervention: Stepwise Animated Video Modeling App

Overview

The toileting routine was structured as a chained sequence of 16 steps. Caregivers selected target steps for training sessions based on the children's needs. All step-specific animated models featured a single rabbit character (Rudy) to provide consistent visual cues across steps and repeated practice opportunities. The app interface is shown in Figure 2.

Figure 2. User interface of the stepwise animated video modeling.



Session Flow and Feedback

Each training session followed a standardized flow for the selected steps: (1) the child watched the step-specific animated model, (2) the app prompted imitation ("Do what I did!"), (3) a pop-up rating question appeared (eg, "Did your child copy well?") with 2 response options ("Good job" or "Not really"), and (4) feedback was delivered based on the caregiver's response. If "Good job" was selected, the caregiver provided brief praise, and the app displayed a reward animation and delivered a digital sticker token that the child could drag and attach to a collection area. If "Not really" was selected, no reward feedback was provided and the modeling segment was replayed, allowing up to 2 additional attempts for that step.

Token Exchange Rule and Session Schedule

Sticker tokens served as digital tokens. Once the child accumulated 10 tokens, the preselected reward was delivered immediately in the bathroom area. During the intervention phase, caregivers were instructed to conduct at least one app-guided training session per day; training frequency could be individualized (eg, once daily vs 3 times daily) and was kept stable within each child once the intervention began.

Outcomes and Measures

Outcomes were grouped into 4 domains to describe elimination performance, toileting routine performance, caregiver-reported functioning, and implementation.

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Caregiver-Recorded Toileting Logs

Caregivers recorded toileting behavior using an online tracking sheet (Google Forms) provided by the research team. Logs were completed whenever the child urinated or defecated or participated in toileting practice and included date and time, location, elimination type (urination or defecation), in-toilet success, and step-level items aligned with the 16-step routine, with optional comments. Because children attended day care, kindergarten, or school, caregivers primarily recorded events occurring when the children were under caregiver supervision; events outside caregiver observation may not have been captured.

Elimination Outcome: In-Toilet Elimination Success

In-toilet elimination was defined as urination or defecation occurring into the toilet bowl. Phase-level success rates were calculated separately for urination and defecation as (number of in-toilet elimination events/total elimination events recorded) × 100. For target-specific elimination outcomes, denominators were based on the elimination type selected in the caregiver log. For urination training participants, events categorized as urination or mixed urination and defecation episodes were included in the urination denominator. Mixed events were coded as in-toilet successes only when the caregiver marked the episode as successful. Records in which urination was mentioned only in free-text comments but not selected as the elimination type were not counted. Practice episodes without elimination, nontarget elimination events, and entries with insufficient information were excluded from the corresponding outcome denominator.

Toileting Routine Performance Outcome: Daily Completion of the 16-Step Routine

Caregivers recorded step-level completion aligned with the 16-step routine for each recorded log entry (including practice episodes regardless of whether elimination occurred). Daily routine completion was calculated as (sum of successfully completed steps recorded that day/total step opportunities recorded that day) × 100. Total step opportunities were defined by the number of recorded log entries for that day multiplied by 16 steps (based on the standardized routine). For example, if 2 log entries were recorded on a given day, the total step opportunities were 32; if 24 steps were completed across those entries, the daily completion for that day was 75%. Given variability in the number of recorded entries per day, day-level percentages were interpreted primarily by patterns over time (eg, trends) rather than isolated single-day values. Because elimination cannot be ethically controlled, routine performance was evaluated separately from elimination outcomes. Step 8 (eliminating in the toilet) was coded as completed only when urination and/or defecation occurred. Practice entries in which elimination did not occur were retained for routine performance analyses, but step 8 was coded as not completed for those entries; elimination outcomes were captured only through the event-based in-toilet success metric.

Toilet Use Method (Initiation and Assistance Categories)

For each log entry, caregivers selected one mutually exclusive category describing how the toileting episode occurred: caregiver prompting, child communication or indication of toileting need, independent toilet use, or accident (elimination outside the toilet). Phase-level percentages were summarized descriptively for each participant.

Caregiver-Reported Outcomes (Standardized Measures)

Caregivers completed standardized questionnaires online at prespecified time points.

The Korean version of the Gilliam Autism Rating Scale–Second Edition (K-GARS-2) is a caregiver, teacher, or clinician–rated autism screening measure for individuals aged 3 to 22 years [26,27]. It includes 42 items across 3 subscales—stereotyped behaviors, communication, and social interaction—yielding standardized scores.

The Korean Scales of Independent Behavior–Revised (K-SIB-R) is a standardized, norm-referenced measure of adaptive functioning [28]. In this study, we summarized (1) toileting age-equivalent scores (years and months) and (2) Personal Self-Care W scores. In addition, to contextualize change relative to age expectations, we expressed Personal Self-Care W scores as deviation from age-based norms in SD units using normative values from the K-SIB-R manual; normative mean and SD values are not reported in this manuscript.

The Behavior Rating Inventory of Executive Function–Preschool Version (BRIEF-P) is a caregiver-rated measure of executive functioning for preschool children [29]. It includes 63 items across 5 clinical scales (inhibit, shift, emotional control, working memory, and plan or organize), with higher scores indicating greater executive function difficulties.

The Korean Parenting Stress Index, Fourth Edition, Short Form (K-PSI-4-SF) assesses parenting stress among parents of children aged 1 to 12 years [30]. It comprises 3 subscales—parental distress, parent-child dysfunctional interaction, and difficult child—and yields a total stress score, with higher scores indicating greater parenting stress.

Treatment Fidelity

Treatment fidelity was evaluated using a 7-item checklist developed for this study based on a prior Korean intervention study using a social validity measure [31]. Caregivers completed the checklist on 5 occasions per participant during the intervention period, rated adherence on a 5-point scale, and reported deviations or modifications. The items assessed were (1) preparation of the training environment, (2) arrangement of materials or reinforcers, (3) caregiver instruction to the child, (4) correct software use, (5) waiting for the child's response, (6) delivery of reinforcement for correct responding, and (7) appropriate responding to incorrect behavior (eg, replay without reinforcement). Fidelity was calculated as (acquired score/total possible score) × 100. The treatment fidelity checklist items can be found in Table S1 in Multimedia Appendix 1.

Social Validity

Social validity was assessed after the intervention using a caregiver questionnaire (9 items, 5-point Likert scale). Items assessed perceived effectiveness, acceptability, safety, feasibility, and overall satisfaction with the toileting program.

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The questionnaire was developed and refined based on a prior Korean intervention study reporting treatment fidelity procedures [31].

Procedure and Study Phases

No parallel control group was included in this study; instead, experimental control was supported by the staggered introduction of the intervention across participants.

Caregivers received study information and completed informed consent; the device was distributed; caregivers received 1:1 training on app use and home implementation, including operational definitions for caregiver recording and completion of the Google Forms–based logs; and preintervention questionnaires and recording instructions were completed. During the study, the research team reviewed submitted records weekly and followed up with caregivers via telephone when needed to clarify missing or ambiguous entries.

At baseline, no app-guided training was conducted. Children followed usual toileting routines, and caregivers recorded toileting events and step-level items. Baseline duration was staggered across participants (minimum of 5 days).

During the intervention, caregivers implemented app-guided sessions daily (minimum once per day; the individualized frequency was kept stable within each child) and continued recording. The intervention was introduced sequentially across participants; a participant began the intervention when the preceding participant met an a priori decision rule (mean routine performance across 3 consecutive intervention days exceeding the baseline mean by ≥15 percentage points). The intervention phase ended when the mastery criterion (≥80% for 3 consecutive sessions or days) was met or when the discontinue criterion was met (no meaningful improvement over 15 sessions).

Caregivers completed questionnaires and implementation measures at the end of the intervention period, and a follow-up was conducted 3 months after the intervention and consisted of 3 recording days using the same logs; the app was not used during follow-up.

Data Analysis

Descriptive analyses other than nonoverlap of all pairs (NAP) were conducted using R (version 4.3.1; R Foundation for Statistical Computing). Outcomes were summarized descriptively using visual analysis and phase comparisons. No confirmatory hypothesis testing was performed. To supplement visual analysis of single-case data, NAP [32] was computed using Python (version 3.13.5; Python Software Foundation) for each participant as a descriptive nonoverlap index for daily toileting routine completion. Follow-up days were not included in these calculations. For K-SIB-R Personal Self-Care W scores, SD unit deviation from age norms was computed descriptively as (W − age norm mean)/(age norm SD) using manual-based norms.

Results

Participant Flow and Available Data

A total of 10 children were enrolled. Four children (T05, T06, T09, and T10; n=2 girls) met the prespecified analytic inclusion criterion (≥5 caregiver-reported app-guided training sessions) and were included in the final analyses. Reasons for noncompletion or exclusion from the final analytic sample are summarized in Table S2 in Multimedia Appendix 1. Across phases, the number of caregiver log entries was as follows: n=10 at baseline and n=32 during the intervention for T05, n=42 at baseline and n=90 during the intervention for T06, n=51 at baseline and n=141 during the intervention for T09, and n=32 at baseline and n=144 during the intervention for T10. Follow-up consisted of 3 recording days, during which caregiver log entries were recorded for T05 (n=6), T06 (n=9), T09 (n=14), and T10 (n=14). Participant characteristics and baseline toileting profiles are shown in Table 1.

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Table . Baseline characteristics of participants included in the final analyses.

Characteristics	T05	T06	T09	T10
Age	4 years, 3 months	5 years, 3 months	4 years, 6 months	6 years, 11 months
Sex	Female	Male	Male	Female
ASD[a] diagnostic status	Confirmed	Confirmed	Clinical ASD concern; diagnosis pending	Confirmed
Relevant comorbidity	None reported	None reported	None reported	Intellectual disability
K-GARS-2[b]	100	79	94	<69
Language level	Spontaneous 2 - to 3-word phrases	Several spontaneous words (eg, “diaper,” “take off,” “pee,” and “wet wipes”)	Spontaneous 2 - to 3-word phrases for requests	Several spontaneous words (eg, “water,” “cup,” “mom,” and “dad”)
Digital device use	Able to use simple controls	Able to use tablet apps for watching videos at home	Able to select desired items with setup assistance	Able to activate a smart device and open desired apps
Training target	Defecation	Seated urination	Seated urination	Toileting request+seated urination
Baseline toileting profile	Defecated while squatting behind a curtain in the bedroom wearing underwear	Had urine accidents in clothing and walked around undressed afterward	Urinated in the toilet when assisted by the caregiver but had no independent toileting behavior	Self-initiated toilet attempts at home but had accidents outside the home without communication

[a]ASD: autism spectrum disorder.

[b]K-GARS-2: Korean version of the Gilliam Autism Rating Scale–Second Edition.

In-Toilet Elimination Success

Table 2 summarizes the phase-level percentage of elimination events that occurred in the toilet bowl (in-toilet elimination). Because Table 2 reports target-specific elimination outcomes, the denominators in Table 2 differ from the total number of caregiver log entries reported above. Baseline in-toilet elimination success varied across participants (0% - 23/27, 85.2%). During the intervention, all participants showed higher in-toilet elimination success than at baseline, and all participants showed 100% in-toilet elimination based on the available events during the limited 3-day follow-up observation window.

Table . Target-specific in-toilet elimination success across study phases. Percentages were calculated using target-specific elimination events as denominators. Practice episodes, nontarget elimination events, and entries with insufficient information were excluded.

Participant IDs	Target outcome	Baseline, n/N (%)	Intervention, n/N (%)	Follow-up, n/N (%)
T06	Urination	10/35 (28.6)	62/84 (73.8)	8/8 (100)
T10	Urination	23/27 (85.2)	115/123 (93.5)	12/12 (100)
T09	Urination	37/45 (82.2)	131/134 (97.8)	13/13 (100)
T05	Defecation	0 (0)	30/32 (93.8)	6/6 (100)

For T06, in-toilet elimination increased from 28.6% (10/35) at baseline to 73.8% (62/84) during the intervention (+45.24 percentage points; Table 2). Follow-up in-toilet elimination success was 100% (8/8) based on the available follow-up events (limited 3-day observation window).

For T10, baseline in-toilet elimination was 85.2% (23/27) and increased to 93.5% (115/123) during the intervention (+8.31 percentage points; Table 2). Follow-up in-toilet elimination success was 100% (12/12) based on the available follow-up events (limited 3-day observation window).

For T09, baseline in-toilet elimination was 82.2% (37/45) and increased to 97.8% (131/134) during the intervention (+15.54 percentage points; Table 2). Follow-up in-toilet elimination success was 100% (13/13) based on the available follow-up events (limited 3-day observation window).

For T05, baseline in-toilet elimination was 0% and increased to 93.8% (30/32) during the intervention (+93.75 percentage points; Table 2). Follow-up in-toilet elimination success was 100% (6/6) based on the available follow-up events (limited 3-day observation window).

It should be noted that percentages were calculated using target-specific elimination events as denominators. Practice episodes, nontarget elimination events, and entries with insufficient information were excluded.

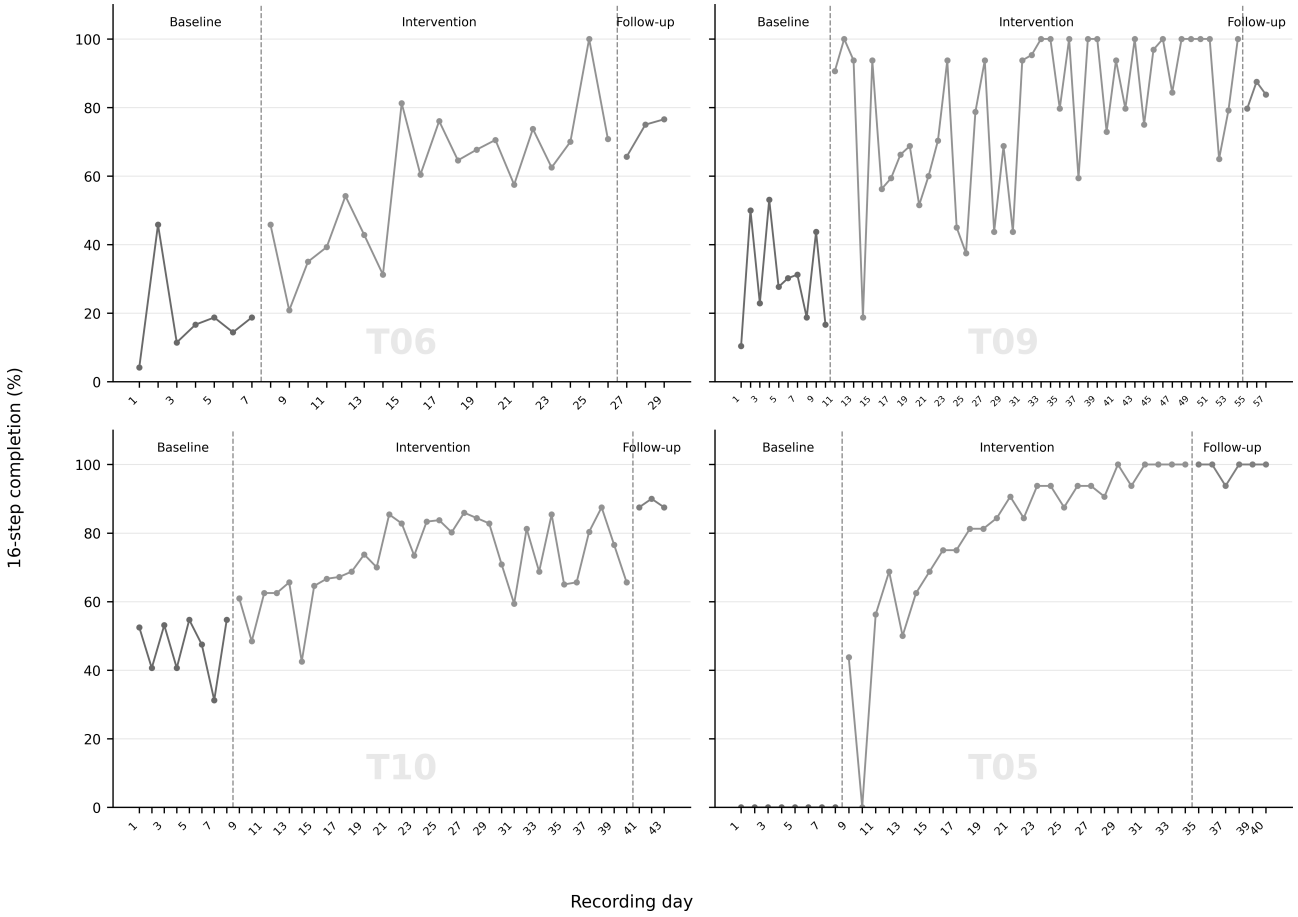
Toileting Routine Performance: Daily Completion of the 16-Step Routine

Daily toileting routine step completion (percentage) for all 4 participants is shown in Figure 3. Because the number of recorded log entries varied by day, day-level percentages were interpreted primarily by patterns over time (eg, level and trend). Visual inspection also indicated differences in the immediacy

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of effect: routine completion for T09 exceeded all baseline values from the first intervention days, and T05 increased from a stable 0% at baseline on the first intervention day, indicating relatively immediate changes in level, whereas T06 and T10 showed more gradual improvements across the intervention phase.

Figure 3. Day-level completion of the 16-step toileting routine across baseline, intervention, and follow-up phases. Each data point represents the mean percentage of completed steps across all caregiver-recorded entries within a recording day. The x-axis represents the sequence of recording days with available caregiver-recorded data and does not reflect the actual calendar interval between phases. Vertical dashed lines indicate phase transitions. Follow-up observations were collected approximately 3 months after the intervention phase, although the exact calendar interval varied across participants.



T06 showed a low and stable baseline followed by a clear upward shift and increasing trend after intervention onset, reaching sustained high performance later in the intervention phase and remaining elevated during follow-up.

T10 showed moderate baseline performance with variability; after intervention introduction, routine completion increased overall with intermittent dips, and follow-up values remained within the higher range observed late in the intervention.

T09 showed baseline variability; during the intervention, routine completion continued to fluctuate but with an overall upward pattern and repeated high-performance days later in the intervention. Follow-up values remained higher than baseline.

T05 showed 0% routine completion during baseline and increasing routine completion during the intervention, with high performance later in training and elevated values during follow-up.

Supplementary nonoverlap analyses using day-level 16-step completion percentages indicated substantial phase separation across participants, with NAP values ranging from 0.9580 to 0.9808 (Table 3). This index complemented the visual analysis by quantifying the degree of nonoverlap between the baseline and intervention phases.

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Table . Nonoverlap indexes for day-level 16-step toileting routine completion[a].

Participant IDs	Baseline days used, n	Intervention days used, n	Baseline daily 16-step completion (%)	Intervention daily 16-step completion (%)	NAP[b]
T05	8	26	0.00	79.57	0.9808
T06	7	19	18.58	59.18	0.9586
T09	10	44	30.48	79.76	0.9580
T10	8	32	46.88	71.93	0.9648

[a]"Days used" refers to recording days with available step completion data. Follow-up days were not included in nonoverlap analyses. T05 was evaluated in an AB design without staggered replication across participants; indexes for T05 are therefore descriptive only.

[b]NAP: nonoverlap of all pairs.

Toileting Method (Initiation and Assistance Categories)

Phase-level distributions of toileting method categories (independent toilet use, caregiver prompting, child communication or indication, and accident) can be found in Table S3 in Multimedia Appendix 1. Overall, accidents decreased for T05, T06, and T09 during the intervention and were not observed at follow-up for any participant. Independent toilet use increased prominently for T05 and T06. Child communication or indication was observed primarily for T09 and T10 during intervention and follow-up, whereas caregiver prompting remained common, particularly for T09.

Standardized Measures

Baseline characteristics, including K-GARS-2 scores, are shown in Table 1. K-SIB-R outcomes are summarized in Table 4.

Table . Korean Scales of Independent Behavior–Revised toileting age-equivalent (AE) scores and Personal Self-Care W scores (with norm-referenced deviation in SD units, which were computed descriptively using manual-based age norms as [W − age norm mean]/[age norm SD]; normative mean and SD values are not reported).

Participant IDs	Chronological age	Toileting AE		Personal Self-Care W, SD units			Norm-referenced deviation, SD units	
		Before	After	Before	After	ΔW	Before	After
T06	5 y, 3 mo	2 y, 2 mo	3 y, 7 mo	467	482	+15	−3.11	−1.08
T10	6 y, 11 mo	1 y, 11 mo	2 y, 7 mo	465	474	+9	−3.73	−2.65
T09	4 y, 6 mo	1 y, 11 mo	2 y, 7 mo	465	474	+9	−3.53	−1.99
T05	4 y, 3 mo	2 y, 8 mo	4 y, 0 mo	476	484	+8	−1.64	−0.27

On the K-SIB-R Personal Self-Care domain, age-equivalent scores increased from before to after the intervention. To contextualize change relative to age expectations, Personal Self-Care W scores increased for all participants (ΔW=+8 to +15), and deviation from age-based normative means decreased (Table 4). Notably, T06 moved from approximately 3 SDs below the age norm at baseline to approximately 1 SD below after the intervention, and T05 moved to within 1 SD of the age norm after the intervention. Despite improvement, some participants remained at 2 or more SDs below age norms after the intervention (eg, T10).

Exploratory changes in BRIEF-P subscale scores and K-PSI-4-SF percentile ranks can be found in Table S2 in Multimedia Appendix 1.

Implementation Outcomes: Treatment Fidelity and Social Validity

Treatment fidelity scores, calculated from caregiver-completed fidelity checklists (5 administrations per participant), indicated favorable adherence to intervention procedures. Social validity ratings (Table 5) indicated favorable caregiver perceptions of acceptability, safety, and feasibility and overall satisfaction with the program.

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Table . Mean scores on the social validity questionnaire from 4 caregivers of participants.

	Mean scores
Total	4.4
Understanding	4.75
Convenience	4.5
Reuse intention	4.25
Recommendation intention	4.75
Children's immersion	4.5
Safety	4.75
Effectiveness	4.25
Expression increase	4.25
Hygiene independence	4

Discussion

Principal Findings

In this pilot study, a caregiver-implemented mobile app that combined stepwise animated video modeling with a structured reward system was associated with improvements in toileting behaviors among young children with ASD. Across participants, the proportion of elimination events occurring into the toilet increased during the intervention and showed 100% in-toilet elimination during the limited 3-day follow-up observation window conducted 3 months after the intervention. In parallel, completion of the 16-step toileting routine improved over time, suggesting gains in broader toileting-related self-care behaviors beyond voiding alone (eg, undressing, flushing, and hygiene steps). Caregivers also reported favorable adherence and favorable perceptions of acceptability and safety, supporting feasibility of home implementation for families who engaged with the app.

A key finding of this pilot study relates to the feasibility boundaries of caregiver-mediated digital interventions. We observed a high attrition rate, with 60% (6/10) of enrolled families discontinuing participation or being excluded from analysis for heterogeneous reasons, including child condition or sleep-related difficulties, low tablet or app engagement, inability to progress beyond toilet sitting readiness, caregiver recording or implementation nonadherence, and postenrollment ineligibility (Table S1 in Multimedia Appendix 1). The high attrition rate represents a major limitation of the present study but also provides useful feasibility information for future research. The pattern of discontinuation suggests that successful implementation of this app requires specific child prerequisites (eg, basic imitation skills and tolerance for tablet interaction) and sufficient parental resources to facilitate the initial sessions. This aligns with broader findings in eHealth research, where open trials often reveal high attrition, highlighting the need to tailor inclusion criteria to the families most likely to benefit [33]. Thus, the findings suggest that the intervention may be beneficial for families able to sustain engagement, but broader applicability requires further study with clearer inclusion criteria. Toileting interventions for children with ASD have historically emphasized in-toilet voiding outcomes using intensive schedules and reinforcement-based packages and may vary widely in components and reporting. Prior reviews indicate that, although many approaches can improve voiding outcomes, the evidence base remains dominated by small-n single-case experimental studies and heterogeneous outcome definitions, which limits comparability and confidence in generalizability [4,5]. Video modeling is often considered well suited for ASD because it reduces verbal demands and leverages visual learning, with evidence supporting its use across functional skill targets [13,14]. Toileting-focused studies have further shown that incorporating animation into video modeling can enable depiction of sensitive behaviors while retaining a complete routine sequence [19,20]. Our findings add to this literature by applying an animated stepwise routine in a mobile format designed for repeated use in naturalistic caregiver-managed settings.

A central conceptual clarification warranted by this study concerns the distinction between the digital platform and the behavioral intervention it delivered. The app served as a structured delivery medium for a multicomponent behavioral intervention that incorporated task analysis, behavior chaining, caregiver-mediated prompting, contingent token-based reinforcement, and stepwise animated video modeling. The study findings therefore reflect the preliminary feasibility and potential benefit of this intervention package as implemented through a caregiver-mediated digital platform rather than evidence on any single technological feature. This distinction is consistent with the broader literature on mHealth interventions, which emphasizes that behavioral mechanisms—not digital packaging—drive therapeutic change. Future work should use dismantling designs or component analyses to clarify the relative contributions of video modeling, token reinforcement, task analytic structure, and caregiver mediation to observed outcomes.

A central design decision was to operationalize toileting as a 16-step task analysis aligned with chaining principles. This allowed caregivers to target discrete steps and reinforce incremental progress rather than focusing exclusively on elimination outcomes [24,25]. Importantly, step completion was tracked even when elimination did not occur (eg, the child sat on the toilet but did not void), reflecting how toileting

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practice occurs in real-world routines. This may be relevant for children with ASD who often experience difficulty with sequencing and adaptive self-care skills [1]. The choice of animation (rather than live action) also addressed privacy and potential discomfort associated with human depictions of toileting-related behaviors while providing a consistent, child-friendly model.

Although the app included interactive elements, we interpret the motivational component primarily as reinforcement support. The token exchange rule (10 digital stickers exchanged for an immediate reward) implemented a clear contingency while allowing for individualized reinforcers (eg, in-app activities and/or caregiver-selected preferred items). This characterization avoids overstating "gamification" and makes the hypothesized mechanism explicit: repeated practice of a structured routine paired with contingent reward.

Beyond caregiver-recorded toileting logs, standardized assessment data provided descriptive contextual information that was generally consistent with the behavioral observations. On the K-SIB-R, toileting age-equivalent scores increased for all participants, and Personal Self-Care W scores moved closer to age-based expectations (Table 4). Norm-referenced deviation (SD units) decreased for each participant. These SD unit values represent distance from age norms rather than an effect size from a controlled comparison and should be interpreted cautiously. However, reporting a standardized measure alongside event-based and routine-based outcomes is consistent with the observation that the pattern of change was not limited to a single measurement approach.

This study has limitations consistent with early-stage digital health and single-case experimental research. First, the analytic sample was small (4 children), and 60% (6/10) of enrolled participants were not included due to discontinuation or insufficient exposure, underscoring the central importance of engagement and feasibility in caregiver-mediated digital interventions. Because baseline characteristics were not systematically available for all participants who were not included in the final analyses, formal comparison between completers and noncompleters was not possible; however, available contextual information and reasons for noncompletion or exclusion are summarized in Table S1 in Multimedia Appendix 1. Second, primary outcomes relied on caregiver-reported logs, which may introduce reporting bias and incomplete capture of events occurring outside caregiver supervision. Although caregivers received structured training and the research team reviewed records weekly with telephone follow-up when needed, independent observation and interobserver agreement data were not collected, limiting the reliability of caregiver-reported outcomes. Third, the follow-up phase consisted of 3 recording days at 3 months after the intervention, providing a limited sample of maintenance. Finally, day-level step completion percentages can be influenced by variation in the number of recorded events per day; therefore, trends over time are more interpretable than isolated daily values. In addition, technology-related factors may have affected feasibility. Children with limited interest in or tolerance for tablet-based activities may have difficulty engaging with the intervention, and caregiver time, digital literacy, and home technology environments may influence implementation. Therefore, app-based toileting interventions may not be appropriate for all children with ASD without additional engagement supports or caregiver assistance. Furthermore, because this was an early-stage single-case pilot feasibility study, a formal group-level sample size calculation was not performed. The enrollment target was determined pragmatically based on the intensive caregiver-mediated home implementation protocol, the multiple-baseline design, and anticipated recruitment constraints in young children with ASD requiring toileting support. These limitations indicate that the present findings should be interpreted as preliminary signals of feasibility and potential benefit rather than definitive evidence of effectiveness.

Future work should prioritize more rigorous evaluation, improved measurement, and strategies to sustain engagement while preserving the pragmatic, home-based nature of delivery. We have initiated an exploratory randomized controlled trial (target N=30) to evaluate effectiveness and implementation outcomes more robustly. This next phase can follow established reporting guidance for eHealth interventions and incorporate objective use metrics (in-app logs), a longer follow-up period, and independent outcome verification where feasible. Additional iterative development may also be warranted to support sustained engagement over longer periods given that low engagement was a reason for discontinuation in some families.

Conclusions

A caregiver-implemented mobile app that integrates stepwise animated video modeling, task analysis–based chaining, and reinforcement support was feasible for families who engaged with the software and was associated with improvements in toileting outcomes and adaptive self-care indicators among young children with ASD. Larger controlled studies are needed to determine effectiveness, characterize engagement and attrition, and establish scalable implementation strategies.

Acknowledgments

The authors sincerely thank the participating families, clinicians, and development teams for their commitment to the study and for contributing to the mobile-based animated video modeling app with token-based reinforcement support. The content is solely the responsibility of the authors and does not necessarily represent the official views of the supporting organizations. During manuscript preparation, AI-assisted tools were used to support language editing, translation, and reference formatting. OpenAI's ChatGPT and Google's Gemini were used to support language editing and translation, and OpenAI's ChatGPT was additionally used to support reference formatting. These tools were not used for study design, data generation, data analysis, or interpretation

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of the results. All final decisions regarding the content and conclusions of this manuscript were made by the authors, who take full responsibility for its accuracy and integrity.

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Data Availability

The datasets generated and analyzed during the current study contain identifiable participant information and are therefore not publicly available to protect participant privacy. However, deidentified data supporting the findings of this study are available from the corresponding author on reasonable request.

Authors' Contributions

Conceptualization: IS, Yearin Kim
Data curation: IS, Younglae Kim
Formal analysis: IS, Younglae Kim
Funding acquisition: DK, JM
Investigation: Younglae Kim, JK
Methodology: Yearin Kim
Project administration: DK
Resources: Yearin Kim, JK
Software: SL
Supervision: BNK
Validation: Younglae Kim, Yearin Kim
Visualization: Younglae Kim
Writing—original draft: IS, Younglae Kim
Writing—review and editing: IS

Conflicts of Interest

IS and Younglae Kim are employees of Emotiv Inc, which developed the animated video modeling app with token-based reinforcement support used in this study. SL and DK are also employees of Emotiv Inc, DK is the head of research and development, and JM is the chief executive officer of the company. All other authors declare no other conflicts of interest.

Multimedia Appendix 1
Supplementary tables on treatment fidelity, participant noncompletion or exclusion, toileting methods, and exploratory outcomes.
[DOCX File, 39 KB - pediatrics_v9i1e92147_app1.docx]

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Abbreviations

ASD: autism spectrum disorder
BRIEF-P: Behavior Rating Inventory of Executive Function–Preschool Version
K-GARS-2: Korean version of the Gilliam Autism Rating Scale–Second Edition
K-PSI-4-SF: Korean Parenting Stress Index, Fourth Edition, Short Form

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K-SIB-R: Korean Scales of Independent Behavior–Revised
mHealth: mobile health
NAP: nonoverlap of all pairs

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Fully Virtual, Focused Applied Behavior Analysis Services: Acceptability and Feasibility Study

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Abstract

Background: Traditional models of applied behavior analysis (ABA) services for those diagnosed with autism spectrum disorder (ASD) involve time-intensive, labor-intensive, comprehensive, in-person services. The increasing prevalence of ASD in the United States has precipitated a need to identify effective, accessible, and innovative methods to address the needs of those with ASD.

Objective: The present descriptive study examines the feasibility and acceptability of a fully virtual, targeted model of ABA service delivery.

Methods: This retrospective analysis evaluated changes over time in adaptive behavior, maladaptive behavior, and caregiver satisfaction during focused, virtual ABA therapy delivered by a Board Certified Behavior Analyst.

Results: Improvements in standard scores across Vineland-3 domains and improvements in quality of life (Child and Family Quality of Life, Second Edition), in addition to high levels of caregiver satisfaction, were observed over time.

Conclusions: While causality cannot be determined for these improvements, results support the feasibility and acceptability of this novel ABA service delivery model.

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KEYWORDS

applied behavior analysis; comprehensive treatment; focused treatment; autism spectrum disorder; Board Certified Behavior Analyst

Introduction

Behavior analytic services can have profound positive impacts on individuals and their families. Behavior analysts identify behaviors to teach or reduce by working closely with stakeholders and use this information to select approaches for analyzing and changing behavior, and ultimately, to create socially significant and meaningful change for individuals [1]. As social significance varies from person to person, environment to environment, and culture to culture, the specific behaviors targeted by behavior analysts can be as varied as vocational skills and dental care, shoe tying and aggressive behavior, or law enforcement personnel behaviors and kindergarten readiness skills [2].

Due to efforts driven by families, grassroots organizations, service providers, and researchers across several decades, behavior analytic services are widely implemented to support autistic individuals and their families [3] (In an effort to respect the diverse perspectives of those on the autism spectrum, we use both identity-first language [eg, “autistic child”], person-first language [eg, “child with autism”], and neutral language [eg, “person on the autism spectrum”] to describe our participants and the recipients of applied behavior analysis [ABA] therapy [4]). According to a review conducted by Gitimoghaddam et al [5], ABA has been recognized as one of the most empirically validated forms of support for persons diagnosed with autism spectrum disorder (ASD). In recent years, the prevalence of ASD has become a topic of national interest within the United States, particularly following the release in April 2025 of updated prevalence data from 2022. This report indicates an increase in prevalence to 1 in 31 children from 1 in 36 children in 2020 [6].

As of 2019, all 50 states in the United States require “meaningful coverage” for autism treatment, including ABA therapy services [7]. When services are covered by medical insurance, providers must demonstrate medical necessity and clinical progress [8], both of which require the assessment of current functioning over time. Despite the widespread nature of insurance mandates and the common need to evaluate current functioning, there is limited consensus about the best measures to evaluate clinical outcomes or response to treatment [9,10]. Two measures identified to include in the ICHOM’s (International Consortium

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for Health Outcomes Measurement) Standard Set of outcomes for ASD are the Vineland Adaptive Behavior Scales-Third Edition (Vineland-3) and the Child and Family Quality of Life, Second Edition (CFQL-2) [9].

The Vineland-3 assessment measures caregiver-reported adaptive and maladaptive behavior [11] and has been used as an outcome measure in a variety of studies evaluating services for autistic individuals [12-15]. One such study evaluated changes in both the adaptive and maladaptive domains from the Vineland-3 as a function of the client's ASD severity level and usage of prescribed therapy hours [14]. The authors stratified participants by age at the first Vineland-3 administration as well as gender and analyzed changes in the adaptive domains and the extent to which participants' maladaptive subdomain scores improved from clinically significant to nonclinically significant following treatment. This approach of including Vineland-3 maladaptive subdomain score changes is not widespread in the ABA therapy outcomes literature, highlighting an important gap in the literature.

Although specific thresholds for minimal clinically important differences (MCID) have not yet been established for the Vineland-3, previous studies, such as Ostrovsky et al [12], have compared their participants' standard score changes over time, with MCID thresholds derived from MCIDs established for the Vineland-II assessment [16]. The MCID thresholds used by Ostrovsky et al [12] were +2.0 for the ABC (Adaptive Behavior Composite) standard score,+2.0 for the communication standard score,+2.6 for the socialization standard score, and +2.6 for the daily living standard score. While these score changes reflect an anchor-based approach to establishing clinical significance, they do not reflect industry data from actual clinical practice. Despite the lack of agreement within the industry about which tools are most appropriate and how to evaluate meaningful change, there is consensus that teaching adaptive behaviors is a primary goal of ABA services [17].

Some research shows a relation between adaptive skills and quality of life (QoL) for individuals with intellectual disability, with stronger adaptive skills being correlated with improved QoL [18]. Among autistic adults, factors associated with QoL may be even more complex than within other adult populations, making the inclusion of this measure critical to understanding how interventions can support improved QoL [19]. Given the interconnected nature of different QoL areas within a family system, one way of evaluating QoL is by assessing the psychosocial aspects at the individual and family level [20]. The CFQL-2 has been established as a reliable measure of psychosocial aspects of QoL, including child, family, caregiver, the financial, external support, partner relationship, coping, and QoL change [21]. Ciobanu et al [22] observed improvement in total QoL and across several subscales for a series of three patients receiving ABA therapy delivered by a parent behavior technician. These results suggest that, for the patients in their study, equipping parents with the knowledge and skills to support their own child's behavior change may have a positive impact on QoL for the whole family system. The extant literature using the CFQL-2 to evaluate QoL among individuals on the spectrum is limited [22,23], but, given the inclusion in the ICHOM ASD standard set [9], this tool may gain traction among ABA service providers interested in evaluating client progress from a variety of angles. A threshold for clinically significant change has not yet been established.

Today, the predominant form of ABA therapy in the United States is center- or home-based services delivered in a 2- or 3-tier model, whereby a Registered Behavior Technician (RBT) is the primary deliverer of care and is directly supervised by a Master's- or Bachelor's-level behavior analyst (often a Board Certified Behavior Analyst [BCBA]). This model is typically considered "comprehensive," which is defined as a scope of treatment that "typically encompasses multiple simultaneous goals within and across multiple domains, such as language, behavior, activities of daily living, social skills, and cognition" in their practice guidelines by the Council for Autism Service Providers [24]. According to these guidelines, comprehensive ABA treatment generally requires 30 - 40 hours of therapy per week to ensure adequate time for teaching and practice opportunities.

Although there is evidence of the efficacy of in-person, comprehensive ABA therapy delivered in a 2- or 3-tier model [25], there are also many challenges related to this service delivery model. The first and most common challenge related to the traditional service delivery model is a lack of access due to geography or a lack of providers within proximity. According to the US Census Bureau census conducted in 2020, a total of 80% of the population of the United States live in urban areas (defined as greater than 2500 people), and 20% live in rural areas (defined as 2500 people or less). Additionally, the availability of services in general tends to be concentrated in larger metropolitan areas [26].

Families who do have access to ABA services within reasonable proximity of their homes may experience other challenges. First, the available services do not always meet the needs of specific autistic individuals. In particular, school-age children with less global functional impairment may not be well-served by a comprehensive treatment program whose time commitment impacts school attendance or participation in enriching extracurricular activities. Recent studies examining the efficacy of lower intensity ABA services have demonstrated support for less time-intensive interventions [13,27].

Next, the comprehensive model relies on lesser-qualified service providers (eg, a provider with a high school diploma and 40 hours of training, supervised by a Master's- or PhD-level provider roughly 5% of the time) to deliver the bulk of client care. Turnover among these providers is high, with the Behavioral Health Center of Excellence reporting annual turnover of 65% in its 2022 ABA Compensation and Turnover Benchmark Report [28]. These high levels of turnover impact caregiver satisfaction [29] and may result in gaps in care or in lower-quality services being provided. According to current literature exploring parent training and caregiver-mediated interventions, increased caregiver participation in intervention can reduce parental stress levels, increase parental self-efficacy, and support positive child outcomes [30]; however, high levels of turnover and other barriers may prevent families from being meaningfully involved in care.

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Finally, the costs associated with health care for a child with autism, including traditional ABA services, are significant. A recent report from the Agency for Healthcare Research and Quality indicates that the average total health cost for a child being treated for autism was US $20,122 compared with the average total health cost of US $2201 for a child not being treated for autism [31].

Given the challenges associated with the comprehensive ABA service delivery model, some providers are seeking alternative models that address the concerns detailed above while still producing meaningful change on behalf of the families they serve. One relatively new option is a BCBA-direct, fully virtual, focused ABA therapy model. Services delivered via telehealth are less constrained by the geographic locations of the client or clinician, making it possible for clinicians to reach clients in more rural areas, as well as those residing in areas with a lower ratio of providers to clients. A growing body of literature supports the use of telehealth as an ABA service delivery modality [32-34]. Another benefit of this approach is that individuals who have more targeted clinical needs can receive more tailored interventions, focusing on the area of functional impairment that is most impactful at the time of treatment. These services can be delivered at a lower "dosage" than the recommended 30 - 40 hours per week for comprehensive services, potentially making them more accessible to busy families and more cost-effective for families and their funding sources. This approach is further bolstered by more frequent and consistent contact with a BCBA, who can make treatment decisions throughout each therapy session and evaluate procedures on an ongoing basis, unlike therapy models that rely on RBTs rendering the bulk of service hours. Finally, the telehealth treatment modality can allow for increased caregiver involvement and, therefore, a potential increase in naturalistic learning opportunities by removing many of the barriers families receiving center-based services encounter, such as logistical difficulty with going to the center for caregiver training sessions and a lack of generalization of skills being targeted in an environment very different from their home.

The purpose of this study was threefold: (1) to describe a novel ABA service delivery model that could serve as an alternative for some families; (2) to examine changes in adaptive skills, maladaptive behaviors, and QoL over time for participants who received this novel form of ABA therapy; and (3) to assess the social validity of this novel treatment model through a caregiver satisfaction survey. Evaluation of the fully virtual, BCBA-only, focused treatment model is important because this model represents a structurally different approach to delivering care compared to in-person, RBT-implemented, comprehensive therapy models and has the potential to mitigate many of the challenges associated with prevailing models.

Methods

Service Model

Behavior analytic services were delivered through a fully virtual, BCBA-only, focused treatment model provided by AnswersNow Inc, an ABA service provider. Clinicians delivered services through proprietary, HIPAA (Health Insurance Portability and Accountability Act)-compliant, synchronous audio-video software. All services were rendered by a BCBA, including assessment, direct therapy, therapy protocol modification, and caregiver training. At the outset of care, the assigned BCBA conducted a comprehensive assessment with each participant that included the Vineland-3, the CFQL-2, indirect behavior assessments (eg, FAST [functional assessment screening tool] and QABF [questions about behavior function]), and direct skill assessments based on the participant's clinical presentation (eg, VB-MAPP [Verbal Behavior Milestones Assessment and Placement Program] and AFLS [Assessment of Functional Living Skills]). The BCBA synthesized assessment results to determine the participant's strengths and areas of need, as well as to identify any behaviors that interfered with the participant being able to learn new skills or successfully contact less restrictive environments. The BCBA then developed goals to address the identified behaviors and selected behavior analytic intervention procedures to implement.

Following the initial assessment and throughout the course of treatment, the BCBA updated goals and adjusted therapy procedures in response to the participant's progress. While the specific goals targeted and teaching procedures used varied and were individualized to each participant, all BCBAs prioritized behaviors that were meaningful for families and/or participants and implemented procedures consistent with the principles of behavior analysis. At 6-month intervals, the BCBA conducted a reassessment to evaluate clinical progress and adjust goals accordingly. This reassessment included readministration of the Vineland-3, the CFQL-2, indirect behavior assessments, and direct assessments based on the participant's clinical presentation.

During ongoing treatment, participants received a combination of direct therapy, caregiver-mediated therapy, and caregiver training without the child present. The ratio of these different service types fluctuated throughout the course of treatment based on the participants' and families' needs; all families participated in caregiver training during the course of treatment, whether through caregiver-mediated services or caregiver training without the participant present, with a mean of 2.6 (SD 1.05) hours per week (range 0.25 total h to 6.37 h/wk). Direct therapy sessions consisted of the child interacting directly with the BCBA via synchronous audio-video, with screen-sharing capabilities. Caregiver-mediated sessions consisted of the child, caregivers, and BCBA being present via synchronous audio-video with the BCBA providing coaching and guidance to the caregiver, focusing on strategies for teaching new skills or reducing challenging behaviors, with the caregivers interacting directly with the child. Finally, caregiver training consisted of the BCBA and caregivers meeting via synchronous audio-video. During these sessions, the BCBA provided training to the child's caregivers on specific interventions for teaching their child new skills or reducing challenging behaviors.

Participants

Following IRB review and obtaining an exempt status determination, a sample of deidentified records from individuals who received ABA services through AnswersNow, Inc, between October 2021 and October 2025 was obtained. Participants were

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included if they had research consent on file, ASD listed as their primary diagnosis, at least two valid administrations of the Vineland-3 Comprehensive Parent/Caregiver Form (defined as the assessment being completed by the participant's parent or caregiver, not the clinician), at least four months between the first and most recent administration, and at least 15 minutes of ABA therapy (irrespective of service type) per week between the first and most recent administrations. When possible, the same caregiver completed the Vineland-3 at each administration; however, there were instances within the dataset in which 2 different caregivers completed the first and most recent assessments.

Ethical Considerations

AnswersNow, Inc, obtained consent to use deidentified clinical data for research purposes from all participants through a general research consent form signed by families either at the outset of treatment or during services. This research-specific consent was voluntary and revocable at any time, with no relationship to services rendered. Participant data were deidentified before analysis, and no personally identifiable information was shared with the researchers or used in this study. The Clemson University Office of Research Compliance determined the proposed activities involving human participants met the criteria for exempt level review under 45 CFR 46.104(d), and exempt level status was rendered on April 2, 2025 (IRB2025-0021). The data were encrypted and stored in accordance with the Clemson University Minimum Security Standards and analyzed using SPSS (version 31; IBM Corp).

Procedures

The analysis involved evaluating change over time in the results obtained from the comprehensive battery of assessments administered every 6 months, beginning with the first administration until the last administration, regardless of the number of administrations. Any participant with only one administration was not included in the sample. The comprehensive assessment included the administration of the Vineland-3, including all adaptive domain scales (communication, socialization, daily living skills, and ABC), Vineland-3 maladaptive domain scales (ie, internalizing and externalizing) for a subset of participants, the CFQL-2 scales (child, family, caregiver, financial, social network, partner relationship, coping, and overall), indirect behavior assessments (eg, FAST and QABF), and direct assessments based on the participant's clinical needs (eg, VB-MAPP and AFLS).

For the purposes of this study, the domain scale scores from the domains in the Vineland-3 assessment tool and the CFQL-2 assessment tool were used to assess participant progress and outcomes while receiving virtual, focused, BCBA-direct ABA therapy. Scale scores from each domain in the Vineland-3 and the CFQL-2 were captured from each administration. MCIDs were calculated for Vineland-3 score changes based on the thresholds used by Ostrovsky et al [12] (ie, +2.0 for ABC standard score, +2.0 for communication standard score, +2.6 for socialization standard score, and +2.6 for daily living standard score). Additionally, comparison analyses similar to those included by Adelson et al [14] were conducted to evaluate maladaptive behavior changes and to determine the potential influence on score change from several variables, including gender, insurer, hours of services, and ASD severity level.

Results

Sample Characteristics

A total of 504 participants from the original dataset of 1441 met the criteria to be included in this study. The total sample of 504 participants included 77% (388/504) males and 23% (116/504) females, and the average age at first Vineland-3 administration was 8.4 (SD 4.3; range 1 - 22) years. Participants were located across five different states: California, Georgia, New York, Texas, and Virginia. Among the 3.8% (19/504) of participants located in California, 18 were Medicaid recipients and 1 participant was not. Participants located in Georgia represented 40.7% (205/504) of the total sample, 153 of whom were Medicaid recipients and 52 of whom were not. The 0.2% (1/504) of participants located in New York consisted of 1 Medicaid recipient. Among the 7.5% (38/504) of participants located in Texas, 25 were Medicaid recipients and 13 were not. Finally, most participants, 47.8% (241/504), were located in Virginia; among these participants, 155 were Medicaid recipients and 86 were not.

ASD severity levels were available for 29.6% (149/504) of participants. This information was not available for all participants because it was not provided by the diagnosing professional. Within the social communication diagnostic domain, 39.6% (59/149) of participants' diagnostic reports indicated diagnostic severity level 1, 34.9% (52/149) indicated level 2, and 25.5% (38/149) indicated level 3. Within the restrictive and repetitive behaviors diagnostic domain, 40.9% (61/149) of participants' diagnostic reports indicated diagnostic severity level 1, 34.9% (52/149) indicated level 2, and 24.2% (36/149) indicated level 3. Across both diagnostic domains, a slight majority of the participants were identified as level 1.

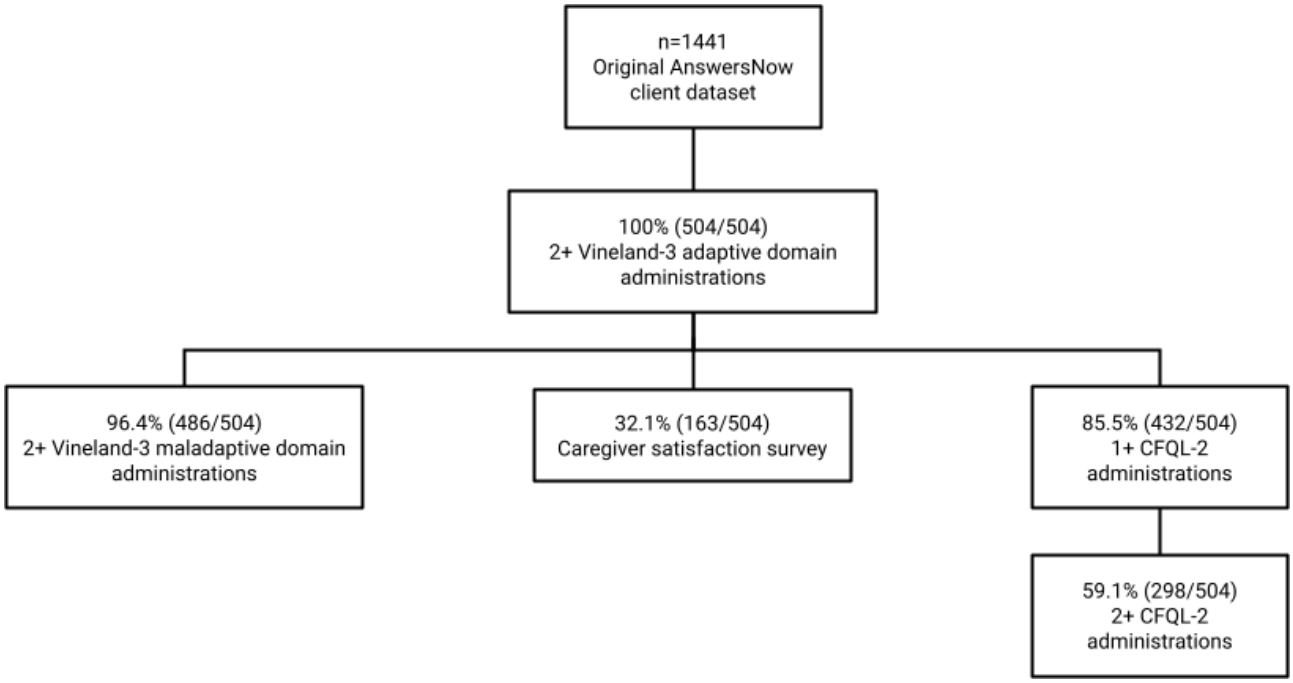
Among the participants included in our dataset, 96.4% (486/504) had at least two administrations of the Vineland-3 that included the internalizing and externalizing subscales of the maladaptive domain. Within the Q-Global assessment administration platform, the maladaptive domain is optional; the clients with missing data for this domain were excluded.

Among the participants in the overall dataset, 85.5% (431/504) had at least one valid CFQL-2 administration on file (administrations were considered invalid if eight or more questions were skipped). To evaluate change in QoL over time, we compared the first and most recent CFQL-2 scores for the 59.1% (298/504) of participants who had at least two valid administrations on file. For this dataset, the CFQL-2 was administered as an interview conducted by the BCBA with the participant's primary caregiver.

The final measure evaluated was caregiver satisfaction. Our dataset contained responses from a sample of 32.1% (162/504) of the total dataset. Figure 1 provides a breakdown of the different measures evaluated, the sample sizes for each, and the percentage of the total sample for which that measure was available.

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Figure 1. Breakdown of subsamples by measure. CFQL-2: Child and Family Quality of Life, Second Edition.



Service Hours

The average hours of services rendered per week are closely aligned across funding sources, with Medicaid recipients receiving a slightly higher number of hours per week on average 2.66 (SD 1.06) hours compared to non-Medicaid recipients who averaged 2.44 (SD 0.99) hours. That weekly alignment translates to a consistent average of total hours of services rendered, where Medicaid recipients received a slightly higher number of total hours on average (117.14, SD 90.08 h) as compared to non-Medicaid recipients who averaged 116.77 (SD 87.63) hours. The combined averages closely resemble the averages for Medicaid recipients, with an average of 2.6 (SD 1.05) hours per week of services rendered and an average of 117.03 (SD 89.26) total hours rendered. These results are consistent with the total sample size being more heavily comprised of Medicaid recipients.

Vineland-3 Descriptives

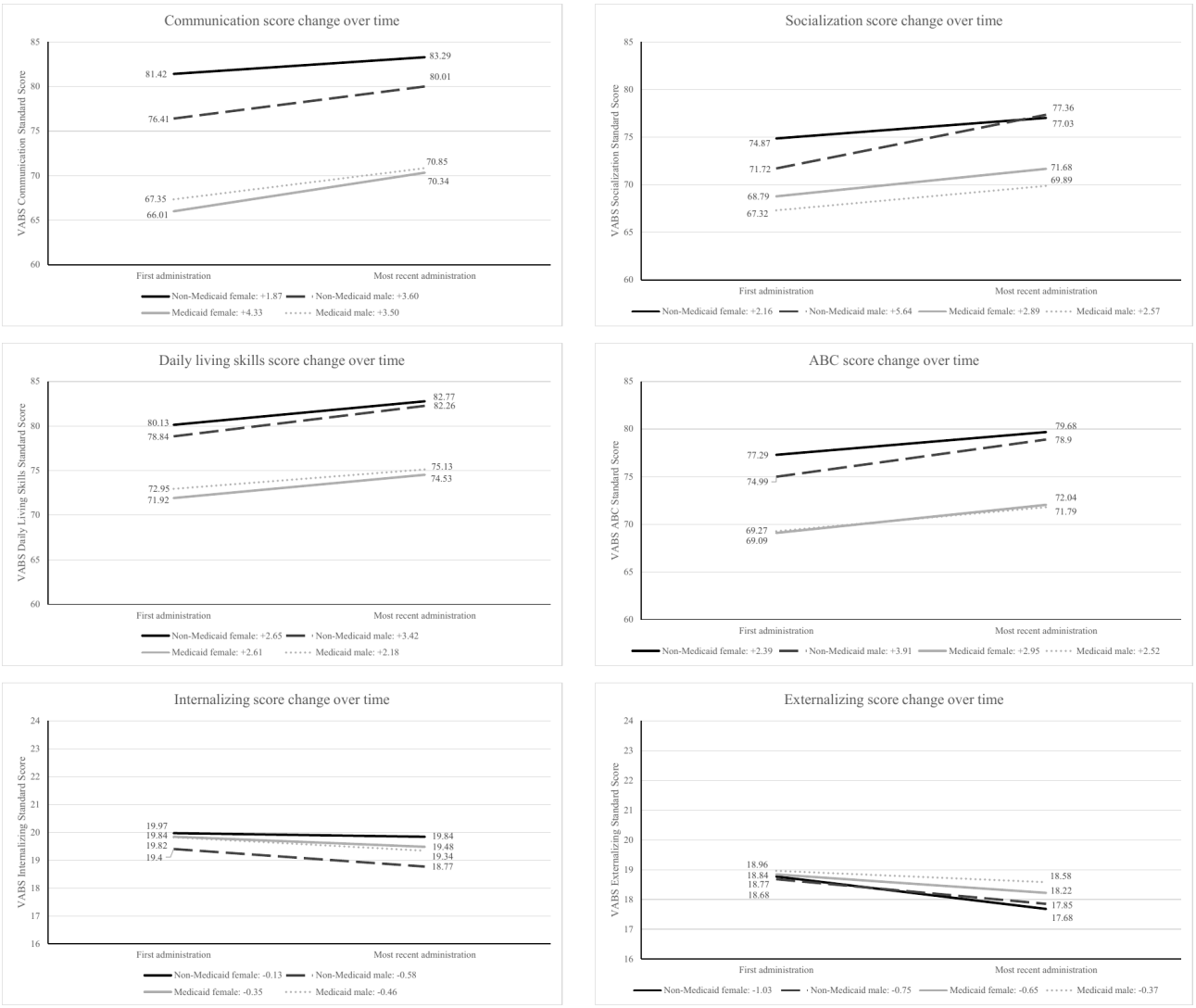
The following section is devoted to providing the descriptive statistics associated with the Vineland-3 administrations. Participants ranged from having 2 to 7 Vineland-3 administrations. Figure 2 displays the various score changes between the first assessment administration and the last assessment (most recent) administration for all participants, broken down by funding source and gender, and includes the adaptive behavior domains, the maladaptive behavior domains, and the ABC. The scoring of the Vineland-3 is based on the following recommended interpretation guidelines: high=130 - 140, moderately high=115 - 129, adequate=86 - 114, moderately low=71 - 85, and low=20 - 70 for scoring the adaptive behavior domains, and average=1 - 17, elevated=18 - 20, and clinically significant=21 - 24 on the maladaptive behavior domains [11].

At the first administration, non-Medicaid funded participants tended to have the highest adaptive behavior domain scores on average, and the averages across both funding groups and genders were consistent in the maladaptive behavior domains. The ideal pattern is for the scores from the adaptive behavior domains to increase across administrations and the scores from the maladaptive behavior domains to decrease. Across both funding groups and genders, there was improvement in all domains over time, suggesting that, on average, participants displayed more adaptive behavior and less maladaptive behavior.

Additionally, further illustrating the change from the first administration to the most recent administration, the average standard score change across domains according to funding source and gender is also included in Figure 2. While there was variability across the domains based on funding source and gender, on average, there were increases in all adaptive behavior domains across gender and funding source, and decreases in the maladaptive behavior domains across gender and funding source, with the least amount of average change being in the maladaptive behavior domains.

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Figure 2. Average domain score and domain score change; first assessment to most recent assessment across Non-Medicaid and Medicaid Recipients. ABC: Adaptive Behavior Composite; VABS: Vineland Adaptive Behavior Scales

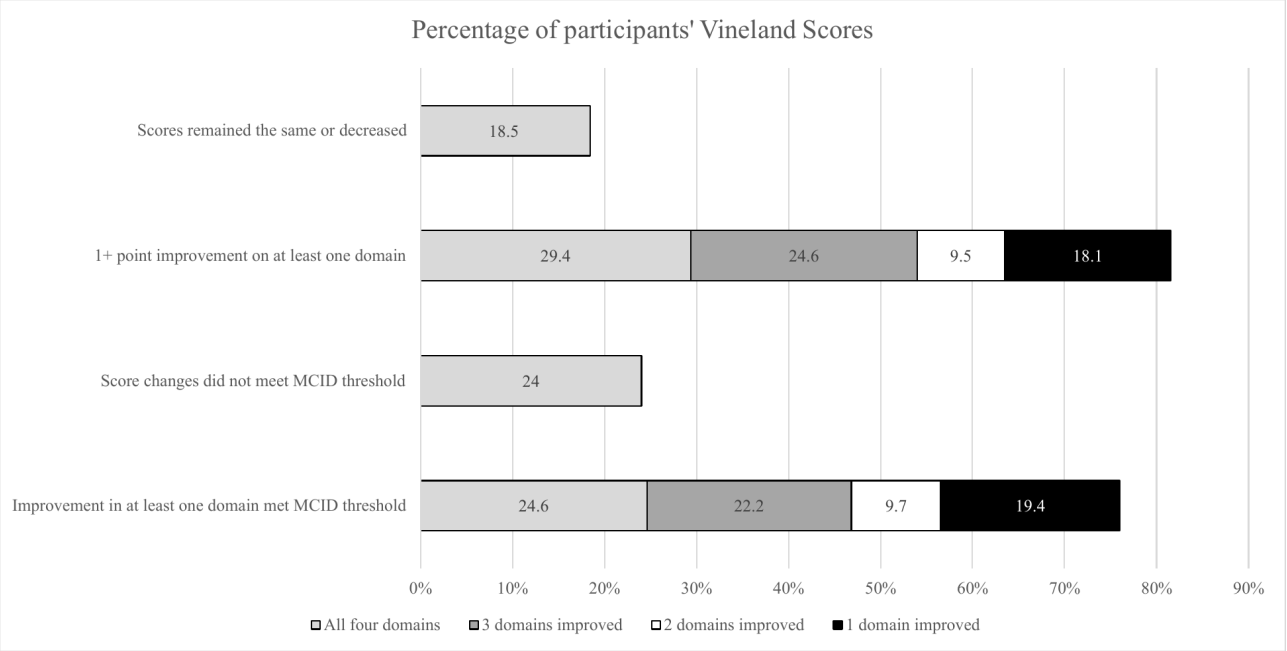


Across all adaptive and maladaptive behavior domains, average aggregate standard score changes were positive. Participants' (n=504) communication standard scores increased an average of 3.56 (SD 9.77) points, socialization standard scores increased an average of 3.34 (SD 11.62) points, daily living skills' standard scores increased an average of 2.58 (SD 7.89) points, and ABC standard scores increased an average of 2.92 (SD 7.89) points. Within the maladaptive behavior domain, participants' (n=486) v-scale scores decreased by 0.45 (SD 1.81) points on the internalizing subdomain and by 0.55 (SD 2.05) points on the externalizing subdomain. The results indicate improvements in both the adaptive and maladaptive domains; however, it is worth noting that the SDs for the socialization and daily living skills domains were higher, which indicates greater variability in those domains.

To further evaluate changes in domain standard scores, the percentage of participants showing a minimum of a 1-point improvement was calculated for the full sample. Figure 3 displays the pattern of standard score changes for the participants in detail, illustrating that 81.5% (411/504) of participants demonstrated a standard score change of +1 point in at least one domain, and 29.4% (148/504) showed a standard score change of +1 point in all domains. Participants who showed either no standard score change or a –1 or greater point change made up 18.5% (93/504) of the sample.

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Figure 3. Bar graph of Vineland scores of participants. MCID: minimal clinically important difference.



Also depicted in Figure 3 are the percentages of participants who met MCID thresholds for improvement from the first to most recent assessment administration, where the MCID scale is change in communication ≥2.0, change in socialization ≥2.6, change in daily living skills ≥2.6, and change in ABC ≥2.0 [12]. A total of 25% (124/504) of participants met MCID thresholds for all the domains, while 24% (121/504) did not meet MCID thresholds in any of the domains. A total of 76% (383/504) of participants met the MCID threshold for at least one domain. A total of 45% (13/31) of non-Medicaid females met MCID thresholds in all internalizing domains, whereas 57.9% (70/121) of non-Medicaid males met MCID thresholds in ABC, 52.9% (64/121) in communication, 48.8% (59/121) in daily living, and 56.2% (68/121) in socialization. A total of 56% (48/85) of Medicaid recipient females met thresholds in ABC and communication, 48.2% (41/85) in daily living, and 57.7% (49/85) in socialization. The data for Medicaid recipient males indicates that 50.9% (136/267) met thresholds for ABC, 56.9% (152/267) in communication, 43.8% (117/267) in daily living, and 44.9% (120/267) in socialization. Overall, the highest MCIDs were observed in the communication and ABC domains across genders and funding sources.

Additionally, changes in internalizing and externalizing scores are often accounted for in terms of the following clinically significant scoring categories: average=1 - 17, elevated=18 - 20, and clinically significant=21 - 24. Due to the nature of how the score ranges differ across the three categories, substantial movement across categories is less likely between the average category and the other categories because the score range for the average category is much larger than the other two categories.

Internalizing Scores

In the context of internalizing scores, in the first assessment administration, 11.9% (32/267) of Medicaid recipient males fell into the average category, 59.9% (160/267) into the elevated category, and 37.1% (99/267) into the clinically significant category. At the most recent administration, there was no substantial change in the percentage of Medicaid recipient males falling into any of the three categories. At the first administration, 17.4% (21/121) of non-Medicaid males fell into the average category, while 61.9% (75/121) fell in the elevated category and 34.7% (42/121) in the clinically significant category. Similarly to Medicaid recipient males, at the most recent administration, there was no substantial change in the percent of non-Medicaid recipient males belonging to all three categories.

While the category composition was slightly different for females compared to males, there was generally a similar trend in the category composition from the first administration to the most recent administration in internalizing scores for females as there was for males. At first administration, 16.5% (14/85) of Medicaid recipient females fell into the average category, 42.4% (36/85) in the elevated category, and 47.1% (40/85) in the clinically significant category. At the most recent administration, 16.5% (14/85) were in the average category, 43.5% (37/85) in elevated, and 40% (34/85) in the clinically significant, indicating a 7.1% decrease in the percentage of Medicaid recipient females who fell into the clinically significant category compared to the first administration. At the first administration, approximately 6.5% (2/31) of non-Medicaid recipient females were in the average category, 58.1% (18/31) in the elevated category, and 35.5% (11/31) in the clinically significant category. At the most recent administration, however, 6.5% (2/31) were in the average category, 61.3% (19/31) in the elevated category, and 32.3% (10/31) in the clinically significant category, indicating a slight decrease in the number of females belonging to the clinically significant category.

Externalizing Scores

The results for externalizing categories generally indicated more pronounced movement as compared to internalizing scores. At the first administration, there were 19.1% (51/267) in the average category, 58.1% (155/267) in the elevated category,

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and 22.9% (61/267) in the clinically significant category. At the most recent administration, however, 24% (64/267) of Medicaid males were in the average category, 58.8% (157/267) in the elevated category, and 17.2% (46/267) in the clinically significant category. These results indicate a reduction in the number of males in the clinically significant category and an increase in the number of those in the average category. Non-Medicaid males followed a similar but more pronounced pattern with 24.8% (30/121) in the average category, 51.2% (62/121) in the elevated category, and 24% (29/121) in the clinically significant category at first administration. Whereas, at the most recent administration, 35.5% (43/121) were in the average category, 51.2% (62/121) in the elevated category, and 13.2% (16/121) in the clinically significant category. These results indicate an increase in the number of non-Medicaid males in the average category and a 55% reduction in the number of non-Medicaid males in the clinically significant category.

At the first administration, 23.5% (20/85) of Medicaid recipient females were in the average category, 50.6% (43/85) in the elevated category, and 25.9% (22/85) in the clinically significant category. At the most recent administration, 31.8% (27/85) were in the average category, 51.8% (44/85) in the elevated category, and 16.5% (14/85) in the clinically significant category. These results indicate a clear increase in the number of Medicaid females in the average category, a negligible change in the elevated category, and a substantial decrease in the number belonging to the clinically significant category. Non-Medicaid females, however, showed the most significant change from the first administration to the most recent administration. At the first administration, 19.4% (6/31) of the non-Medicaid females were in the average category, 51.6% (16/31) were in the elevated category, and 29% (9/31) were in the clinically significant category. By contrast, at the most recent administration, 38.7% (12/31) were in the average category, 54.8% (17/31) were in the elevated category, and 6.5% (2/31) were in the clinically significant category indicating a 50% (6/12) increase in the number of non-Medicaid females in the average category and a 77.8% (7/9) decrease in the number of non-Medicaid females in the clinically significant category. These results indicate an overall reduction in external maladaptive behavior for males and females across both funding categories.

Vineland-3 Statistics

Several statistical analyses were conducted to determine the potential relationships between relevant variables and any possible predictive power of outcomes. Those variables included gender, funding source, diagnosis severity levels, treatment modality, and age at first administration. The following section provides a summary of the analyses conducted and the resulting conclusions.

Table 1 illustrates the level of variance associated with each adaptive behavior domain according to funding source type. There is a larger sample size of Medicaid participants vs non-Medicaid participants. Despite that difference, there is a similarity between the two groups outside of the ABC composite score, where there is less variance noted for Medicaid participants. There is, however, a substantial amount of variance for each domain and for each funding source, with the highest levels of variance associated with the socialization domain for both participant groups.

Table . Variance.

Domain	Medicaid count	Medicaid variance	Non-Medicaid count	Non-Medicaid variance
ABC[a]	352	56.37	152	75.58
Communication	352	93.53	152	100.23
Daily living	352	97.02	152	117
Socialization	352	133.86	152	134.6

[a]ABC: Adaptive Behavior Composite.

Table 2 displays a summary of the various statistical tests run: *t* test results and Cohen *d* calculations testing for statistical significance across adaptive behavior domains, CIs for domain standard score change, and the *t* test results testing for statistical significance across domains by gender and funding source. There was slight statistical significance for the socialization domain as compared to the other domains (P=.04). The socialization domain has the largest effect size of the domains (0.197), but it is still relatively small. The Cohen *d* calculations suggest a smaller and therefore minimal difference across the domains. All domains other than socialization cross zero, further emphasizing the lack of statistical significance. There is a demonstrated statistically significant difference (P=.02) between males across funding sources in the socialization domain, however. Males who were supported by non-Medicaid sources showed more significant improvement as compared to males supported by Medicaid. No other gender or funding-related differences were observed.

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Table . Test statistics summary.

Domain	*t* stat[a] (*df*)	*P* value	Sig[b] (*P*<.05)	Cohen *d*	95% CI	Male			Female		
						Mean (SD)	Non-M.[c] mean (SD)	*P* value	Mean (SD)	Non-M. mean (SD)	*P* value
ABC[d]	−1.2 (185)	.23	No	0.124	−0.067 to 0.314	2.52 (0.56)	3.91 (1.02)	.13	2.95 (0.77)	2.39 (0.33)	.75
Communication	0.47 (185)	.64	No	−0.046	−0.236 to 0.144	3.49 (0.56)	3.60 (1.02)	.92	4.31 (0.77)	1.87 (0.33)	.32
Daily living skills	−0.96 (185)	.34	No	0.096	−0.094 to 0.287	2.18 (0.56)	3.42 (1.02)	.29	2.61 (0.77)	2.61 (0.33)	.99
Socialization	−2.03 (186)	.04	Yes	0.197	0.007 to 0.388	2.57 (0.56)	5.65 (1.02)	.016	2.89 (0.77)	2.16 (0.33)	.76

[a]Stat: statistic.

[b]Sig: significance.

[c]Non-M.: non-Medicaid.

[d]ABC: Adaptive Behavior Composite.

Multiple regression analyses were conducted (Table 3). The first regression analysis assessed the relationship between age at first administration and domain standard score change. The results indicate that older age is associated with smaller improvements in domain standard scores. Additionally, statistically significant relationships were found between age at first administration and the ABC (*P*=.03), communication (*P*=.02), daily living skills (*P*=.02), and socialization (*P*=.02) domains. This further emphasizes how one's age at first administration has some relationship to the extent to which adaptive behavior development occurs in general. It is important to note, however, that ABC is a composite score, so there should be some statistically significant relationship between ABC and the other domains. Finally, the R^2 values are low, which indicates that age at first administration explains only a small portion of the variance in standard score changes.

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Table . Regression analysis summary.

Analysis and predictor, and domain	Coefficient	*P* value	R^2	95% CI	Significant
Age → score change					
Age at first administration					
Int.[a]	−0.0123	.48	0.008	N/A[b]	No
Ext.[c]	−0.0187	.39	0.011	N/A	No
ABC[d]	−0.0452	.03	0.064	N/A	Yes
Com.[e]	−0.0528	.02	0.072	N/A	Yes
DLS[f]	−0.0496	.02	0.069	N/A	Yes
Soc.[g]	−0.0581	.02	0.078	N/A	Yes
Severity → score change					
SC[h] severity					
Overall	1.2308	.61	0.008	–3.509 to 5.971	No
RRB[i] severity					
Overall	−0.967	.69	0.008	–5.708 to 3.774	No
Age and hours → MCID[j]					
Age					
Com.	−0.0087	.68	N/A	N/A	No
Hours					
Com.	0.0009	.51	N/A	N/A	No
Age					
DLS	−0.0031	.55	N/A	N/A	No
Hours					
DLS	0.0008	.55	N/A	N/A	No
Age					
Soc.	−0.0074	.72	N/A	N/A	No
Hours					
Soc.	0.0012	.41	N/A	N/A	No
Age					
ABC	−0.0036	.86	N/A	N/A	No
Hours					
ABC	0.0009	.56	N/A	N/A	No

[a]Int.: internalized.
[b]N/A: not available.
[c]Ext.: externalized.
[d]ABC: Adaptive Behavior Composite.
[e]Com.: communication.
[f]DLS: Daily Living Skills.
[g]Soc.: socialization.
[h]SC: social communication.
[i]RRB: restrictive and repetitive behavior.
[j]MCID: minimal clinically important difference.

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Next, a regression analysis was conducted to assess whether severity level is a predictor of positive domain standard score change (Table 3). The model explains less than 1% of variance in average standard score change (R^2=0.008). Therefore, the results suggest that severity level is neither statistically significant (P=.61) nor is it a strong predictor of overall improvement across domains.

Lastly, a regression analysis (Table 3) was conducted to determine if age and hours of service were predictors of domain MCID thresholds being met. The results suggest that neither age nor hours of service was a significant predictor of MCID improvement (P<.05).

With regard to the maladaptive behavior domains (internalizing and externalizing), a paired sample t test was conducted for internalizing standard scores and externalizing v-scale scores between first administrations and most recent administrations. The internalizing standard scores from the first Vineland-3 administration were a mean of 9.73 (SD 1.96), and the most recent administration results were a mean of 19.28 (SD 2.07). This yielded an analysis result of t_{485}=5.43, P<.001. The change in internalizing standard scores from the first administration to the most recent administration is statistically significant (P<.001). The decrease in mean indicates a decrease in internalizing standard scores overall, which suggests improvement (reduction) in maladaptive internalizing behaviors between administrations.

With regard to externalizing standard scores, the paired sample t test comparing externalizing scores from the first Vineland-3 administration to scores from the most recent Vineland-3 administration was mean 19.37 (SD 1.79) for the first administration, and mean 18.96 (SD 1.93) for the most recent administration. This yielded an analysis result of t_{485}=6.01, P<.001. The change in externalizing v-scale scores from the first administration to the most recent administration is highly statistically significant (P<.001). The decrease in mean indicates a decrease in externalizing standard scores overall, which suggests improvement (reduction) in maladaptive externalizing behaviors between administrations.

CFQL-2 Descriptives

This section is devoted to providing descriptive statistics for CFQL-2 administrations. Of the total sample of 504 participants, 431 (85.5%) participants received at least one CFQL-2 administration. Some participants received treatment before AnswersNow, Inc, adding the CFQL-2 to its assessment battery, while other participants did not have the CFQL-2 administered for clinical or operational reasons. Most participants (231/431, 53.6%) were males who received support from Medicaid. Medicaid-funded participants also accounted for the majority (304/431, 70.1%) of the total sample (n=431). The process of evaluating CFQL-2 results primarily focused on assessing total QoL and changes in total score.

The scores for each CFQL-2 scale across all participants (n=431) at the most recent administration were child QoL (mean 12.9, SD 2.57; range 0 - 20), family QoL (mean 13.3, SD 4.2; range 0 - 20), caregiver QoL (mean 14.1, SD 3.82; range 0 - 20), financial QoL (mean 11.3, SD 2.86; range 0 - 15), social network QoL (mean 15.1, SD 3.44; range 0 - 20), partner network QoL (mean 11.5, SD 7.64; range 0 - 20), and coping QoL (mean 11.7, SD 2.31; range 4 - 15). Total QoL score mean at most recent administration was 92.4 (SD 16.13; range 51 - 125).

Table 4 represents the percentage of participants' QoL scaled scores where improvement occurred, as well as the type of change that occurred based on the most recent CFQL-2 administration. Improvement was determined based on the following scale thresholds: child QoL, family QoL, caregiver QoL, social network, and partner network QoL (high=16 - 20, adequate=8 - 15, and low=0 - 7); financial QoL (high=12 - 15, adequate=6 - 11, and low=0 - 5), and coping QoL (high=12 - 15, adequate=8 - 11, and low=4 - 7). Overall, 40.9% (122/298) of participants showed an increase in total QoL, 32.9% (98/298) remained the same, and 25.8% (77/298) decreased, with 72.1% (215/298) of the participants experiencing adequate QoL according to the assessment.

Table . Percentage of participants showing improvement and directional change at the most recent administration.

	Improvement scale thresholds			Change direction		
	High	Adequate	Low	Same	Increased	Decreased
Child	15.31	81.67	2.32	43.62	34.11	22.27
Family	35.03	51.04	12.99	42.23	37.12	20.65
Caregiver	38.05	56.38	3.94	42.46	35.96	21.58
Financial	69.61	22.04	7.42	51.74	28.77	19.49
Social network	0	0	0	46.4	25.99	27.61
Partner relationships	0	0	0	58.47	17.63	23.43
Coping	72.85	25.06	2.09	45.48	31.09	23.43
Total	27.84	71.69	0.46	33.18	40.6	26.22

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CFQL-2 Statistics

Several statistical analyses were conducted to determine the potential relationships between relevant variables and any possible predictive power of the CFQL-2 outcomes. Those variables included gender, funding source, diagnosis severity levels, and age at the first administration. The following section provides a summary of the analyses conducted and the resulting conclusions.

Table 5 displays the results of a regression analysis testing whether age at first administration, Medicaid status, ASD severity level, initial total QoL, average service hours per week, or gender are significant predictors of change in total QoL standard scores. The results indicate that age at first administration (*P*=.95), Medicaid status (*P*=.58), ASD severity level (*P*=.55), average number of service hours per week (*P*=.41), and gender (*P*=.56) were not significant predictors of change in the average total QoL score. Initial total QoL (ie, the first total QoL score captured), however, was a significant predictor (*P*<.001) of change, indicating that the higher the initial total QoL score, the less likely the participant will be to show improvement in scores over time and the more likely a participant with a lower initial total QoL score would be to show improvement.

Table . Regression analysis of predictors of clinically significant changes in total QoL[a] scores.

Predictor	OR[b] (CI)	*P* value
Intercept	25.15 (1.12 to 565.21)	.04
Age at first administration	1 (0.92 to 1.1)	.95
Medicaid status	1.25 (0.56 to 2.83)	.58
ASD[c] severity level	1.17 (0.71 to 1.92)	.55
Initial total QoL score	0.96 (0.93 to 0.98)	.001
Average hours per week between	1.17 (0.81 to 1.71)	.41
First and most recent administration	1.17 (0.81 to 1.71)	.41
Gender	1.3 (0.54 to 3.11)	.56

[a]QoL: quality of life.

[b]OR: odds ratio.

[c]ASD: autism spectrum disorder.

Additionally, a chi-square test of independence was conducted to examine the relationship between Medicaid status and total QoL score. The results indicated that 127 of 211 (60.2%) Medicaid participants experienced positive changes, and 48 of 87 (55.2%) of non-Medicaid participants experienced positive changes. The difference between the two groups, however, was not statistically significant, χ^2_1=0.5, *P*=.50, indicating that Medicaid status was not associated with a higher likelihood of positive total QoL change.

Caregiver Satisfaction

An optional 4-question Likert scale–based caregiver satisfaction survey was conducted to capture more anecdotal information related to caregiver experience and provide a mechanism for caregivers to give feedback regarding services. Of the 504 participants in the sample, 32% (n=162) completed the satisfaction survey. The survey included the following questions and response options related to satisfaction and experience: (1) how likely are you to recommend services to a family with a child similar to yours (scored on a scale of 1 - 10 where 1=not at all likely and 10=extremely likely), (2) have services been effective for your child (with the answer options of very effective, effective, unsure, ineffective, or very ineffective), (3) what aspect of services is most important to you (with the answer options of accepts my insurance, caregiver training, effective therapies, experienced BCBAs, no waitlist, virtual or video format, all the above, or other), and (4) in the last month, how many times have you considered moving your child to residential services and/or calling emergency services to support your child (with the answer options of never, 1 - 2 times, or 3+ times).

The responses to the questions provide a better understanding of how the caregivers who responded view the services they are receiving. A large portion of the respondents indicated being extremely likely (136/162, 84%) to recommend services, with only 16% (26/162) answering the question with a score of 9 or less. An overwhelmingly large portion of caregivers indicated services were very effective or effective (154/162, 95.1%), with only 2% (3/162) indicating services were ineffective or very ineffective. Just under half the respondents (66/162, 40.7%) indicated effective therapies as the most important aspect of services, followed by the virtual or video format (34/162, 21%) and having experienced BCBAs (32/162, 20%), with only 17.9% (29/162) of respondents indicating caregiver training, accepts my insurance, no waitlist, all the above, and other combined. Lastly, 93.8% (152/162) of respondents indicated they had never considered moving their child to residential services and/or calling emergency services, with 3.7% (6/162) indicating they had considered the options 1 - 2 times, and 1.8% (3/162) indicating they had made those considerations 3 or more times.

A chi-square test of significance (χ^2_3=31.9, *P*=.60; n=162) was conducted to assess the relationship between positive change in Vineland-3 scores across domains and caregiver satisfaction. There was no significance between Vineland-3 domain score change and caregiver satisfaction (*P*=.52). In addition, a

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chi-square test of significance (χ^2_{21}=2116.6, *P*=.74; n=162) was conducted to evaluate the association between caregiver satisfaction and which aspect of service was indicated as being most important. There was no statistically significant association between caregiver satisfaction and which aspect of services was indicated as being most important (*P*=.76). Last, a chi-square test of significance (χ^2_6=623.8, *P*<.001; n=162) was conducted to assess the relationship between caregiver satisfaction and frequency of considering residential or emergency services. The results indicate there is a significant statistical association between caregiver satisfaction and the frequency of considering residential or emergency services (*P*<.001). These results suggest that families who considered crisis interventions more frequently are more likely to report lower satisfaction with the services being received, and those who did not consider crisis interventions are more likely to report higher satisfaction with the services being received.

Discussion

Principal Findings

This study was designed to evaluate the acceptability and feasibility of a novel approach to delivering ABA services, specifically a fully virtual, BCBA-delivered, focused ABA service model for individuals diagnosed with ASD. This study explored caregiver perceptions of service effectiveness and satisfaction, which indicate high family satisfaction and positive caregiver perceptions of effectiveness. We also found that participants' adaptive functioning, maladaptive behaviors, and QoL improved between the first assessment battery and the most recent assessment battery according to standard assessments. Given the retrospective design of this study, these changes are being interpreted as changes over time during service delivery and not the direct results of treatment.

Prior research on comprehensive, in-person ABA interventions generally shows that participants demonstrate adaptive behavior improvements, as measured by the Vineland-3, through participation in those programs. For example, Aitken et al [15] found that out of a sample of 1225 children diagnosed with ASD who participated in comprehensive in-person services, 61% demonstrated improvement across multiple adaptive domains of the Vineland-3. Similarly, Adelson et al [14] observed improvements in all Vineland-3 adaptive domains and both maladaptive subdomains. In the present study, the greatest improvements were observed in communication and socialization; however, 81.5% (411/504) of participants exhibited at least a one-point improvement in one or more adaptive behavior domains, and 29.4% (148/504) improved across all adaptive behavior domains. In the maladaptive behavior domains, 38.1% (185/486) of participants showed improvement in the internalizing domain, and 34% (165/486) showed improvement in the externalizing domain. These outcomes translate to significant reductions in either the frequency, intensity, and/or duration of maladaptive behavior observed over time. Furthermore, 76% (383/504) of participants met MCID thresholds in at least one domain. The results indicate the feasibility of this virtual-focused service model as an option for families seeking services to address adaptive behavior deficits and challenging behavior excesses.

QoL changes, as measured by the CFQL-2, were also encouraging. Most participants (175/298, 58.79%) showed improvement in overall QoL scores over time. Previous research has demonstrated the positive impact of caregiver involvement in services on parental self-efficacy and parental stress [30] as well as QoL within the family system [14]. Families in the present study participated in caregiver training, which could be correlated with improvements in QoL observed from the first to the most recent CFQL-2 administration. Regression analyses indicated that initial (baseline) QoL scores were predictive of improvement, with lower baseline scores associated with greater gains. This finding suggests that individuals with less adaptive behavior and lower perceived QoL at the outset of therapy may experience more pronounced benefits from intervention over time as compared to those with a more robust adaptive behavior repertoire and higher perceived QoL at the outset. Recent systematic reviews and meta-analyses examining the role of a child's age, baseline cognitive ability, and the amount of intervention received suggest findings across studies remain inconsistent and advocate the need for further research with controlled designs to better understand how preprogram characteristics are associated with intervention-related outcomes [34,35]. Future studies should further analyze these variables using a comparison group to better evaluate the differential impact of services across groups.

Caregiver satisfaction data revealed overwhelmingly positive opinions of service effectiveness, with 95.1% (154/162) of respondents rating services as effective or very effective and 84% (136/162) reporting they were extremely likely to recommend services. However, exploratory analyses examining associations between satisfaction and other variables yielded mixed results. No significant relationship was found between caregiver satisfaction and Vineland-3 score improvements or between caregiver satisfaction and the aspect of services the caregivers identified as being most important. These findings suggest that caregiver satisfaction may be additionally influenced by factors beyond measurable clinical outcomes, such as communication quality, accessibility, or perceived responsiveness of providers.

Conversely, a significant association between caregiver satisfaction and the frequency of caregivers considering residential or emergency services (χ^2_6=23.82, *P*<.001; Cramér *V*=.27; n=162) did emerge. Families who reported considering crisis interventions more frequently were also more likely to express lower satisfaction with services, whereas those who never considered such interventions reported higher satisfaction with services. This moderate effect size underscores the importance of addressing caregiver stress and crisis risk as part of service delivery, as these factors may substantially impact overall satisfaction and engagement throughout the course of therapy.

Previous studies have found similar results when evaluating the feasibility and acceptability of behavior-analytic virtual services for autistic children. Simcoe et al [36] evaluated a treatment model in which a trained consultant (ie, BCBA, speech and

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language pathologist, or early childhood educator) supervised early intervention providers who delivered caregiver coaching in naturalistic developmental behavioral interventions either in-person or virtually. The researchers evaluated three different caregiver- and consultant-completed child outcome measures, as well as acceptability of treatment (caregivers and early intervention providers). They found improvement across all child outcome measures and high acceptability among caregivers and consultants. Similarly, a 2019 review study examined the results of 28 different studies evaluating telehealth as a treatment model for delivering behavior analytic services to individuals on the autism spectrum and found that telehealth can be an acceptable model for these services [32].

This study extends the existing literature by specifically evaluating a fully virtual, BCBA-delivered, focused ABA therapy model for autistic individuals. This study demonstrated the feasibility of implementing this novel treatment model at scale by analyzing data for 504 distinct clients who had at least two Vineland-3 administrations on file. While most ABA therapy programs take a comprehensive approach and require high weekly hours, this study shows that lower dosage focused programs delivering an average of 2.6 hours per week can be acceptable to families seeking support, and that families report positive changes in behavior and QoL over time during service delivery. Finally, this study is aligned with previous research demonstrating that caregiver involvement in therapy is associated with positive behavior change. Taken together with prior research, this study supports the growing body of evidence suggesting the feasibility and acceptability of virtual ABA therapy services. Given the potential challenges associated with in-person, RBT-implemented, comprehensive services some families face, such as lack of access, limited appropriateness of the model for some autistic individuals, lesser qualified providers delivering the majority of services, and high costs, it is important to continue studying and evaluating the impacts of this novel therapy model.

Limitations

This study was descriptive in nature and relied on deidentified archival data, thus limiting our ability to control for potentially confounding variables such as the specific behavior interventions used, socioeconomic status, comorbid conditions, or caregiver stress levels. Given the descriptive nature of this study, we are unable to determine whether the treatment itself produced improvements in adaptive functioning, maladaptive behaviors, or QoL. Demonstrated improvements could be attributed to maturation effects, regression to the mean, or other causes outside the scope of the services delivered. Similarly, the absence of a comparison group limits our ability to draw direct conclusions about the effectiveness of the fully virtual, focused service model compared to that of traditional in-person comprehensive service models.

Some aspects of the current sample also limit the generalizability of the observed changes in adaptive behaviors, maladaptive behaviors, and QoL, in addition to the levels of caregiver satisfaction. One such aspect is the limited geographic representation within our sample. Participants reside across five states, with most participants concentrated in just two states. In addition, diagnostic severity level was only available for a small subset of the total sample, making the composition of the full sample unclear. Taken together, these two features of the current sample suggest cautious interpretation of the generalizability of the findings.

Another important limitation of the analytic sample was that it was derived from a broader clinical population that received services concurrently. The included participants were those who had research consent on file, at least two valid Vineland-3 assessments, a minimum interval between assessments, and ongoing service exposure. Similarly, CFQL-2 and caregiver satisfaction data were available for even smaller subsets of the clinical population. Individuals excluded based on these criteria may have received a qualitatively different experience; it is possible that families who met criteria for inclusion tended to be more engaged, participated longer in services, or had more favorable outcomes than those who were excluded. This further limits the interpretation and generalizability of the data.

An additional limitation of this study is the heterogeneity of the services participants received during treatment. Participants in this study experienced variability in the number of hours received, the ratio of hours by service type, the specific behavior-analytic procedures implemented, and the time between the first and most recent Vineland-3 administrations. We also did not have a direct measure of caregiver engagement or individual goals or goal mastery, both of which were individualized to each participant. Further, there are potential biases associated with the outcome measures evaluated. Specifically, Vineland-3 scores were based on caregiver report; in some cases, a different caregiver completed subsequent Vineland-3 administrations than the caregiver who completed the baseline administration. The CFQL-2 was administered as an interview by the treating BCBA, and satisfaction data were collected voluntarily. These factors introduce a level of variability and potential bias that limit our ability to make direct conclusions about the impact of the services delivered on changes in behavior and QoL. It is possible that some observed differences among participants could be attributed to specific aspects of their treatment that were different from the treatment other participants received. It is also possible that these measurement biases could have resulted in apparent changes in behavior and QoL that were related to momentary caregiver perception rather than true change.

Next, the lack of clear industry benchmarks or MCIDs for the Vineland-3 and CFQL-2 makes evaluation of changes over time difficult. The MCIDs established for the Vineland-II have been used by some existing research, but it is unclear to what extent these MCIDs apply to the Vineland-3. Similarly, there are no established thresholds for clinical significance when evaluating QoL over time using the CFQL-2, making it difficult to determine the extent to which improvements are meaningful.

Finally, there are limitations with the extent to which we evaluated caregiver satisfaction and the specific scores used for evaluating change on the Vineland-3. Specifically, the caregiver satisfaction survey was completed by only a subset of participants who represented less than half the sample of participants (162/504, 32.1%). Representation from the total

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dataset was limited by 2 factors: (1) the first caregiver satisfaction survey was sent in November 2023, at which time some families had already exited treatment, and (2) participation in the caregiver satisfaction survey was voluntary. This reality introduces potential response bias depending upon the nature of those who completed the survey and their histories with other services, existing familiarity with ABA methodology, and their familiarity with alternative service delivery options. With regard to the Vineland-3 evaluation, we analyzed standard score changes; however, there are scores that may be more sensitive to change over time and therefore better for longitudinal tracking. For example, the growth scale values monitor a person's progress in the same domain across multiple assessments, vs comparing standard scores from an individual's performance to that of same-age peers within a domain.

Implications for Practice

While this study's design substantially limits causal inference, the findings do highlight the need for further exploration of this novel treatment model in clinical practice. Fully virtual, focused, BCBA-delivered interventions may offer a viable alternative to traditional high-intensity, center-based comprehensive models, particularly for families seeking flexible and/or targeted support or those who have difficulty accessing therapy. The strong caregiver satisfaction ratings suggest that fully virtual focused services can address family needs. Given the strong caregiver satisfaction observed, it is possible that this model could have a multifaceted impact on the socially significant behaviors that affect the independence, well-being, and individual success of those diagnosed with ASD and their families.

The significant association between satisfaction and crisis considerations highlights the need for integrated caregiver support strategies, including proactive crisis planning, coordination of care with a family's other providers, and stress management resources. Families who are facing crises with their children potentially require support beyond what is typically made available by ABA service providers. It is plausible that a more BCBA-directed and implemented model of services could provide that level of necessary proactive crisis planning and stress management by having the luxury of more frequent connections being created in a more targeted manner. By working directly with caregivers to decrease maladaptive behavior as the primary objective of intervention programming, the BCBA's support may more meaningfully improve the family's experience with services as well as the family's general QoL.

Future Directions

A great deal of research addressing the role, experience, and needs of the caregiver in the context of participation in ABA service models is needed. For example, research could look to provide deeper insight into caregiver perceptions and to more specifically identify factors that drive satisfaction beyond a child's progress alone. Future caregiver research might more closely examine the relation between caregiver satisfaction and treatment fidelity, caregiver satisfaction and service duration (eg, do satisfied caregivers stay in treatment longer?), and the level of caregiver involvement and client outcomes. Exploring interventions that specifically target caregiver stress and crisis prevention within remote service frameworks may enhance both satisfaction and overall treatment frequency and efficacy.

Greater emphasis could be placed on examining the combinations of adaptive and maladaptive skills at therapy onset that equate to specific outcomes, rather than more commonly examined variables such as age, gender, diagnostic severity level, and treatment intensity as the primary predictors of outcomes. Additionally, it is feasible to consider the implications of how types of treatment goals, the density of treatment goals, and mastery of goals impact the development of adaptive behavior and the reduction of maladaptive behavior over the course of intervention programming. The relationship among these factors alone could have a direct influence over the Vineland-3 and the CFQL-2 scores, as well as the types of intervention outcomes achieved. Lastly, as noted as a study limitation, growth scale values may be more sensitive to change over time and therefore more effective at longitudinal tracking as opposed to relying on standard scores and/or standard score changes as the primary tracking mechanisms.

Given the difference in treatment plan compositions between comprehensive and focused ABA therapy services, the Vineland-3 ABC standard score may be more appropriate for evaluating improvements in adaptive behavior that result from participation in a comprehensive treatment model. In a focused treatment model, we may expect more targeted gains, with scores in other domains remaining the same or decreasing over time. It would be valuable to assess the extent to which focused services produce improvement in the specific domains directly related to the participant's treatment focus, and whether those gains are maintained over time when treatment shifts to a different focus. This study described a novel model for delivering ABA services, specifically fully virtual, BCBA-delivered, focused treatment, and evaluated changes in behavior and QoL over time, as well as caregiver satisfaction using a real-world clinical dataset. Future research should compare fully virtual ABA services with those of traditional delivery models through an examination of clinical outcomes, caregiver preferences, and BCBA experiences. Longitudinal studies are needed to assess the durability of adaptive skill gains and QoL improvements over time for recipients of both types of service models, and the inclusion of a comparison group would improve experimental control, allowing for a more robust interpretation of results. Fully virtual, BCBA-delivered, focused ABA services appear to be acceptable and feasible for the families in this study. For some families, these services may address a broad range of needs in an ostensibly more economical and accessible fashion than comprehensive in-person services, without potentially sacrificing the quality of services provided or lessening the socially significant impact on the lives of children and families that the practice of ABA has become synonymous with providing.

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Data Availability

Data from this research will be made available at the authors' discretion through requests made in writing to the corresponding author.

Authors' Contributions

Conceptualization: WHE (lead), BCW (equal)
Data curation: BCW
Formal analysis: WHE (lead), BCW (supporting)
Funding acquisition: WHE
Investigation: WHE (lead), BCW (equal)
Methodology: WHE (lead), BCW (equal)
Project administration: WHE (lead), BCW (supporting)
Resources: WHE
Supervision: WHE
Validation: WHE
Visualization: WHE (lead), BCW (supporting)
Writing – original draft: WHE (lead), BCW (supporting)
Writing – review & editing: WHE (lead), BCW (equal)

Conflicts of Interest

This project was fully funded by AnswersNow, Inc, as part of an agreement between the Clemson Center for Behavior Analysis and AnswersNow, Inc, to evaluate the service model being implemented by AnswersNow, Inc. BCW participated in designing this study, aggregating the data sample, writing the manuscript, and deciding to submit for publication. BCW holds stock in and is employed by AnswersNow Inc. All participants in this study received applied behavior analysis therapy services from AnswersNow Inc, a behavioral health care company.

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Abbreviations

ABA: applied behavior analysis
ABC: Adaptive Behavior Composite
AFLS : Assessment of Functional Living Skills
ASD: autism spectrum disorder
BCBA: Board Certified Behavior Analyst
CFQL-2: Child and Family Quality of Life, Second Edition
FAST : functional assessment screening tool
HIPAA: Health Insurance Portability and Accountability Act
ICHOM: International Consortium for Health Outcomes Measurement
MCID: minimal clinically important difference
QABF : questions about behavior function
QoL: quality of life
RBT: Registered Behavior Technician
VB-MAPP: Verbal Behavior Milestones Assessment and Placement Program
Vineland-3: Vineland Adaptive Behavior Scales-Third Edition

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Original Paper

Facilitating Communication With Children and Young Adults With Special Health Care Needs Through a Web-Based Application: Qualitative Descriptive Study

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Abstract

Background: Children and young adults with special health care needs comprise a significant portion of the pediatric population in the United States, where 1 in every 5 children has a complex health care need. These patients are more likely to receive unsafe care and have their needs unmet in part due to lack of accessible information and limited training support. Barriers in communication may contribute to detrimental outcomes for this vulnerable, high-risk population.

Objective: This project aims to identify barriers to communication in children and young adults with special health care needs in the health care setting. These barriers will inform prototype development using human-centered design approaches to create a web-based application. Feedback from patients, caregivers, and health care providers (HCPs) was obtained on the usability and usefulness of the tool within the health care setting.

Methods: A needs assessment was conducted in which participants shared their experiences in providing or receiving health care services via a semistructured interview that was recorded and transcribed. Transcripts were analyzed inductively for themes, coded, and used to categorize the data. On the basis of these themes, iterative development of a web-based application for social stories took place. Focus groups were held to provide relevant feedback on the prototype.

Results: There were 15 participants (n=10, 67% HCPs and n=5, 33% patients and caregivers) interviewed for the needs assessment that informed prototype development. A web-based application for social stories depicting different aspects of health care interactions was created. Focus group feedback from 19 participants (n=12, 63% HCPs and n=7, 37% patients and caregivers) on usability through the System Usability Scale, along with narrative feedback, was obtained. Overall, the usability of the application was supported by caregivers and HCPs.

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Conclusions: Children and young adults with special health care needs require medical services that their peers generally do not, thereby compounding potential barriers in communication surrounding health care delivery. Using social stories geared toward health care interactions may help reduce anxiety and difficulty.

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KEYWORDS

pediatrics; complex care; human-centered design; qualitative; communication

Introduction

Complex care is defined as "a person-centered approach to address the needs of people whose combinations of medical, behavioral health, and social challenges result in extreme patterns of healthcare utilization and cost" [1]. Approximately 20% of adolescents (aged 12-17 years) in North America live with at least one chronic condition or special health care need, >90% of whom will require ongoing care into adulthood [1-3]. Unfortunately, 67% to 75% of individuals living with special health care needs experience frequent visits to the emergency room, forego recommended care (including lack of annual checkups), and frequently have multiple comorbid health issues [2-4]. As a result, their health care expenditures are estimated to be 5 times greater than those of the general population [5,6]. In addition, patients with complex, special health care needs often require individualized treatment plans to overcome the unique barriers they face in obtaining care [7]. These barriers often result in inequities in patient safety and health care outcomes in this population, particularly in individuals with intellectual disabilities [8]. The complexity of navigating health care systems may be lessened with care coordination in a medical home model; there have been reports of improved family satisfaction with overall care and improved health outcomes with dedicated care coordination [9]. As a result, high-quality and timely access to care services [10] and care coordination is cited as a top priority for individuals with disabilities living with specialized health care needs [11].

Complex care approaches focus on the patient, treating them as an individual embedded within a social context. Complex care programs benefit greatly from strong patient–health care provider (HCP) relationships, excellent communication practices, time, and use of interdisciplinary teams who work with specialized care providers to coordinate and provide patient-centered care [12].

Social stories are personalized narratives used to help teach children and young adults with autism spectrum disorder how to navigate social situations [13]. To do this, social stories use a combination of visual aids and text to teach social skills and increase understanding of social context and cues. The structure and predictability of a social story can decrease anxiety in new or unexpected environments. In addition, they can increase a patient's independence [14] and communication skills, and the skills taught via social stories may then generalize to other social contexts [15].

Patients with complex, special health care needs face several barriers in the health care system when seeking care. These barriers include difficulty communicating with HCPs, a lack of processes to accommodate individual needs, and difficulty accessing recommended care [16]. Specifically for individuals with autism spectrum disorder, patient behavior in combination with deficits in expressive and receptive communication may contribute to challenging medical encounters. A combination of environmental challenges in the setting where medical care is provided, demands placed on the patient (physical examinations or procedure based), and challenges with HCP communication and interaction may invoke challenging behavior in a patient population with reduced communication ability [17].

We sought to address some of these barriers within the health care system for this complex population of patients using the interface between technology and communication. We engaged in a multiphasic study through which we developed an application to address the information and design needs of patients; caregivers; and HCPs who engage in the direct care of patients living with complex, specialized health care needs. The widespread use of technology provides a digital space to create social stories describing health care interactions through visual and narrative means. This intersection of social context in the health care setting may help reduce communication barriers with children and young adults with special health care needs and their caregivers.

We hypothesize that (1) a web-based application can be developed to facilitate communication in the context of health care–specific interactions and flexibility to customize the technology for the patient and (2) a customized web-based application can help close the communication gap that exists for patients with complex, special health care needs, which will lead to fewer poor experiences for patients and caregivers.

Methods

Study Design and Setting

We conducted a human-centered design study in three phases consisting of (1) identifying end user needs using qualitative interviews; (2) conducting rapid, iterative prototyping of a web-based application; and (3) holding focus group sessions with end users for prototype feedback. This study relied on a convenience sample recruited from a large academic-affiliated health system (from both outpatient clinic and inpatient units) located in the Midwest region of the United States. The study population included patients with special health care needs, their caregivers, and HCPs who provide health care to patients with special health care needs.

Ethical Considerations

This project was approved by the University of Illinois College of Medicine Peoria Institutional Review Board under expedited

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review (2053251). Assent for pediatric patients aged <18 years or adults without decision-making capacity was obtained along with parent or guardian consent. In addition, adults with decision-making capacity provided consent. Transcripts from interviews and focus groups were deidentified before analysis. Participants in the study were not provided with compensation for taking part.

Human-Centered Design Approach

The first phase of this study comprised semistructured interviews. The interviews were designed to elicit participants' perceptions of end user communication needs to inform the development of a prototype of a web-based application to facilitate communication among patients, caregivers, and health care personnel. We conducted qualitative interviews to inform the development of a prototype, which was subsequently tested via focus groups with anticipated end users.

Inclusion Criteria and Participant Eligibility

We gathered a convenience sample from a tertiary care hospital and outpatient care clinic that provides care to patients with special health care needs. To be eligible to take part in all phases of the study, participants needed to meet one of the following criteria: (1) being employed as health care personnel participating in the care of patients with special health care needs in the inpatient or outpatient setting, (2) being a pediatric or adult patient with special health care needs with decision-making capacity who presented for inpatient or outpatient care, or (3) being a caregiver of children or adults with special health care needs who presented for outpatient or inpatient visits.

Recruitment

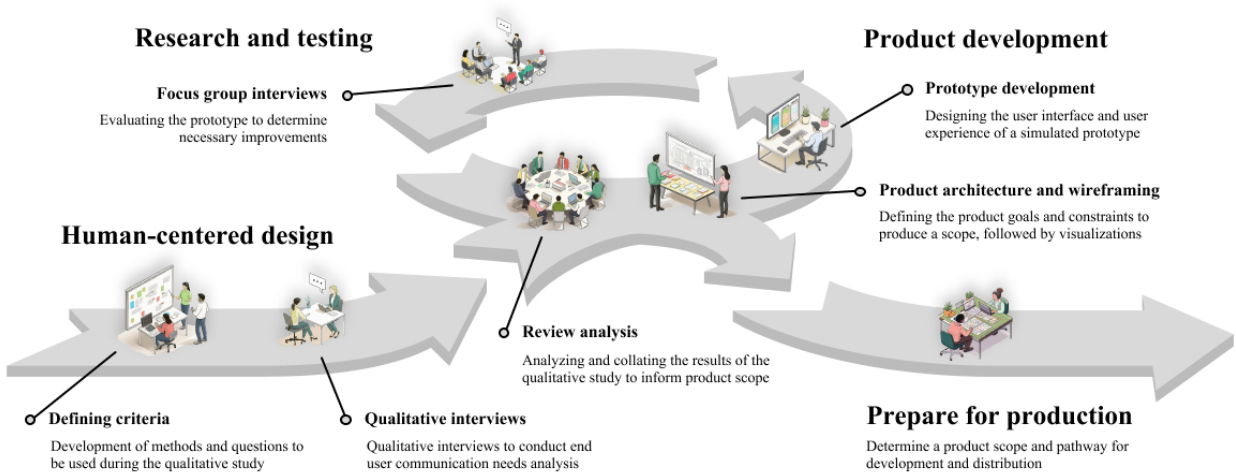
Recruitment for participation in the interviews to aid in the development of the web-based application and for the focus groups to provide feedback on the prototype took place via informational study fliers that were distributed electronically via email and physically within inpatient and outpatient clinical settings. The flier included a QR code to a participation questionnaire, as well as QR codes to the various types of age-appropriate consent information, giving prospective participants an opportunity to take part in the study. The participants provided their email address to be contacted for the needs assessment interview via phone call or audio-only Zoom videoconference (Zoom Video Communications).

HCPs providing inpatient or outpatient care were identified by their respective departments and emailed the study details and invitation to participate, in addition to the posted fliers.

Caregivers and patients were primarily recruited using fliers posted in clinical settings. To maximize the likelihood of reaching saturation, patients and caregivers were further identified through convenience sampling. They were contacted via phone or email directly for recruitment. For the purposes of saturation in qualitative methods, we targeted a minimum of 5 participants per category (HCPs, caregivers, and patients) [18].

After completing the initial interview, participants were asked whether they would like to take part in future focus groups providing feedback on the web-based application prototype (Figure 1).

Figure 1. Process map outlining the 3 phases of the study protocol. Phase 1 provided an overview of the human-centered design approach through qualitative interviews, phase 2 incorporated thematic feedback for prototype development, and phase 3 included focus group interviews on the prototype.



Interview Guide Development

The semistructured interview guide underwent several iterations. First, a draft interview guide was developed based on the study aims and clinical context. This was done via discussion among the investigative team; the initial guide was then pilot-tested with 1 caregiver and 1 HCP and subsequently revised. After 4 interviews, transcripts were reviewed in relation to the study's overarching research question. It was determined that the interview questions were too broad in relation to the study's research questions, and the guide underwent subsequent revision. Upon approval of the revised questions, follow-up interviews using the new guide were conducted with 2 of the previous 4 participants.

Before conducting interviews, all interviewers underwent interview training. The training materials were developed based on content made available by the University of Illinois Chicago's

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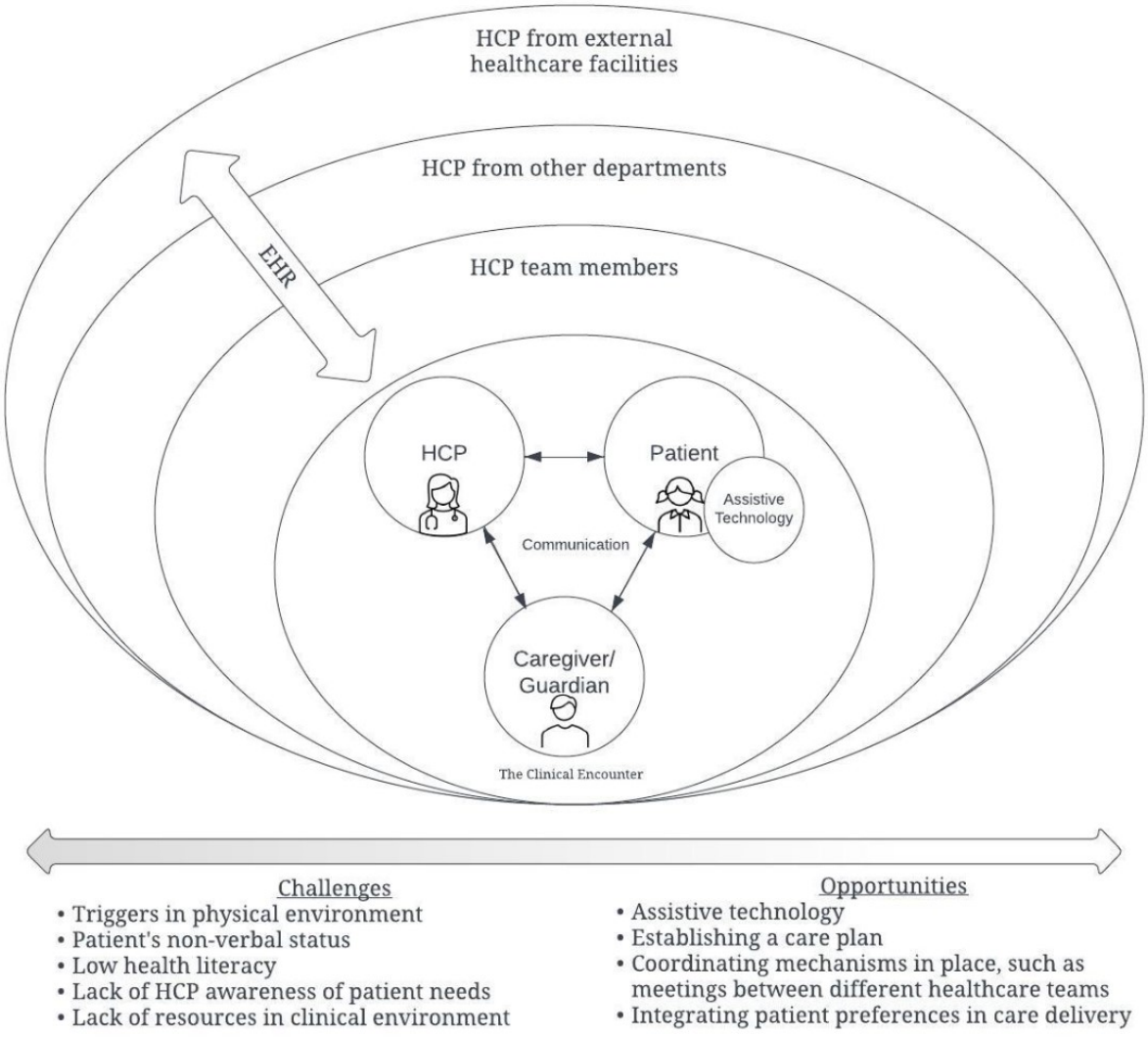
School of Public Health Collaboratory for Health Justice [19]. Training materials were presented, followed by opportunities to practice using the guide. The first 2 to 4 interviews were conducted under the supervision of a faculty member with expertise in qualitative human-centered design methods (AMH). Interviews were recorded and transcribed verbatim using Zoom (audio only). A member of the research team reviewed the auto-generated Zoom transcriptions for accuracy and to strip transcripts of identifiable information before analysis.

Qualitative Analysis

Deidentified transcripts were uploaded to ATLAS.ti (Scientific Software Development GmbH) [20] for subsequent analysis. Approaches to coding were inductive. Coders with backgrounds in medicine (DK), premedicine (MM), and human factors (AMH) reviewed the first 5 transcripts to identify codes and develop a codebook [21]. The remaining transcripts were coded independently by at least 2 trained coders; all discrepancies were identified and resolved for 100% consensus. Emergent themes were identified, sorted into challenges and opportunities, and interpreted for design recommendations. Distributed cognition and communication theories that consider complex interdependencies among multiple individuals, coordinating mechanisms, communication, and information sharing patterns were used for interpretation [22].

The results identified layers of the health system reliant on communication and coordination practices (Figure 2); challenges and opportunities arise within each layer of the complex system. However, at the core of these interactions is communication, which occurs within the clinical encounter. We thereby focused on codes and emergent themes that attested to challenges and opportunities regarding communication as identified in the clinical encounter.

Figure 2. Phase 1 interviews identified opportunities and challenges in communication with health care providers (HCPs) during health care interactions. There are many layers of communication that occur in the coordination of the care of complex patients and their families.



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Product Development

Prototyping

In phase 2, qualitative themes from the interviews were provided to the design team responsible for the development of a prototype for a web-based application through a series of meetings with members of the investigative team (AMH, JRH, and MJM) and designer (KF) to develop multiple iterations of the application. Iterative feedback was received from the investigative team and qualitative lead at that point for clinical expertise (JRH and MJM) and participant voices (AMH) and was incorporated. Each iteration of the prototype was shared with the research team to meet the specifications of the prospectively identified communication and end user needs. Approximately 3 iterative cycles were completed to achieve a final prototype.

Clinical Scenario Development

Interviews revealed a common need in both inpatient and outpatient settings: to convey routine tests and procedures in an understandable and nonthreatening manner. To this end, members of the study team developed 2 clinical scenarios through which interaction with the application would guide and convey the steps of a visit or procedure. Our principal investigators, subject matter experts, and internal medicine/pediatric physicians (JRH and MJM) worked closely with content creators to develop a realistic clinical scenario that met the identified areas of need and preference relevant to both inpatient and outpatient care settings. This was developed and refined over several iterations and was ultimately used to inform the flow of the application.

Product Design Integration

A user flow was built to represent high-level user experience. An information flow diagram helped identify how this application might connect to other utilities in the health system. A technical assessment began to explore the feasibility of certain features. On the basis of the feedback received, the user flow and technical assessment were refined to address any identified issues and further focus the scope of the application. In conjunction with clinical scenario development, wireframes were built to visualize the prototype layout and structure and develop a preliminary art style for the content. As a result of project team feedback, the wireframes were revised to represent a final scope for the prototype to be used in focus group user testing. Art styles were explored considering the original research data, market evaluation, and potential full-scale production technical constraints. The final phase involved iterating on the art style and developing all necessary design assets to produce a prototype for user testing.

Research and Prototype Testing

The third phase of our human-centered design study tested the resulting prototype with end user groups. These user groups consisted of patients, caregivers, and HCPs. For participants aged <18 years, caregivers provided verbal consent, and the participating children provided assent. Decisions to participate were audio recorded. Caregivers of adult patients without decision-making capacity provided consent for the patient to participate.

HCPs, patients, and caregivers who consented to participate convened in person and met in separate focus groups (ie, HCPs met separately from patients and caregivers). Focus group participants were welcomed, provided with the project aims and objectives, provided with a tablet and QR code, and briefed on how to access the prototype application from the tablet provided to them. To interact with the prototype, patients and caregivers were given a medical social story to simulate receiving the social story before an upcoming appointment. They then chose whether they wanted to be represented by an animal or person avatar throughout the medical social story.

HCPs were given the same medical social story under the pretense of having to prepare and send the social stories before an upcoming medical encounter with a patient with special health care needs. All participants were presented with the System Usability Scale (SUS) questionnaire upon completion of the scenarios and then took part in a facilitated focus group interview session to provide more granular feedback. Focus group interviews were recorded and transcribed verbatim with participant consent.

Focus Group Data Collection Forms

To evaluate prototype success in the focus group, we adapted survey questions from the SUS [23] and from existing educational immersion scales [24]. Furthermore, we used a semistructured guide to elicit open-ended feedback on the application experience from end users. The SUS is a scale designed to measure participants' perceived usability of a product. Scores range from 0 to 100, with the average score (50th percentile) being 68 [25]. A score above 70 is generally considered acceptable [26-28]. The Learning Immersion Scale in Simulation is a psychometrically validated and reliable survey consisting of 4 factors: cognitive assimilation, emotional buy-in, focused attention, and autotelic experience [24]. We focused on the cognitive assimilation subscale, which measures to what extent an individual differentiates between interaction with the simulated environment and reality [29]. The questionnaire uses a 7-question, 5-point scale adapted from Ko et al [24]. It ranges from "strongly disagree" (1) to "strongly agree" (5). This scale was only administered to caregivers and patients.

Focus Group Data Analysis

SUS surveys were pooled and analyzed descriptively, examining overall usability and usability differences by role (caregivers and patients vs HCPs). The caregiver or parent survey asked 3 additional questions about how they thought their child or the individual under their care would feel about the prototype, which caused the SUS scale score range to change to 0 to 130. Scores are reported as both out of 130 and normalized to fit the original scale from 0 to 100. The resulting focus group transcripts were reviewed iteratively for trends, including areas of feedback (positive and negative) on the prototype interaction experience.

Results

Overview

Results are presented and discussed in the order in which the phase of research took place. There were 15 participants (n=10,

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67% HCPs and n=5, 33% patients and caregivers) in the phase 1 individual interviews (Table 1).

Table 1. Participant demographics.

	Patients and caregivers, n (%)	Health care providers, n (%)
Phase 1 interviews (n=15)	5 (33)	10 (67)
Phase 3 focus groups recruited in phase 1 (n=9)	4 (44)	5 (56)
Phase 3 focus groups recruited in phase 3 (n=10)	3 (30)[a]	7 (70)
Phase 3 total (n=19)	7 (37)	12 (63)

[a]One pediatric participant.

Human-Centered Design

Qualitative analysis of the interviews completed in phase 1 identified both challenges and opportunities of care, illustrating design needs for our web-based application. Themes were identified to help prioritize the creation of a web-based application as a potential solution to reduce challenges and facilitate interaction (Multimedia Appendix 1).

Challenges in Communication Based on Cognitive Status

Equating verbal status with cognitive ability emerged as a barrier to effective communication. This challenge was mentioned by HCPs, with 1 patient and 1 caregiver noting this barrier from their perspective. Mainly, HCPs indicated difficulty assessing patient capabilities and capacity to communicate and understand interactions autonomously due to time constraints or unfamiliarity with the patient:

> *Because a lot of times they are so afraid of what's going on, and they're not understanding. And sometimes...providers in the room aren't understanding them. And that can cause a lot of problems.* [HCP]

> *That they're special needs and they don't have the capacity when so many of them have the capacity we [HCPs] just don't have the time to spend with them to understand what they do have.* [HCP]

Meanwhile, patients and caregivers described how this challenge manifested on their end in that HCPs may not provide enough information on what they do with a patient, expressing a desire for more explanation that warranted more communication. One caregiver described their intensive care unit experience as follows:

> *[A] nurse will come in and start something [a routine medical procedure]. You're like, wait a minute, what are you doing? So I don't know if like just a little more communication as to the doctors thought processes of: This is what we're doing. This is what we're thinking and what we're going to try.* [Caregiver]

Several caregivers noted that the barrier was the verbal status (eg, the patient's ability to talk) rather than their cognitive ability or capacity for understanding. One caregiver noted the following:

> *Just because he can't talk doesn't mean he doesn't have feelings and doesn't understand everything.* [Caregiver]

> *Now his mom never left she was able to communicate a lot with us [HCP team].... I didn't know him [the patient] very well. And so if mom worked or couldn't be here, there would have been a lot of gap(s) in communication and understanding what he needed.* [HCP]

Some HCPs corroborated this element of patient understanding despite verbal status:

> *[Patient name] is very, very smart and understands a lot of what we are saying or doing. So even though a child may have special needs and are non-verbal and not able to communicate what they want, how we do, I feel like it's important to know that they still sometimes are aware of their surroundings and are smarter than we really realize.* [HCP]

Opportunities to Improve Communication

The challenge of ascertaining a patient's cognitive status is prevalent, often requiring intervention and the constant presence of a caregiver. Overall, there was a preference for more streamlined and direct communication between HCPs and patients. Ideas for supporting direct communication during an encounter included the use of simplified messaging. For instance, one HCP highlighted the need to use simple language to explain routine procedures in terms readily understood by patients and caregivers:

> *Yes, and it fits people that are aware of medical jargon...[but] our special needs are not. And so we have to be able to. Adjust [using jargon] as according to our patients you know.* [HCPs]

Assistive devices were noted in their ability to promote more direct and patient-centered communication during clinical encounters, potentially bypassing the otherwise constant need for caregiver presence. These devices were often noted to be available through specialty hospital services or otherwise belong to the patient privately for at-home use, and it was noted that they were useful in the health care environment to aid in direct communication between HCPs and their patients. In other cases, involving the caregivers in the health care delivery provides insights into the patient's mannerisms and needs in a way that only those who know them best can decipher. One HCP noted the following:

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> *[D]epending on what's going on with them. Absolutely. Yeah, so more individuality in a system, you know. Ability to change it to a specific patient would be helpful.* [HCP]

> *So if they are like not actually having access to smart tablets or for understanding and navigating the My Chart system. So that technology.... To feel comfortable with doing that is one of the barriers.* [HCP]

When describing aspects of an assistive device used for communication, several facilitating device features were noted to enhance communication during the clinical encounter:

> *So from, provider to patient communication, just having some, a bunch of preset sort of procedures, the very, you know, illustrations that sort of simplify it and make it easy to understand for the patient and then on the opposite, you know, things that allowed them to quickly say and communicate with you without.... That doesn't mean they're the same as everyone else. And so I think a goal with the app is to sort of a breakdown communication barriers so that there's an easier time getting to know them and then also you know those individual preferences as individual traits and things like that can be quickly communicated and just sort of be embedded and quickly understood by providers.* [HCP]

Prototype Development

In the process of prototype development in phase 2, we focused on actionable themes that met the following criteria: (1) opportunities to improve communication in clinical encounters (the reason for this being that broader coordination issues worsened in part because of communication problems, ie, communication is often necessary for coordination) and (2) common or routine tests and procedures experienced in both inpatient and outpatient encounters.

A tappable prototype was built and prepared for testing on tablet devices. Story development and key features targeted emergent qualitative themes, with a focus on routine procedures performed in both inpatient and outpatient visits and on a standardized outpatient visit.

Common procedures patients undergo in both settings are phlebotomy and measurement of vital signs, and a common visit focus in the outpatient setting is a preventative examination or annual physical examination (including obtaining vital signs). An outline of narrative details was created that would help shape the final visual representation of each step within the procedure or visit. A landing page of potential scenarios for social stories was created (Figures S1 and S2 in Multimedia Appendix 2), with the standardized outpatient visit fully developed with 2 different representations, an animal or a person avatar. This allowed the end user to choose the avatar that best reflected their desire to represent themselves in an upcoming encounter.

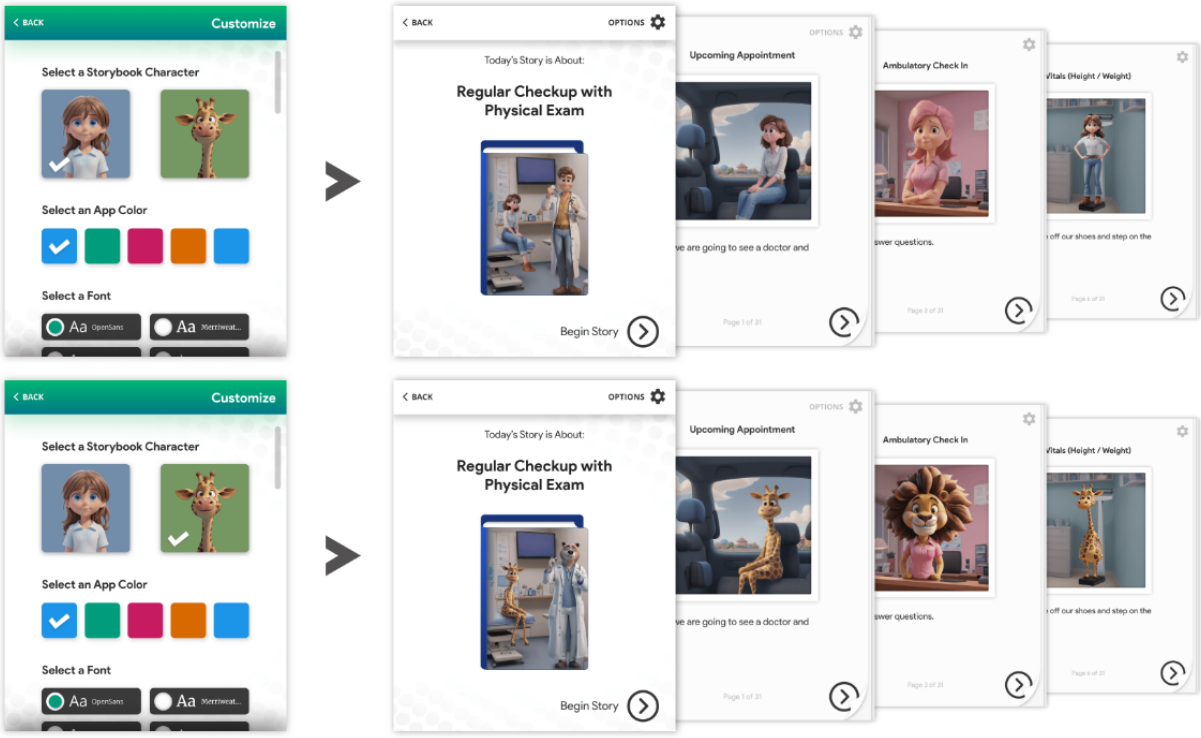
Research and Prototype Testing

The scope of the themes was then identified by the research team to provide the framework for the iterative prototyping of the web-based application. The web-based application focused on providing a visual and narrative aid to explain treatments or procedures to the patients and caregivers. It also provided the opportunity for the patient to react to the content (Table S1 and Figure S1 in Multimedia Appendix 3).

In the phase 3 focus groups, there were a total of 19 participants (Table 1) who provided feedback on the visual and narrative examples (Figure 3) for the web-based application.

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Figure 3. Social story outlining the steps of a routine outpatient preventative examination. The patient or caregiver can select between an animal and a person avatar that represents them throughout the social story.



SUS Results

HCP Results

On the basis of the HCP SUS scores (Table 2), the prototype ranked in the "best imaginable" range with an average score of 93.125 (SD 6.67; 96th-100th percentile). However, due to the small sample size, more participants would be needed to accurately judge the usability and generalizability of the prototype.

Table 2. System Usability Scale scores from health care providers.

Respondent ID	Score (range 0-100)[a]
HCP1	97.5
HCP2	100
HCP3	90
HCP4	92.5
HCP5	100
HCP6	90
HCP7	97.5
HCP8	100
HCP9	97.5
HCP10	87.5
HCP11	80
HCP12	85

[a]Average score: 93.125 (SD 6.67).

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Caregiver Results

The caregiver SUS scores (Table 3) also ranked the prototype in the "best imaginable" range, with an average normalized score of 88.08 (96th-100th percentile).

Table 3. System Usability Scale scores from caregivers.

Respondent ID	Original score (0-130)[a]	Normalized score (range 0-100)[b]
CGP1	127.5	98.08
CGP2	112.5	86.54
CGP3	97.5	75
CGP4	125	96.15
CGP5	110	84.62

[a]Average score: 114.5 (SD 12.17).

[b]Average score: 88.08 (SD 9.36).

Patient Results

The 2 patients surveyed rated the prototype just below the average SUS score with an average score of 66.25 (SD19.45; 41st-59th percentile). This would place it in the "OK" range.

Cognitive Assimilation

Caregivers (n=5) consistently provided high scores on the cognitive assimilation scale, with the lowest score being 4.2 for "I was able to see it I was doing it right" and "The situation seemed to flow smoothly" (Table S1 in Multimedia Appendix 4). However, patients (n=2) provided low scores on cognitive assimilation, with an average of 2 for most of the questions (Table S2 in Multimedia Appendix 4).

Focus Group Themes

Common themes from both HCPs and patients and caregivers on the prototype centered on the user-friendly application design, including the avatar choice between an animal and a person. The design was overall appreciated as a general medical social story. However, broad use among patients with special health care needs of all age ranges may be limited by the spectrum of ability. The current narrative explanations and visual aids are most applicable to patients of a certain cognitive ability regardless of chronological age. When used outside of that scope, they may not be as effective for end user interaction. However, both groups generalized applicability to neurotypical children of a similar cognitive level:

> *Yeah, I thought that it was really well laid out. I thought that as a mom and then also as like I'm a pediatric nurse. So from both of those aspects, I feel like this is something that we're currently missing. We're not able to make those connections with our pediatric patients because you know we don't have a lot of child friendly resources to kind of help them prepare for different things that they may go through in their health care process.* [Caregiver]

Both patients and caregivers and HCPs provided feedback on preferences regarding the ability to modify the scope of the medical social story for various end users, including narrative explanations, length, and increased avatar options, which may increase general applicability and end user satisfaction:

> *You know some more of an adult or approaching adults. A tween? Yeah, a tween. I would expect most children would pick the giraffe. Yeah, but I would think more teens and tweens would choose a teenager type avatar. That would kind of bridge the gap between the very childlike and juvenile appearance and the more capturing the ages in between.* [HCP]

Caregivers and patients with specific health care needs identified potential areas of improvement to meet broader patient care accessibility needs. The addition of an audio version with sign language should be considered so that individuals that are hard of hearing or cannot read can still use the application fully.

In the HCP feedback specifically, there was some concern about being able to capture the many different permutations through which an HCP could approach a case to meet the needs of each individual patient or account for variances within a health care system in terms of what information is included. In addition, as the nature of patients with special health care needs may result in frequent encounters with the health care system, the application needs to have the ability to be personalized for repeated similar health care interactions for patients:

> *We use freezy spray so I can speak to that, but you know the hospital will use numbing cream, you know, and it is, you know, you use these words, but they have different things that we can use. Some people use a little light to see your vein. Sometimes you know.* [HCP]

> *Going back to this surgery example, kids have to be under a certain weight to get a mask induction versus the IV induction and so you can't even break it down by 8 years if you have a 7-year-old that weighs the same as in 12-year-old. The seven-year-old will get the IV right? Yeah, it it's very specific.* [HCP]

Discussion

Principal Findings

The initial objective of this project was to create a web-based application that would facilitate communication for patients with complex, special health care needs during interactions with their health care team. Through a 3-phase human-centered design process, we identified communication needs for patients

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with complex, special health care needs; their caregivers; and their HCPs. Key themes informed prototype development. The prototype was then reviewed by a group of stakeholders; the results of focus groups with end users support overall usability and utility for certain patient populations.

The results from the phase 1 interviews identified areas of opportunities and challenges in communication for patients with special health care needs in health care encounters. Specifically, HCPs' level of comfort and inclusive communication with the patients and their caregivers during clinical encounters were two areas identified as needing improvement. Patients notably display a broad range of communication abilities, particularly when using alternative and augmentative communication methods. Interestingly, capacity for direct verbal communication may not directly reflect an individual's cognitive ability. This finding highlights how assumptions on patient function and ability and possible ableism may create additional communication barriers during a patient encounter. Additionally, a high reliance on caregivers for verbal communication of the patient status may further complicate the patient's relationship with the health care team, whereas using communication devices available allows for direct communication with the patient. This was consistent with our initial hypothesis and experience within the health care system. Although our data suggest additional multiple areas of opportunity to enhance communication, we focused on the findings most relevant to the interactions among HCPs, patients, and caregivers during an encounter for prototype development. In phase 2, construction of the prototype elements was important to consider for scalability and future digital interfaces. The design of the medical social stories was chosen to depict routine experiences for all patients and their families but potentially significant barriers for patients with complex, special health care needs due to the physical environment and impaired communication and rapport with the health care team. Generated images of an animal or person avatar were incorporated to provide options for individual preferences, but creating avatars using personalized variables was not possible during prototype creation to remain within the scope. Striking an appropriate balance among the development of a web-based application, functionality, and scalability was at the forefront of our decisions when finalizing prototype details. In phase 3, the qualitative feedback from stakeholders highlighted consistencies and potential applicability to a focused patient population with communication barriers and intellectual disabilities. The qualitative feedback from HCPs and caregivers identified that this prototype may be applicable to patients with typical development at the same cognitive level. Overall, caregiver and HCP testing was supportive of the prototype meeting the standards for usability [30]. The combination of the qualitative and quantitative data was positively congruent with HCPs and caregivers, but the small sample size prevents solid conclusions on usability and generalizability to both other institutions and other patient groups with special health care needs.

Limitations of this study include the representativeness of the sample in both size and diversity of disease processes that result in specialized health care needs. Therefore, the full scope of opportunities and challenges faced by patients across the continuum may not be identified. Thus, the broad applicability of a prototype designed for all patients with special health care needs would need further validation across a larger sample size and across multiple areas of care delivery within the health care system. In addition, there was a broad range of levels of ability among patients in the phase 1 interviews, which created variable outcomes in the design of the prototype. Building a prototype that would meet the needs of an innately unique population of patients with varying levels of ability within the same diagnoses exceeded the scope and timeline of the first cycle of this project but is a rich area for further refinement and implementation. Finally, just as the patients are unique, so are the individual approaches that health care team members bring to their patient care. For example, the approach to anesthesia for a surgical procedure may vary depending on the HCP and the patient's unique needs, which, therefore, could limit the generalization of the medical social story.

Conclusions

Our study identified an area of further exploration for increasing successful health care interactions with patients with special health care needs through using social stories in a web-based application. Providing a mechanism to prepare patients and their caregivers for health care interactions by introducing a standardized process allows for structure, visibility, and appropriate anticipation. This also allows for the engagement of HCPs to communicate with patients and families before busy encounters to help set expectations and also potentially reduce anxiety about the unknown. As noted in the stakeholder feedback, these features are also applicable for health care interactions involving neurotypical patients. Future areas of research will be to further the development of the web-based application, including expansion of the medical social stories for increased applicability and evaluating implementation in the workplace for feasibility. In future ambulatory workflow states, distributing the relevant social stories through the electronic medical record before an upcoming health care encounter would mimic the use of social stories in other settings. During inpatient admissions, the social stories may be deployed by caregivers or bedside nursing staff for individualized preparation for the health care process and procedures. Once the workflows are established, an evaluation of patient, caregiver, and HCP satisfaction is warranted to ensure usability and impact. In addition, consideration of a built-in functionality for a caregiver or patient to select an estimated cognitive ability, which may increase applicability to broader neurotypical and neurodivergent patient populations, would require flexibility in terms of social story content and avatar selection. Finally, other common themes that were identified as areas of need were the ability to provide an updated interface with the health care team highlighting important, individualized care elements; patient advocacy; and preferred interfaces with electronic health records.

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Acknowledgments

The views expressed in this manuscript are those of the authors and do not necessarily reflect the positions or policies of the US Department of Veterans Affairs or the US government. The authors thank Lauren Stufflebeam and Jakob Plotts as part of the design team, and Lidia Barraza for contributions with coding.

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Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Codes used in the qualitative analysis of phase 1 interviews with patients, caregivers, and health care providers.
[DOCX File , 16 KB - pediatrics_v9i1e76512_app1.docx]

Multimedia Appendix 2
Screenshot of the web-based application home page and of the landing page depicting the table of contents of potential social stories for health care interactions.
[DOCX File , 144 KB - pediatrics_v9i1e76512_app2.docx]

Multimedia Appendix 3
Outline of the thematic takeaway from phase 1 for the creation of the prototype and potential directions for future iterations and an accompanying visualization of the function of the prototype.
[DOCX File , 420 KB - pediatrics_v9i1e76512_app3.docx]

Multimedia Appendix 4
Cognitive assimilation scores for caregivers and patients. Scores measure to what extent an individual differentiates between interaction with the simulated environment and reality.
[DOCX File , 15 KB - pediatrics_v9i1e76512_app4.docx]

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Abbreviations

HCP: health care provider
SUS: System Usability Scale

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Original Paper

Striving for Triadic Collaboration in Pediatric Speech Sound Disorder Intervention: Grounded Theory Study

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Abstract

Background: Collaboration between speech-language pathologists (SLPs) and parents is central to pediatric speech sound disorder (SSD) intervention. Prior research has emphasized the relational and home-practice components of collaboration; however, little is known about the enactment, organization, and maintenance of collaborative processes across SLP sessions and home practice in relation to speech sound generalization.

Objective: This study examined the enactment and organization of collaboration between SLPs and parents in pediatric SSD intervention, with attention to children's participation. Using a grounded theory approach, it aimed to develop an empirically grounded conceptual account of how collaboration is organized in relation to speech sound generalization.

Methods: This qualitative study adopted a Strauss and Corbin–oriented grounded theory approach. Semistructured interviews were conducted with 12 SLPs and 10 parents of children aged 4 to 7 years receiving SSD intervention in South Korea. Data collection and analysis proceeded iteratively using open, axial, and selective coding with constant comparison. A paradigm model explicated relationships among categories, and selective coding integrated categories around a core category.

Results: The central phenomenon was conceptualized as striving for triadic collaboration, reflecting SLPs' and parents' efforts to coordinate roles, expectations, and practice while supporting children's participation across SLP sessions and home practice. Three interrelated action/interaction strategies were identified: SLP-led monitoring strategies, parent-led home-based intervention strategies, and gradual motivation strategies. These collaborative processes were shaped by background and practice-level constraints. A category integration diagram was developed to represent how the core category, action/interaction strategies, and contextual concerns were organized around triadic collaboration.

Conclusions: The findings suggest that collaboration in pediatric SSD intervention is a contextually embedded process in which SLPs and parents coordinate roles and practices across SLP sessions and home practice while supporting children's participation. The category integration diagram represents how collaborative processes were organized across settings in relation to the gap between structured target sound production and everyday speech use. These findings highlight the relevance of coordinated collaboration for supporting practice across settings in relation to speech sound generalization.

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KEYWORDS

child participation; digital health; grounded theory; home-based practice; pediatric speech intervention; qualitative study; speech sound disorder; speech sound generalization; speech-language pathology; triadic collaboration

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Introduction

Background

Speech sound disorders (SSDs) are among the most common communication disorders in early childhood, affecting approximately 8%-9% of preschool-aged children [1]. SSDs comprise a heterogeneous set of developmental difficulties in speech sound production, including phonological impairment, childhood apraxia of speech (CAS), childhood dysarthria, and articulation impairment, which differ in terms of underlying mechanisms and treatment approaches [2-5]. These challenges are described alongside phonological (linguistic) and motor speech (speech-motor planning, programming, or execution) dimensions [6,7]. Children with SSDs are at increased risk of language and literacy difficulties in later life [8,9]. Persistent speech errors are associated with social–emotional challenges and decreased participation within social and academic contexts [10].

In South Korea, SSDs comprise 44.1% of speech-language service caseloads, and children aged 4 to 7 years comprise approximately half of these cases [11]. Services are delivered in individual one-on-one sessions scheduled on a regular weekly basis, with children typically working with the same speech-language pathologist (SLP) across sessions to support treatment continuity. Parents are involved through brief consultations before or after therapy. These consultations last approximately 10 minutes and focus on reviewing session content and assigning home-based practice. Direct parent participation during therapy sessions is uncommon in many clinical settings, and parental involvement is therefore primarily structured through postsession consultations and home practice guidance. Coordinating therapy implementation within the home environment has become a crucial component of service delivery [12].

Clinical assessments use standardized tools that quantify speech accuracy and severity based on age-referenced norms [13]. Moreover, intervention approaches differ according to diagnostic subtype [5,14]. For example, contrast-based linguistic interventions address phonological impairments [14,15], targeting the reorganization of the phonological system [14,16]; meanwhile, CAS requires motor-based treatment targeting speech planning and sequencing [17,18], focused on accuracy and consistency of motor plans [17,19]. However, standardized assessment tools used in routine clinical settings often provide limited differentiation among SSD subtypes [20,21]. Consequently, in routine service contexts, children are broadly characterized by functional speech sound difficulties, and standardized subtype classification is not documented [22-24]. A key therapeutic objective is to promote generalization from trained stimuli to functional speech use across linguistic units and everyday communication contexts [25-27]. Achieving this generalization requires sufficient practice intensity [26,28].

Evidence suggests that high-intensity interventions—particularly those with increased session frequency and higher practice dose—may facilitate efficient gains associated with generalization [14,28]. However, sustaining high-intensity intervention in routine services is challenging owing to contextual constraints such as limited therapist availability, scheduling demands, and caregiver burden, contributing to the gap between evidence and practice [28-30]. Thus, extending practice opportunities beyond clinic-based intervention is important for supporting generalization [26,28].

SLPs collaborate with parents to extend clinic-based intervention into home-based contexts [31,32]. While relationship-based approaches consider family-specific constraints [31], several barriers hinder consistent home-based practice. Parents frequently face logistical demands, lack of readiness, and experience uncertainty regarding specific roles or activities [33]. Monitoring and supporting home-based practice across contexts are challenging for clinicians [34]. Consequently, clinical practice lacks a structured framework for defining participant roles, facilitating systematic interaction, and providing clear therapeutic guidance [35,36].

Scholars have discussed digital technologies in speech sound intervention as potential tools for alleviating spatiotemporal constraints and extending therapy continuity and practice intensity beyond the clinic into home-based contexts [37,38]. Prior research has mainly focused on their functional utility, including support for child engagement, intervention intensity, and associated outcomes [39-41]. However, research on digitally mediated collaboration among SLPs, parents, and children remains limited [41] and lacks a systematic examination of the organization and maintenance of digitally mediated collaboration under home constraints, including barriers to caregiver participation [42,43]. Studies on telepractice and remote service delivery have reported that digital technologies can enhance flexibility and accessibility and may expand opportunities for collaboration [43,44]. Challenges in rapport building and inequities in technology access may constrain participation [42,45]. These findings highlight the need to investigate the contribution of digitally mediated conditions to collaborative processes in pediatric speech sound intervention [41]. Prior research has highlighted the importance of collaboration between SLPs and parents in pediatric SSD intervention [31,32,46], which facilitates information exchange regarding children's status while enabling the codevelopment of individualized treatment plans [31]. Speech sound objectives relevant to children's daily life can be identified, and intervention strategies can be tailored [31,47]. Scholars have proposed realist-informed frameworks, such as preliminary program theory, for outlining the influence of contextual factors on collaborative practice [46].

Nevertheless, the SSD literature has frequently described collaboration in terms of discrete components, mechanisms, or facilitating and constraining conditions [31,32,46]. Existing studies offer limited guidance on the organization and maintenance of collaboration within clinical and home-based settings [31,46]. Qualitative studies have indicated that parents' understanding of their roles and engagement in home-based practice may change during service engagement in response to family routines, competing demands, and ongoing interactions with services [33,36,48]. Few studies have examined the evolution of collaborative processes among SLPs, parents, and children over time. Moreover, research has paid limited attention to the implementation of collaborative processes and their role

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in sustained home-based practice and speech sound generalization [31,33,46]. Thus, a process-oriented examination is required to elucidate how collaboration is sustained across contexts.

Research Objectives

This study aims to examine the enactment and organization of collaboration between SLPs and parents in everyday clinical settings for pediatric SSD intervention involving children with heterogeneous speech sound difficulties. It identifies the roles, interactions, and conditions that influence collaboration across SLP sessions and home practice. It examines children's participation through SLP and parent narratives, focusing on how children are positioned within collaborative processes. Based on interview data on collaborative experiences, the study aims to develop an empirically grounded conceptual account of how collaboration is organized in relation to speech sound generalization.

Methods

Study Design

This qualitative study adopted a Strauss and Corbin–oriented grounded theory (GT) approach to examine real-world interactions among SLPs, parents, and children across clinical and home settings in pediatric speech sound intervention [49]. Analysis focused on interactional processes and contextual constraints through which collaboration was enacted across clinical and home-based contexts [31]. Semistructured interviews were conducted with 10 parents of children with SSDs and 12 SLPs. Children were not directly interviewed because of age and speech-language limitations [50]. The study examined children's participation as described by parents and SLPs during interviews. Data collection and analysis proceeded iteratively using constant comparative methods. Analysis informed subsequent data collection and sampling, enabling the elaboration and refinement of emerging concepts [49]. Consistent with Strauss and Corbin's GT, this study maintained a systematic analytic framework while enabling interpretive flexibility during analysis [49,51]. It used multiple strategies to enhance rigor, including analyst triangulation, member checking, and peer debriefing [51]. The first author, who conducted the interviews and led the analysis, is a PhD candidate in human–computer interaction with training in qualitative research. The research team included members with backgrounds in speech-language pathology and digital health. Analytic memos and team discussions were used to examine emerging interpretations. The reporting of this qualitative study was guided by the COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist (Multimedia Appendix 1).

Recruitment

The study used purposive sampling to recruit participants with various clinical experiences, service settings, and levels of involvement in pediatric speech sound intervention. SLPs and parents were independently recruited through social media platforms (eg, Instagram) and online communities. In the initial phase of recruitment, 10 SLPs and 8 parents from Seoul and surrounding metropolitan regions in South Korea were recruited. Eligible parents were primary caregivers of children aged 4 to 7 years receiving speech-language therapy (SLT) for functional speech sound difficulties, including those formally diagnosed with SSD or clinically identified by certified SLPs. These children were currently undergoing or had completed professional SLT within the past 3 months. To focus on functional SSDs, cases involving identifiable organic or neurological conditions—including cleft palate, hearing impairment, intellectual disability, cerebral palsy, autism spectrum disorder, or chromosomal abnormalities—were excluded [2,3,52]. Most children were receiving face-to-face SLT at the time of the interviews, although 1 case involved remote service delivery. Diagnostic information was obtained from available clinical records provided by parents. Available documentation varied across cases; 5 cases included percentage of consonants correct indicators. Additionally, as supplementary information on functional speech intelligibility, Intelligibility in Context Scale scores were collected for all children (range: 2.29-4.29). Standardized subtype classification (eg, phonological vs motor-based subtypes), standard scores for speech production tests, and oral motor assessment results were not routinely documented in clinical records. Information about specific treatment approaches was not documented in the available clinical records. Eligible SLPs were required to have treated at least 5 children with SSDs. All participants were informed of the study objectives and procedures and provided written informed consent electronically via a secure online platform.

Data collection and analysis proceeded concurrently [49]. Guided by emerging analytic categories, the second phase of the recruitment was conducted using theoretical sampling [49,51]. Two SLP–parent dyads (2 SLPs and 2 parents) were recruited through snowball sampling. The members of both dyads were engaged in ongoing therapy with the same child, thus enabling examination of the alignment and negotiation of collaborative expectations within shared therapeutic contexts. The SLPs recommended parents who were eligible to participate.

Data Collection

Data were collected between June and August 2024 using semistructured, in-depth interviews. Interview guides were developed based on the study aims and refined through pilot testing. They were further tailored using prequestionnaire responses and revised in response to ongoing analysis, consistent with the GT methodology [53]. Early interviews broadly explored collaborative practices, while later interviews incorporated focused questions to elaborate and refine emerging themes [49,53]. A brief preonline questionnaire collected contextual information, including parental level of education, session frequency, presence of home practice assignments, and perceived importance of home practice.

Individual interviews with SLPs and parents were conducted by the first author and lasted approximately 60 to 90 minutes. Interviews were conducted in a one-on-one format to support confidentiality and minimize response biases. No prior relationships existed between the interviewer and participants. Interviews were held at locations preferred by the participants, including homes, therapy rooms, and meeting spaces. Participants were informed that the study focused on

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collaborative practices in pediatric SLT. They were asked to describe their children's participation and interactions during therapy and home-based practice.

All interviews were audio-recorded and transcribed using an automatic speech recognition tool (Clova Note; NAVER Corporation), followed by manual verification. The first author took field notes to capture contextual details and nonverbal cues. Analytic memos were taken during and after the interviews to document emerging themes and inform subsequent data collection and analysis [49]. Videos and photographs were shown during interviews for contextual illustration only, but were neither collected nor analyzed due to child privacy considerations.

Follow-up interviews were conducted via videoconferencing (Zoom; Zoom Communications Inc) or email when clarification was required during analysis. Data collection continued until theoretical saturation was reached, defined as the point at which additional data no longer contributed to the elaboration of categories and their relationships [51]. Multimedia Appendix 2 outlines the initial interview protocols, originally developed in Korean and translated into English summary tables for reporting.

Data Analysis

Data analysis followed Strauss and Corbin's GT approach using open, axial, and selective coding with constant comparison [49]. Data analysis and collection were conducted simultaneously, enabling emerging concepts to inform analytic focus [49,53].

During open coding, interview transcripts and field notes were examined per line to identify actions, interactions, and conditions [49]. Analytic memos documented emerging concepts and supported comparison across interviews. To calibrate analytic focus and coding boundaries, 3 researchers independently coded 2 interview transcripts (1 with a parent and 1 with an SLP) and engaged in analytic discussions. This process resulted in an initial set of open codes and provisional categories (Multimedia Appendix 3). The analytic coding framework was used as a working tool and iteratively revised as categories were compared, integrated, and elaborated through team discussion.

Axial coding focused on relating categories to subcategories by examining relationships among conditions, action/interaction strategies, and consequences. A paradigm model was used as an analytic tool for organizing these relationships [49,51]. Comparisons across participant groups (SLPs and parents) and contexts (clinical and home-based settings) supported refinement of the properties and dimensions of the categories.

Selective coding included the integration of categories around a core category representing the central collaborative process [49]. Categories were integrated to examine coherence and explanatory adequacy. Data from SLP–parent dyads were used to examine whether these relationships were sustained across shared therapeutic experiences, further refining the core category.

Children's participation was analyzed through SLP and parent narratives, focusing on adults' descriptions of guiding children in participation and the enactment of children's behaviors and expressions during adult–child interactions. Atlas.ti (ATLAS.ti Scientific Software Development GmbH) supported initial coding and management of coded excerpts. Excel (Microsoft Corporation) was used to document the evolving coding framework and track analytic decisions during team discussions.

Ethical Considerations

This study received ethical approval from the Yonsei University Institutional Review Board (number 7001988-202406 -HR-2290-03). Participants provided informed consent and were assured of their right to withdraw at any time without penalty. Data were anonymized and stored securely on an encrypted server. The participants received monetary compensation for their participation.

Results

Participant Characteristics

The study recruited 22 participants (10 parents of children with SSDs and 12 SLPs). Among the parents, 7 (70%) and 3 (30%) were aged in their 30s and 40s, respectively, while 6 (60%) and 4 (40%) resided in Seoul and nearby metropolitan areas, respectively. Regarding education, 1 (10%), 6 (60%), and 3 (30%) completed high school, a bachelor's degree, and a master's degree, respectively.

The children were evenly split by gender (boys: 5/10, 50%; girls: 5/10, 50%) and aged 4 to 6 years, with 5 (50%), 2 (20%), and 3 (30%) aged 4, 5, and 6 years, respectively. Intelligibility in Context Scale scores (5-point parent-rated scale) ranged from 2.29 to 4.29. Among 5 cases with available percentage of consonants correct data, values ranged from 70.83% to 90.69%. Clinical records lacked diagnostic subtype classification; therefore, cases were described as functional speech sound difficulties. Service settings included hospital-based centers, private clinics, and 1 case of home-based therapy. The duration of therapy was less than 1 year for 3 (30%) children, 1-2 years for 4 (40%), and more than 2 years for 3 (30%). Eight children were actively receiving intervention, while 2 had completed intervention within the past 3 months. All children received SLT once or twice per week. Eight parents reported receiving home assignments; 2 reported none. Most parents reported inconsistent home practice because of time constraints; 1 reported consistent implementation. All parents perceived home practice as influencing therapy outcomes, while 3 described it as crucial. Information on specific therapy methods was obtained during parent interviews, as it was unavailable in clinical records.

Among the SLPs, 8 (67%) were aged in their 20s, 2 (17%) were in their 30s, and 2 (17%) were in their 40s. The majority worked in private clinics (7/12, 58%) or hospital-based centers (5/12, 42%), held a master's degree (7/12, 58%) or were enrolled in graduate programs (2/12, 17%) and had clinical experience of less than 4 years (4/12, 33%), 4-8 years (5/12, 42%), and more than 8 years (3/12, 25%). Regarding SSD caseloads, 6 (50%), 4 (33%), and 2 (17%) treated more than 20, 10-20, and fewer than 10 children, respectively. Multimedia Appendix 4 provides detailed participant characteristics.

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Central Phenomenon: Striving for Triadic Collaboration

Through interviews, collaboration between SLPs and parents was described as an ongoing effort to align roles, expectations, and practices within clinical and home-based settings. Participants emphasized that collaboration required ongoing adjustment rather than agreement: “It’s not that we just follow instructions. We try, and then we adjust depending on how things actually work at home” (P04).

Collaboration was enacted not as passive adherence but as a process of repeated recalibration. Accordingly, the central phenomenon was conceptualized as “striving for triadic collaboration.”

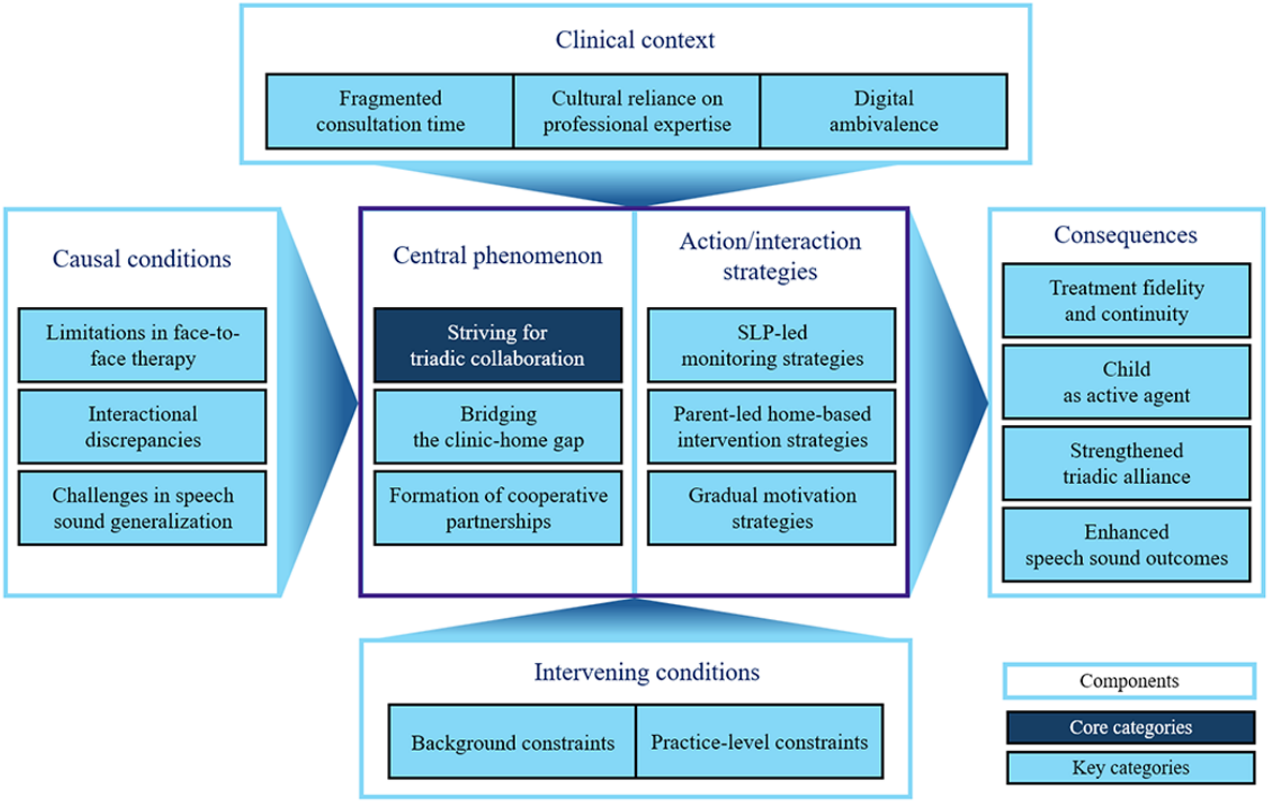
Striving unfolded within a clinical context characterized by fragmented consultation times, cultural reliance on professional expertise, and digital ambivalence. Digitally mediated conditions supported cross-context communication and progress monitoring but raised concerns regarding diminished face-to-face engagement and technological overreliance. Expectations regarding roles and responsibilities centered on the SLP. Several causal conditions intensified this striving. Limitations in face-to-face therapy, interactional discrepancies, and challenges in achieving speech sound generalization were described as influencing efforts to extend practice beyond clinic sessions.

Participants described efforts to bridge the clinic–home gap as the formation of cooperative partnerships. This process involved elucidating roles, negotiating expectations, and extending practice beyond therapy sessions. SLPs adjusted clinical guidance to align with family routines and children’s responses, while parents engaged in repetitive attempts to implement and refine home-based practice: “Even when we agree on the plan, it doesn’t always unfold the way we expected” (SLP05).

Collaboration unfolded not as a fixed agreement but as an ongoing process requiring recalibration in response to contextual constraints, children’s responses, and changes in parental attitudes. Through these adjustments, collaboration evolved over time.

Within the paradigm model, striving for triadic collaboration served as a central phenomenon linking causal conditions, action/interaction strategies, and consequences. Clinical contexts and causal conditions influenced this striving, which was enacted through the action/interaction strategies presented in the following section. These processes were reflected in treatment fidelity and continuity, children’s participation as active agents, a stronger triadic alliance, and changes observed in speech sound performance. Figure 1 presents the paradigm model illustrating these relationships. Multimedia Appendix 5 provides a detailed coding matrix outlining relationships among components, key categories, and subcategories within the paradigm model.

Figure 1. Paradigm model of striving for triadic collaboration. Derived through axial coding, this model illustrates relationships among causal conditions, intervening conditions, the central phenomenon, action/interaction strategies, and consequences. SLP: speech-language pathologist.



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Action/Interaction Strategies for Triadic Collaboration

Overview

A total of 3 interrelated action/interaction strategies were identified in response to the central phenomenon of striving for triadic collaboration: SLP-led monitoring strategies, parent-led home-based intervention strategies, and gradual motivation strategies. These strategies were enacted in response to clinical and causal conditions and addressed the clinic–home gap. SLP-led monitoring strategies facilitated goal alignment and progress tracking; parent-led home-based intervention strategies extended therapeutic practice into daily contexts; and gradual motivation strategies supported children's engagement in therapeutic tasks. Table 1 summarizes the paradigm-informed coding structure underlying these action/interaction strategies, including key categories and subcategories derived through open and axial coding.

Table 1. Key categories, subcategories, and key codes associated with the action/interaction strategies identified within the paradigm model.

Key categories and subcategories	Key codes
SLP[a]-led monitoring strategies	
Collaborative goal setting	• Explain children's condition objectively to parents • Set therapy goals that reflect children's status and parents' needs • Establish stepwise goals based on difficulty levels
Transparent communication	• SLPs share therapy progress and updates • Parents share observations in daily life • Collaborate with preschool and kindergarten teachers
Progress monitoring	• Visualize progress using graphs and metrics • Compare pretherapy and posttherapy outcomes • Adjust detailed goals according to status changes
Parent-led home-based intervention strategies	
Parent coaching supported by SLP	• Provide home practice guidelines • Encourage and positively reinforce parents' efforts
Parent-led speech practice	• Facilitate consistent child practice • Manage children's stress during home practice
Guided self-monitoring	• Provide visual and auditory discrimination tasks • Offer appropriate cues during practice • Share feedback to promote accurate speech production • Create opportunities for self-correction
Contextualized practice	• Promote generalization through repeated practice in diverse linguistic contexts • Simulate peer interaction scenarios • Encourage generalization in various locations with family support
Gradual motivation strategies	
Choice-supportive interaction	• Incorporate preferred activities into therapy (eg, toys, games, and play) • Apply gamification elements (eg, collection, missions, and challenges) • Offer structured choices during activities (eg, selecting tasks or materials)
Incentive-based participation	• Provide tangible rewards (eg, snacks and drinks) • Use activity-based rewards (eg, playtime and games) • Visualize effort and progress (eg, stickers, stamps, and tracking charts)
Socially mediated reinforcement	• Deliver verbal reinforcement (eg, praise and encouragement) • Use nonverbal reinforcements (eg, high-five and clapping) • Facilitate social recognition (eg, sharing achievements with family members)

[a]SLP: speech-language pathologist.

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SLP-Led Monitoring Strategies

Overview

SLPs described monitoring as a strategy for maintaining collaboration with parents and tracking children's progress. Monitoring involved 3 interconnected elements: collaborative goal setting, transparent communication, and progress monitoring.

Collaborative Goal Setting

Collaborative goal setting was described as a process in which SLPs and parents developed a shared understanding of children's status and negotiated therapy goals. SLPs discussed therapy goals with parents based on formal and informal assessment results and positioned this discussion as an initial step in collaborative work.

> *If the mother shares her goals, I try to incorporate them. If they seem appropriate, I include them; if it is too high, I explain why. I set goals together with the mother.* [SLP02]

In clinical settings, parents were often reluctant to express their opinions, citing respect for the expertise of the SLP. This pattern was associated with challenges in collaborative goal setting.

> *The moment a mother says something, she might think she's expressing dissatisfaction with the teacher's curriculum.* [P09]

Parents had limited access to information enabling an objective understanding of their child's status. They reported difficulty in assessing the necessity of therapy and the appropriateness of goals without standardized assessment results.

> *We did an assessment, but I didn't receive a result sheet. They didn't give it to me. So, I had to listen and take notes...because I need to know too.* [P02]

Parents expressed the need for assessment results in an understandable format.

> *It would be good if we could see something like that. Within the children's average range... (so we can know our child's position) similar to pediatric health checkups...* [P01]

Receiving assessment results in a format similar to that used in pediatric health checkups was described as supporting parental understanding.

Transparent Communication

Participants described mutual information exchange about children's progress as part of maintaining collaborative relationships. SLPs sought updates on children's daily lives, while parents expected feedback from therapy sessions. However, time constraints due to back-to-back therapy schedules frequently limited these exchanges.

> *During consultations, I feel extremely rushed. The consultation ends at the same time the next child's class begins...There's so much to talk about, but time is really tight.* [SLP12]

Parents also recognized these constraints and expressed regret about insufficient communication. Consultation time was approximately 5 minutes per session.

> *In 5 minutes, the consultation time is extremely short for asking questions and getting answers.* [P09]

In response to these limitations, SLPs attempted asynchronous communication using digitally mediated communication tools. This approach, however, depended on parental participation.

> *I asked them to record videos of the child practicing. But the mother did it for a while but later asked to stop because it was very demanding.* [SLP06]

These structural and practical barriers limited consistent communication and information exchange between home-based practice and clinic-based intervention.

Progress Monitoring

Progress monitoring was described as a part of maintaining collaboration. SLPs and parents reported that presenting comparative therapy data influenced parental perceptions of therapy.

> *What parents are most curious about is knowing the numbers—how well the child is doing right now.* [SLP05]

SLPs described changes in parental perceptions when objective comparative data were provided. One SLP described playing before-and-after recordings to a parent.

> *The mother didn't really know how unclear her child's pronunciation was. I sent her part of a recording from class...after that she said, "When I listened to just the voice without any context, I could really feel that my child had improved."* [SLP08]

Parents similarly reported that listening to recordings supported clearer recognition of their child's speech difficulty and therapy progress.

> *I told the teacher that I didn't think my child's pronunciation was that bad. But after listening to the recording, I could really hear the difference and realized the improvement.* [P07]

Some parents referenced familiar technology platforms, such as Wink, when discussing potential monitoring formats.

> *Like Wink (a customized learning device for young children), it would be good if teachers could share the child's activities and data that parents can see.* [P09]

Participants described objective digital measurement tools as facilitating shared access to therapy-related information.

Parent-Led Home-Based Intervention Strategies

Overview

SLPs described continued speech practice at home as part of extending therapy beyond clinic sessions. Parent-led home-based intervention involved 4 interconnected elements: parent coaching supported by SLP, parent-led speech practice, guided self-monitoring, and contextualized practice.

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Parent Coaching Supported by SLP

SLPs described systematic coaching as part of supporting parent-led home practice, as many parents lacked familiarity with specific guidance methods. Parents demonstrated varying levels of awareness and ability to implement home practice, and many reported difficulty in maintaining it over time. SLPs recognized this gap and provided specific methods to connect therapy-room activities with home-based practice.

> *I let them (parents) feel how my mouth moves, and I also help position theirs, such that they understand the articulation; however, with their daily routines and work, they often forget this technique.* [SLP10]

In response to these limitations, SLPs developed strategies for providing recorded materials with explanations.

> *When I edit and bring recorded materials, we listen to them together and I explain, "This is how I provided stimulation, and at this point the child produced correct articulation.*" [SLP12]

Parents expressed anxiety about providing feedback as nonexperts, which was associated with more passive responses: "If I do this wrong, I might actually create bad habits" (P06).

> *When I really can't understand the pronunciation, I just say "good" and move on. I don't keep asking about it.* [P08]

Three parents enrolled in related academic programs or obtained certifications to provide therapy more formally. This process required considerable time and introduced additional difficulties.

> *I started grad school hoping to help my child more with his therapy but juggling school, practicum hours, and everything at home frequently meant I had to leave him with a sitter, and I ended up being less engaged in his day-to-day therapy.* [P03]

This case reflected challenges in sustaining home practice through individual parental effort and highlighted the need for ongoing professional support.

Parent-Led Speech Practice

Participants described challenges in sustaining speech sound practice at home. Parents reported difficulty in ensuring sufficient practice time due to constraints such as work demands, caring for siblings, and household tasks.

> *I think there are definitely areas that improve if you consistently practice at home too. But it's hard to practice at home. It's difficult to get them to sit down, and I'm tired too.* [P02]

Lack of child cooperation added to challenges in home practice: "They don't want to do homework, and they don't sit for long periods, so sometimes we can't do it" (P04).

Parents limited practice to avoid stressing the children, whereas SLPs emphasized the value of continued home practice.

> *My child said, "Do you think here is a lip teacher's academy?" (during COVID-19, therapists wore clear masks that only showed their mouths). So, I thought I should not stress them anymore, and I don't force them to do this at home.* [P02]

SLPs expressed understanding of the parents' practical difficulties while expressing concern about reduced home practice.

> *I understand being busy, but it's a bit disappointing. It seems like a child could maintain progress if they practiced a little, so it's unfortunate.* [SLP09]

Across interviews, SLPs emphasized the value of home practice, whereas parents described implementation challenges. Divergent perspectives between SLPs and parents emerged consistently.

Guided Self-Monitoring

Guided self-monitoring strategies focused on supporting children's ability to monitor and correct their speech sounds. SLPs described self-monitoring as related to speech sound generalization.

> *The ultimate goal for these children is to monitor themselves without anyone else's help and think "I just made a mistake, I need to do it again"—that's the goal of all therapy.* [SLP07]

Given this purpose, SLPs provided cues that encouraged children to recognize errors before providing correction.

> *Let them think and try as much as possible on their own, and only if that doesn't work, provide the correct sound. The priority is not to give them the answer right away, but to let them figure it out first.* [SLP01]

SLPs described self-evaluation using mobile phone video or recording functions as an effective strategy.

> *If "tiger (Horangi (호랑이))" inconsistently becomes "horanee" or "horiri"...I show children their own appearance and let them hear their own sounds. The process of making them aware is necessary.* [SLP11]

Parents noted that digital recording functions were useful for supporting self-monitoring during home-based practice and mentioned specific tool functionalities.

> *The recording button should be available for repetitive listening...so they can press it many times enough to catch that something is strange by listening to it.* [P09]

SLPs and parents described tools that increased awareness of speech errors and supported children's self-monitoring behaviors (error recognition and self-correction) at home.

Contextualized Practice

Participants described contextualized practice as a way to support children's use of target sounds beyond structured SLP sessions. SLPs emphasized that accurate production during brief clinical sessions did not necessarily extend to everyday speech use without continued home practice.

> *Generalization is practically impossible if we rely only on one 40-minute session a week. The mother needs to guide this at home.* [SLP02]
>
> *Because meeting once or twice a week is too short, generalization does not really happen. If the child*

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> *does well only here and then leaves, it goes back to the same.* [SLP06]

SLPs described everyday communication contexts as important because children needed to use target sounds with different people and in comfortable settings, not only during structured interaction with the therapist.

> *To help a child speak well with any person and in any place—not only speaking well because they are tense in front of the therapist—I think support through home practice is needed.* [SLP10]

Parents described successful peer communication as a primary goal of therapy, noting that their children frequently struggled to interact with friends.

> *A frequently asked question was "What?", while many kids commented, "I don't understand what you're saying at all"...They got pointed out a lot by other kids...Occasionally, they didn't interact and couldn't get along with other children.* [P05]

SLPs and parents described peer interaction, story materials, play, and daily routines as contexts for practicing target sounds in varied interactions. SLPs also described gradual increases in practice complexity as relevant to children's use of target sounds in spontaneous speech.

> *If we practice at the word, phrase, and sentence levels first, then when the child says what they really want to say to someone in a longer unit, they can develop control. I don't think that ability suddenly appears when we move to sentences or conversation without practice at the word level.* [SLP12]

> *They don't like it when it feels too formal or like studying, so we end up playing a lot of word chain games—whether we're driving somewhere or just going about our day.* [P01]

These accounts described contextualized practice as connecting structured target sound production in SLP sessions with home routines and everyday speech use.

Gradual Motivation Strategies

Overview

SLPs and parents reported that maintaining children's motivation was important during therapy, as children's willingness to participate shaped therapy activities. SLPs adjusted motivational strategies according to children's developmental level and therapy progression. Three subcategories were identified within gradual motivation strategies: choice-supportive interaction, incentive-based participation, and socially mediated reinforcement.

Choice-Supportive Interaction

SLPs used children's interests and preferences as starting points to foster enjoyment and sustain participation in therapy. They identified these interests during initial consultations and integrated them into sessions by creating customized materials or introducing play-based elements.

> *I try to proceed according to children's interests as much as possible. Characters the child likes or games they enjoy—I blend these in more—I make personalized materials directly.* [SLP12]

SLPs also described offering structured choices, such as allowing children to select materials or activity order, as a way to support participation during repetitive speech practice. These choice-supportive strategies were described as helping children engage with therapy tasks while maintaining a sense of involvement in the activity.

Incentive-Based Participation

SLPs and parents described using external reinforcement strategies to support children's participation during repetitive practice. These strategies included tangible rewards, sticker charts, and activity-based rewards. SLPs described shifting from material rewards to activity-based rewards as therapy progressed.

> *Since we have 40-minute classes, if they concentrate for 30 minutes and finish all these tasks, then they can choose and do activities, board games, toys, or whatever they want for the remaining 10 minutes!* [SLP12]

Parents also used rewards during home practice, but described difficulty adjusting the timing and frequency of reinforcement.

> *At first, I gave them a gift every time they did well, but they started expecting something for even the smallest things. The therapist said the rewards were too frequent, so I switched to giving a gift only after they filled up their grape chart (sticker chart).* [P07]

These accounts described incentive-based participation as a way to support children's cooperation while adjusting reward type and frequency across SLP sessions and home practice.

Socially Mediated Reinforcement

SLPs and parents described socially mediated reinforcement as a way to sustain children's participation through praise, encouragement, and recognition from others. SLPs emphasized process-oriented praise that recognized children's effort during difficult speech tasks rather than simple result-oriented praise.

> *I tell children, "Producing the right sounds is really, really hard—even for older kids—but just trying to practice is already amazing. You're doing such a great job.*" [SLP12]

Parents described learning these specific praise methods from SLPs and applying them at home. They further extended social reinforcement by sharing children's achievements with family members to provide social recognition.

> *I say, "Let's send a video to grandma and grandpa too," then grandma and grandpa call and say "you did so great," and when this continues, the child wants to practice more.* [P05]

These accounts described socially mediated reinforcement as a way to support children's participation through praise, encouragement, and family recognition across SLP sessions and home practice.

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Intervening Conditions

Overview

Intervening conditions described by parents and SLPs shaped how the 3 action/interaction strategies were enacted. These conditions were grouped into background constraints and practice-level constraints. Background constraints reflected participants' caregiving responsibilities, work demands, emotional burden, and scheduling constraints, whereas practice-level constraints reflected gaps in feedback continuity, limited visibility of home practice and progress, and burdens associated with material and documentation management across SLP sessions and home practice.

Background Constraints

Parents and SLPs described workload and burnout as limiting sustained engagement in therapy-related activities. Parents reported difficulty maintaining home practice while managing caregiving responsibilities, sibling schedules, and work demands. One parent described being unable to give sufficient attention to the child receiving therapy because she also had to support an older child's schoolwork and was too exhausted after work to complete assigned practice activities (P04). SLPs also described workload constraints in clinical settings. One SLP reported seeing 9 to 10 children consecutively in a day, leaving little time for breaks or extended postsession consultation (SLP12).

Participants also described emotional burden as a background constraint. Parents reported anxiety, guilt, and distress related to their child's developmental trajectory, including concerns about delayed speech, possible disability, and whether they had sought services early enough (P07). SLPs described emotional labor when working with children who resisted therapy tasks or when communicating difficult feedback to parents. One SLP reported that repeated negative feedback and the need to manage children's strong emotional responses sometimes required suppressing her own emotions during sessions (SLP03).

Participants further described scheduling constraints as limiting the regularity and intensity of intervention. Parents coordinated SLT with sibling care, schoolwork, private education, and other rehabilitation services. One parent described moving between an older child's schedule and the younger child's center-based therapy (P09). SLPs similarly noted that some children were managing multiple activities and center visits, making it difficult for families to add or maintain twice-weekly SLT sessions (SLP10). These constraints were described as opportunities for consistent parent-led practice and for intervention at the frequency SLPs sometimes recommended.

Practice-Level Constraints

Parents and SLPs described practice-level constraints involving gaps in feedback continuity, limited visibility of home practice and progress, and burdens associated with material and documentation management across SLP sessions and home practice.

First, participants described gaps in feedback continuity between SLP sessions and home practice. Communication often depended on brief postsession consultations, which limited opportunities for detailed discussion of children's progress, home practice difficulties, or changes in family routines. Some parents described receiving only brief updates when sessions were scheduled back-to-back or when consultation time was embedded within a short therapy slot (P09). One parent explained that, in a hospital-based setting, she had to interrupt the final minutes of the child's session to ask questions, which made consultation difficult because she also wanted the child to use the full therapy time (P03). SLPs similarly described consultation as compressed by clinical schedules, with limited time to explain what had occurred during the session and how practice should continue at home (SLP12). Thus, feedback was present but often brief or fragmented.

Second, participants described limited visibility of home practice and progress. Parents reported difficulty judging changes in their child's speech because they had become accustomed to the child's pronunciation patterns in daily life. In some cases, parents recognized progress only after comparing recordings or hearing feedback from another person (P07). SLPs also described uncertainty about whether children used target sounds outside the therapy room because they could not directly observe home or everyday communication contexts (SLP01). This constraint was especially relevant when children produced target sounds during structured SLP sessions but did not consistently use them in spontaneous speech or home routines.

Third, participants described material and documentation management as a practice-level burden. SLPs prepared paper-based worksheets, individualized word lists, and activity materials for each child, while parents were expected to store, retrieve, and use these materials during home practice. Parents described difficulties when paper worksheets were misplaced, forgotten, or difficult to organize across repeated sessions (P10). SLPs also described the burden of creating, modifying, and checking practice materials. One SLP described using Google Forms and generative artificial intelligence to prepare vocabulary quizzes, but still needed to manually check and revise materials before use (SLP05). These accounts indicated that material and documentation management were part of the work required to connect SLP sessions with home practice.

Together, these practice-level constraints described limitations in how SLP sessions and home practice were connected. Brief consultation time, limited access to children's performance outside the clinic, and burdens associated with material and documentation management were described even when parents and SLPs were engaged in supporting children's speech practice.

Integration of Categories Around the Core Category

During selective coding, the identified categories were integrated around the core category of striving for triadic collaboration. This core category captured participants' accounts of collaboration as an ongoing effort to coordinate roles, expectations, and practice across SLP sessions and home practice. As described in the contextualized practice category, participants' accounts repeatedly pointed to a gap between structured target sound production in SLP sessions and children's everyday speech use. Structured target sound production and everyday speech use were included in Figure 2

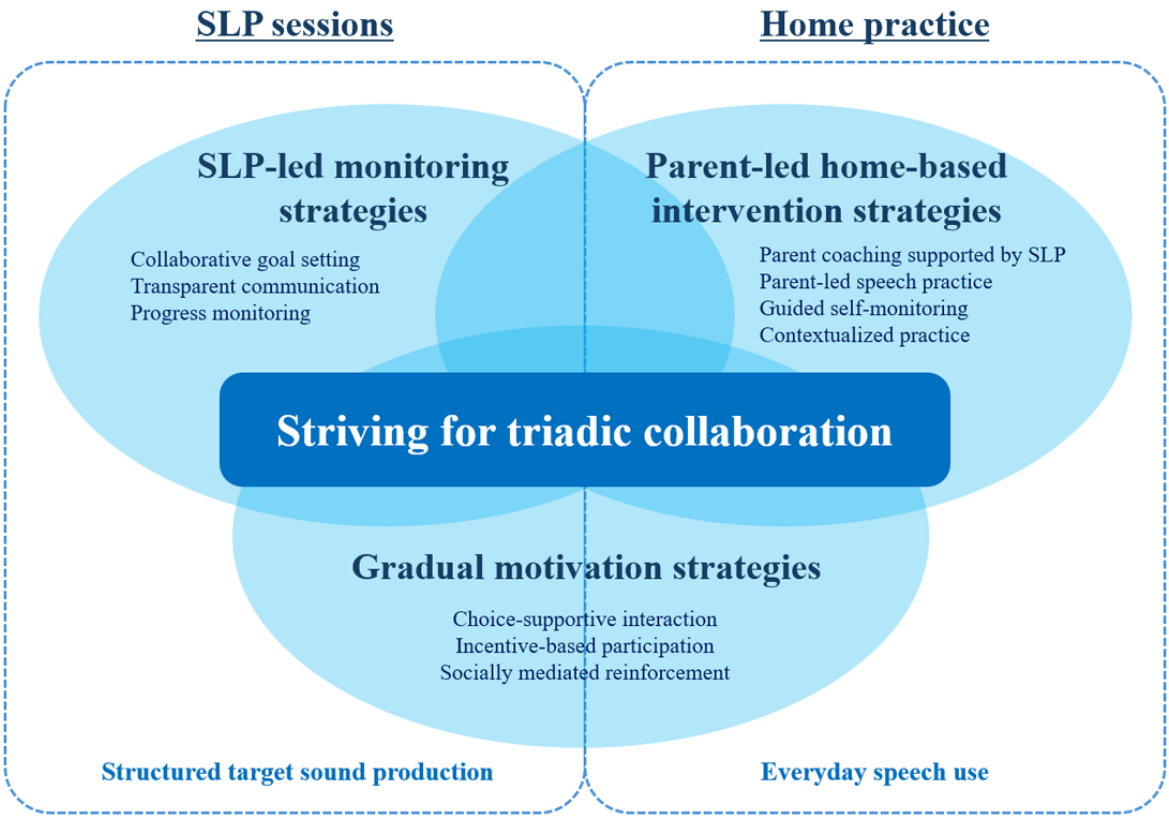
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as contextual concerns through which participants described the clinic–home gap.

Within this integration, SLP-led monitoring strategies, parent-led home-based intervention strategies, and gradual motivation strategies were organized as overlapping components rather than separate steps. Their overlap reflected participants' accounts that the clinic–home gap required coordination among clinical guidance, home-based practice opportunities, and children's engagement. SLP-led monitoring strategies supported shared understandings of therapy goals, children's progress, and expectations for home practice. Parent-led home-based intervention strategies described how practice guidance was taken up, adapted, or constrained within family routines. Gradual motivation strategies operated across both settings because children's participation had to be supported during structured SLP sessions as well as repeated home practice.

Taken together, these categories represented collaboration as a contextually embedded process of continued adjustment among SLPs, parents, and children. Figure 2 provides a visual representation of category integration derived through selective coding. The dashed areas indicate the 2 settings in which participants described collaborative work: SLP sessions and home practice. The overlapping ovals represent the 3 action/interaction strategies—SLP-led monitoring strategies, parent-led home-based intervention strategies, and gradual motivation strategies—and their subcategories as described above. The central bar represents the core category of striving for triadic collaboration, around which these strategies were integrated. Structured target sound production and everyday speech use are shown as contextual concerns that reflected participants' descriptions of the gap between structured SLP sessions and daily speech use.

Figure 2. Category integration diagram of striving for triadic collaboration. The diagram illustrates how speech-language pathologist (SLP)–led monitoring strategies, parent-led home-based intervention strategies, and gradual motivation strategies were organized as overlapping components around the core category of striving for triadic collaboration across SLP sessions and home practice. Structured target sound production and everyday speech use are shown as contextual concerns described by participants.



Discussion

Principal Findings

The findings provide an empirically grounded account of how SLPs and parents organized collaboration across SLP sessions and home practice in relation to the gap between structured target sound production and children's everyday speech use. The core category, striving for triadic collaboration, captured collaboration as an ongoing effort by SLPs and parents to coordinate roles, expectations, and practice while supporting children's participation. This collaboration was enacted through 3 action/interaction strategies: SLP-led monitoring strategies, parent-led home-based intervention strategies, and gradual motivation strategies. These strategies were shaped by background and practice-level constraints, including workload and burnout, emotional burden, scheduling constraints, gaps in feedback continuity, limited visibility of home practice and progress, and material and documentation management burden. Together, the findings suggest that collaboration in pediatric SSD intervention was organized as a contextually embedded

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process of continued adjustment across SLP sessions and home practice.

Triadic Collaboration as an Organizing Process Across Contexts

Prior research has described collaboration in pediatric SLT as involving relational practices and joint planning between SLPs and parents [31,46,54]. Shared decision-making has also been identified as a key component of pediatric care [55]. Family-centered practice further emphasizes negotiated partnership, mutual understanding, and shared responsibility in service planning [56,57]. Recent work on collaborative relationships between families and SLPs also highlights communication, trust, and shared responsibility within early intervention contexts [58].

The present findings build on this literature by conceptualizing collaboration as a triadic organizing process involving SLPs, parents, and children. This formulation is consistent with research on triadic pediatric consultations, which suggests that children's participation can reshape interactional dynamics rather than positioning children as passive recipients of care [59]. In this study, striving for triadic collaboration captured how participants described the coordination of roles and practices across SLP sessions and home practice.

In interpreting these findings, the 3 action/interaction strategies may be understood as a tentative, nonsequential conceptual lens of alignment, expansion, and internalization. SLP-led monitoring may support alignment by helping SLPs and parents share information about goals, progress, and expectations for home practice. Parent-led home-based intervention may expand practice opportunities into family routines. Gradual motivation strategies may support internalization by helping children move from externally prompted participation toward more self-directed engagement in repeated practice across SLP sessions and home routines.

Collaboration in Relation to Speech Sound Generalization

In relation to speech sound generalization, the findings suggest that collaboration may be relevant because it organizes how practice, feedback, and child participation are coordinated across SLP sessions, home routines, and everyday speech use. Prior SSD research has identified self-monitoring as relevant to generalization [60]. Motivation and engagement have also been discussed in relation to sustained participation in learning and therapeutic contexts [61,62]. Motor learning and speech practice research emphasizes practice conditions, repetition, and feedback in speech intervention [63,64].

Evidence on parent involvement in childhood SSD intervention emphasizes extending practice beyond therapy sessions and supporting home practice [31-33]. Studies of parental roles and coworking further show that home practice is shaped by parents' beliefs, role expectations, and family routines [36,48].

The present findings connect these strands by situating these practices within collaborative work across SLP sessions and home practice. Guided self-monitoring was described as one component of parent-led home-based intervention. Contextualized practice was described as connecting structured target sound production with home routines and everyday communication contexts. These SLP- and parent-supported practices were described as creating opportunities for children to notice and adjust speech production during practice.

Broader work on self-regulation and motivation further supports attention to how children participate in learning and therapeutic activities [65,66]. In this framing, guided self-monitoring is best understood as a participant-described practice within collaborative intervention, with its relation to speech sound generalization requiring further study. Future studies could examine whether and how adult-supported collaborative practices contribute to children's independent self-monitoring and speech sound generalization over time.

The organization of triadic collaboration may also vary according to children's clinical presentation, treatment focus, family resources, and service context. SSD includes heterogeneous clinical presentations, and diagnostic and dimensional accounts emphasize differences across phonological, motor-based, and articulation profiles [2,6,67]. Intervention focus and intensity may also vary by clinical profile and treatment approach [14,15]. Treatment evidence for CAS suggests that some children may require more intensive or specialized clinician-guided intervention [68]. This study identified shared collaborative processes across participants but did not compare these processes by diagnostic subtype or treatment approach.

Family and service constraints also shaped how collaboration was sustained. Studies on parent-mediated interventions have reported challenges related to competing demands on parents' time, children's behavior, and alignment of goals [69]. Recent work on family-centered planning similarly highlights implementation challenges for health professionals and families [30]. In this study, background constraints, including workload and burnout, emotional burden, and scheduling constraints, shaped parents' and SLPs' capacity to sustain therapy-related work. Practice-level constraints, including gaps in feedback continuity, limited visibility of home practice and progress, and material and documentation management burden, shaped how SLPs and parents coordinated practice across settings. These findings suggest that home practice should be introduced with attention to family routines and service constraints to avoid increasing parental burden while extending practice beyond SLP sessions.

Implications for Digital Support

The practice-level constraints identified in this study suggest possible implications for digital support in pediatric SSD intervention. Participants described gaps in feedback continuity, limited visibility of home practice and progress, and burdens associated with material and documentation management. Human–computer interaction research involving pediatric speech-language pathology has highlighted the need to design digital tools that respond to the abilities and contexts of children with disabilities [70]. Related work on parent-clinician communication suggests that visualization tools may support communication when clinical information is difficult to share or interpret across stakeholders [71]. Digital tools could be

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explored as supports for feedback continuity, visibility of home practice and progress, and material and documentation management across SLP sessions and home practice. Recent work on automatic speech recognition assessment for children with SSD also suggests the relevance of digital assessment tools for speech-related monitoring and feedback [13]. Design-based research on children's apps emphasizes iterative development and attention to child-centered use contexts [72]. Research on children's digital technologies also suggests that adults' roles in selecting, managing, and implementing tools should be considered during design [73]. These perspectives are relevant because digital support in pediatric SSD intervention would need to consider the practice-level constraints identified in this study, including feedback continuity across settings, visibility of home practice and progress, and material and documentation management. These possibilities should be interpreted as design implications for future research.

Limitations

The findings should be interpreted while accounting for the limitations of the study. First, children's perspectives were examined indirectly through parent and SLP reports due to age and speech-language limitations that constrained direct interviewing. Although this approach provided insights into children's participation within adult–child interactions, it only partially captured children's lived experiences and interpretations of the intervention. Future studies should incorporate developmentally appropriate and creative methods to directly elicit children's perspectives.

Second, this study was conducted within the clinical and cultural context of South Korea; therefore, transferability to other linguistic or health care settings should be considered with caution. Although SSD is a heterogeneous clinical category, formal subtype classification was not routinely conducted within the participants' settings, and subtype-specific differences were not examined. While the study identified common collaborative processes, coordination may vary according to clinical presentation and service context. Information on parents' socioeconomic background was not collected, and variation in these contextual factors may also influence collaborative processes. Future research should examine how socioeconomic variation shapes collaboration across service contexts.

Third, the category integration diagram should be interpreted as a conceptual representation derived from qualitative data. The diagram clarifies relationships among the core category, action/interaction strategies, and contextual concerns identified in this study, but it does not establish feasibility, effectiveness, or implementation requirements across service contexts. Similarly, the digital support implications were inferred from practice-level constraints and participant-described examples. Future research should examine how collaborative processes and potential digital supports operate across SLP sessions and home practice, including their fit with family routines, service delivery constraints, and digital implementation conditions.

Conclusions

This study identified striving for triadic collaboration as the central phenomenon through which SLPs and parents coordinated roles, expectations, and practice while supporting children's participation across SLP sessions and home practice. Three action/interaction strategies—SLP-led monitoring strategies, parent-led home-based intervention strategies, and gradual motivation strategies—were organized around this core category and shaped by background and practice-level constraints. The category integration diagram represents how collaborative processes were organized in relation to the gap between structured target sound production and everyday speech use. These findings provide a process-oriented account of collaboration in pediatric SSD intervention and highlight the relevance of coordinated SLP–parent collaboration and children's participation for supporting practice across settings in relation to speech sound generalization.

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Data Availability

The qualitative datasets generated and analyzed during this study are not publicly available due to confidentiality protocols approved by the institutional review board and restrictions specified in the participant consent forms, but deidentified data are available from the corresponding author on reasonable request, subject to ethics approval and applicable data-sharing agreements. Deidentified underlying study data may also be provided to the journal for inspection or verification purposes.

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Authors' Contributions

Conceptualization: SK (equal), JK (equal)
Data Curation: SK
Formal Analysis: SK (lead), YM (supporting), BM (supporting)
Funding Acquisition: JK
Investigation: SK
Methodology: SK (lead), YM (supporting), BM (supporting), YK (supporting)
Project Administration: SK
Supervision: JK
Validation: YK
Visualization: YM
Writing – Original Draft: SK
Writing – Review & Editing: SK (lead), YM (supporting), BM (supporting), YK (supporting), JK (supporting)

Conflicts of Interest

None declared.

Multimedia Appendix 1
COREQ checklist.
[DOCX File , 31 KB - pediatrics_v9i1e86364_app1.docx]

Multimedia Appendix 2
Semistructured interview protocol for speech-language pathologists and parents.
[DOCX File , 34 KB - pediatrics_v9i1e86364_app2.docx]

Multimedia Appendix 3
Initial coding framework generated during open coding, comprising 47 provisional categories and 227 codes prior to iterative refinement.
[DOCX File , 38 KB - pediatrics_v9i1e86364_app3.docx]

Multimedia Appendix 4
Participant characteristics and contextual information for children described in parent interviews.
[DOCX File , 30 KB - pediatrics_v9i1e86364_app4.docx]

Multimedia Appendix 5
Paradigm model developed through axial coding, illustrating relationships among causal conditions, clinical contexts, intervening conditions, action/interaction strategies, and consequences.
[DOCX File , 30 KB - pediatrics_v9i1e86364_app5.docx]

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Abbreviations

CAS: childhood apraxia of speech
COREQ: Consolidated Criteria for Reporting Qualitative Research
GT: grounded theory
SLP: speech-language pathologist
SLT: speech-language therapy
SSD: speech sound disorder

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Original Paper

The Arabic Canadian Occupational Performance Measure (Arabic-COPM) in Pediatric Rehabilitation: Quantitative Reliability Study

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Abstract

Background: The Canadian Occupational Performance Measure (COPM) has achieved global implementation across 35 countries in more than 20 language versions. However, its psychometric properties for children with physical disabilities remain unverified.

Objective: This study aimed to evaluate the interrater and test-retest reliability of the Arabic version of the COPM (Arabic-COPM) in this pediatric population.

Methods: A cross-sectional study was conducted using a convenience sample of parents of children with physical disabilities recruited from multi-rehabilitation centers. For the interrater reliability assessment, 100 parents completed the Arabic-COPM through independent interviews with 2 raters. A subsample of 30 (30%) parents repeated the assessment after a 14-day interval for the test-retest reliability analysis, in which they identified their children's 5 most significant daily activity problems and rated the performance and satisfaction levels for each problem using standardized 10-point scales.

Results: Reliability analyses demonstrated excellent psychometric properties. Intraclass correlation coefficients (ICCs) for interrater reliability were 0.84 (performance) and 0.80 (satisfaction), while test-retest reliability coefficients were 0.83 and 0.91, respectively. Interrater agreement analysis revealed 73% concordance in problem prioritization between independent assessors. Bland-Altman plots indicated narrow limits of agreement for both performance (−1.69 to 1.60) and satisfaction scores (−1.03 to 0.98). Cohen κ analysis for problem categorization demonstrated slight-to-fair interrater agreement and slight-to-moderate test-retest agreement across COPM domains. Content analysis identified a predominant concern with daily activities (82%-85% of problems), particularly mobility functions, followed by dressing and eating subcategories.

Conclusions: The Arabic-COPM demonstrated excellent reliability metrics for both interrater consistency and temporal stability when administered to parents of children with physical disabilities. These robust measurement properties support its application as a validated instrument for implementing family-centered rehabilitation approaches in Arabic-speaking clinical contexts.

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KEYWORDS

Canadian Occupational Performance Measure; psychometrics; interrater reliability; children with disabilities; family relations

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Introduction

Pediatric physical disability encompasses a spectrum of nonprogressive developmental conditions, including cerebral palsy and spina bifida, which originate from impairments in the developing nervous system [1]. A primary consequence of these disabilities is a significant limitation in the performance of daily activities, adversely affecting fundamental skills such as transferring, standing, and walking, and ultimately compromising functional independence [2,3]. In contemporary rehabilitation, enhancing functional performance and community participation are central objectives. This aligns with a paradigm shift over recent decades toward a family-centered model of care in pediatric rehabilitation [4,5]. This approach necessitates a direct focus on the challenges faced by parents of children with disabilities [6], particularly concerning the breadth and quality of their children's performance in daily activities [7]. Within this model, families are integral partners in all phases of service delivery, from goal-setting and treatment planning to evaluating outcomes. The therapist's role is to be responsive to parental concerns and to equip families with the necessary information for collaborative decision-making [8]. A prominent outcome measure designed to capture this family perspective is the Canadian Occupational Performance Measure (COPM) [9].

The COPM is a semistructured interview developed as a client-centered instrument by Law et al [10]. Its international adoption is evidenced by its availability in over 20 languages across 35 countries [11]. The measure is designed to holistically capture and quantify an individual's functional performance, roles, and environmental needs, facilitating a process in which clients can freely articulate and explore their problems with a therapist [12]. By eliciting clients' perceptions of their own performance and their satisfaction with that performance in self-identified areas of concern, the COPM fosters a collaborative partnership. This cooperation ensures the client's active involvement throughout the evaluation and intervention process [13].

The reliability of the COPM has been investigated in populations with various health conditions [14-16]. Studies have consistently reported excellent interrater reliability, with intraclass correlation coefficients (ICCs) for performance and satisfaction scores ranging from 0.84 to 0.92 in clients with chronic obstructive pulmonary disease [14], psychiatric disorders [15], and stroke [16]. Furthermore, the consistency of problem identification has been demonstrated across different client groups. For instance, 1 study found that 80% of problems prioritized by parents of children with physical disabilities were reidentified in a second interview with a different rater [17]. Similarly, Eyssen et al [18] reported that 66% of problems were consistently prioritized across assessments in patients with neurological disorders.

Despite the expanding use of the COPM in clinical and research settings [8,19-21], the reliability of the Arabic version of the COPM (Arabic-COPM) for parents of children with physical disabilities remains unestablished. Given its importance in family-centered rehabilitation, this study aimed to evaluate the interrater and test-retest reliability of the Arabic-COPM in this population, while also identifying the activity and participation priorities most reported by families.

Methods

Study Design and Participants

This study used a cross-sectional, multicenter design to evaluate the reliability of the Arabic-COPM. A convenience sample of 113 parents or primary caregivers of children with physical disabilities was recruited from various rehabilitation centers and societies in Jordan. The final analysis included 100 participants who completed the study protocol, while 13 were excluded due to scheduling conflicts or failure to attend follow-up appointments.

Inclusion criteria were (1) parents or primary caregivers of children diagnosed with physical disabilities stemming from nonprogressive neurological disorders, as confirmed by neurologists; (2) children demonstrating functional limitations in multiple activities of daily living; and (3) parents possessing sufficient proficiency in Modern Standard Arabic to comprehend and respond to interview questions. Exclusion criteria included parents of children with progressive neurological conditions, parents of children with cognitive or communication impairments that would hinder interview participation, and families unable to commit to the study timeline.

Ethical Considerations

The research protocol received full approval from the institutional review board of King Abdallah University Hospital of Jordan University of Science and Technology (KAUH342020). The study adhered to the principles outlined in the Declaration of Helsinki. Prior to enrollment, all participants engaged in comprehensive briefing sessions detailing the study objectives, procedures, potential risks, and benefits, following which written informed consent was obtained using institution-approved documentation.

COPM Administration and Assessment Protocol

The COPM was used as the primary client-centered assessment to identify significant challenges in the children's daily functioning. Problem areas identified by families were categorized using a standardized coding system developed by Pollock and Stewart [22], which organizes priorities into 3 main domains: daily activities (with subcategories of self-care, mobility, and communication), productivity (including household management, school participation, and community engagement), and leisure (encompassing socialization, community entertainment, quiet recreation, and physical recreation). The self-care domain was further broken down into 5 specific components: eating, dressing, bathing, toileting, and hygiene.

Standardized Administration Protocol

All assessments were conducted by two independent licensed clinical rehabilitation therapists, each assessing participants independently with experience in pediatric rehabilitation and prior training in the administration of the COPM. Both raters underwent standardized calibration sessions before data

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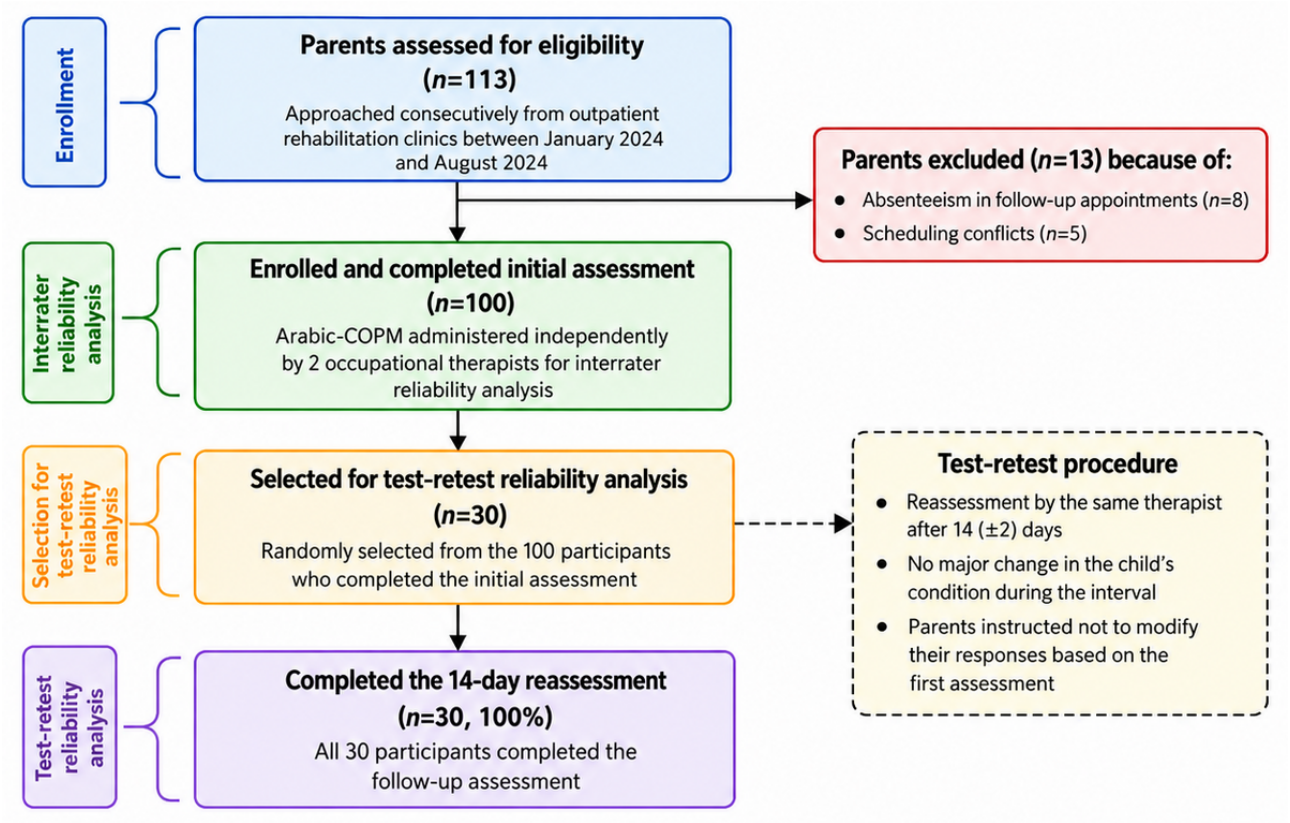
collection to ensure consistency in interview administration, scoring procedures, and problem categorization. The administration followed a structured five-step [22] process using the validated Arabic translation of the COPM. The first step was problem identification: parents enumerated activities and tasks presenting significant challenges in their child's daily routine. The second step was importance scaling: using a 10-point metric (1="minimal importance" to 10="critical importance"), parents rated all identified concerns. The third step was priority selection: through facilitated discussion, parents distilled their concerns to 5 paramount issues. The fourth step was performance evaluation: each prioritized activity received a performance rating (1="complete inability" to 10="optimal performance"). The fifth step was satisfaction evaluation: parents rated their satisfaction with their child's performance or each problem (1="not satisfied" to 10="extremely satisfied"). Mean scores for performance and satisfaction were calculated by averaging the ratings across the 5 prioritized problems.

Reliability Testing Framework

Although the COPM is classified as a patient-reported outcome measure (PROM), it differs from conventional self-administered PROMs because it is conducted through a semistructured clinician-led interview rather than a fixed questionnaire completed independently by respondents. During COPM administration, the clinician actively facilitates problem identification, clarification, prioritization, and scoring of performance and satisfaction. Therefore, the interrater reliability assessment is considered crucial and relevant, as it has also been evaluated in previous COPM validation studies to determine the consistency of identified priorities and scores across independent assessors.

A multiphase protocol was implemented to assess reliability. To evaluate interrater reliability, 100 parents completed the Arabic-COPM twice on the same day, administered by 2 independent raters who were blinded to each other's findings. For test-retest reliability, a random subsample of 30 (30%) parents repeated the assessment with the same rater after a 14-day interval, following an identical administration procedure (Figure 1).

Figure 1. Study flowchart. COPM: Canadian Occupational Performance Measure.



Statistical Analysis

The psychometric evaluation of the Arabic-COPM incorporated comprehensive reliability and agreement analyses. Reliability was assessed using ICCs with a 2-way mixed-effects model, applying absolute agreement for interrater comparisons and consistency for test-retest analyses [23]. Interpretation of reliability coefficients was performed cautiously and in the context of previous COPM and rehabilitation reliability studies, in which the interpretation followed established benchmarks of 0.40 to 0.59 (fair), 0.60 to 0.74 (good), and >0.75 (excellent). However, categorical thresholds for ICC interpretation may vary across methodological frameworks and should not be considered absolute indicators of measurement quality.

Agreement assessment used multiple complementary approaches. For quantitative agreement, Bland-Altman methodology was implemented to evaluate measurement concordance [24]. This involved plotting differences between

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paired measurements against their means, with calculation of mean bias ($\bar{d}$) and 95% limits of agreement (LOA; LOA=$\bar{d}$±1.96×SD) [25]. To address visualization challenges in datasets with restricted ranges, traditional scatterplots were enhanced through hexagonal binning techniques that aggregate observations into density-based visualizations, providing better pattern recognition than conventional displays.

For qualitative agreement, problem prioritization consistency was assessed by calculating the proportion of first rater–identified problems that were similarly prioritized by the second rater. Additionally, Cohen κ coefficient was computed to evaluate interrater agreement across COPM domains (daily activity, productivity, and leisure) [26], with interpretation standards: <0.00 (none), 0.00 to 0.20 (slight), 0.21 to 0.40 (fair), 0.41 to 0.60 (moderate), 0.61 to 0.80 (substantial), and 0.81 to 1.00 (almost perfect agreement) [27].

All analyses were conducted using Python (version 3.12; Python Software Foundation; *Matplotlib*) with statistical significance set at $P<.05$, maintaining methodological consistency across comparisons in accordance with contemporary quantitative method evaluation standards.

Results

Sample Characteristics

The final sample consisted of 100 parents of children with physical disabilities. The children had a mean age of 5.4 (SD 2.7) years, with a near-even sex distribution (54 male children and 46 female children). The majority of respondents (n=83, 83%) were the children's mothers. Detailed demographic characteristics are presented in Table 1.

Table 1. Demographic characteristics of the parents and their children with physical disabilities.

Characteristics	Participants
Children's characteristics (n=100)	
Age (years), mean (SD)	5.4 (2.7)
Weight (kg), mean (SD)	17.6 (6.8)
Height (cm), mean (SD)	98.3 (19.5)
Diagnosis, n (%)	
Cerebral palsy	60 (60)
Spina bifida	20 (20)
Other diagnoses	20 (20)
Sex, n (%)	
Male	54 (54)
Female	46 (46)
Parents' characteristics (n=100), n (%)	
Relationship with the child	
Mother	83 (83)
Father	10 (10)
Other	7 (7)
Educational level	
University degree	57 (57)
Nonuniversity degree	43 (43)
Monthly income	
High income (US >$900)	24 (24)
Middle income (US $450-$900)	56 (56)
Low income (US <$450)	20 (20)

Interrater Reliability and Agreement

The Arabic-COPM demonstrated excellent interrater reliability. The ICCs for the mean scores were 0.84 (95% CI 0.77-0.89; $P<.001$) for performance and 0.80 (95% CI 0.70-0.86; $P<.001$) for satisfaction.

Regarding qualitative agreement on problem identification, the first and second raters identified 460 and 450 problems, respectively. A high level of concordance was observed, with 338 (73.5%) of the 460 problems prioritized by the first rater being similarly prioritized by the second rater (Table 2). On the other hand, Cohen κ analysis across the COPM main categories (daily activity, productivity, and leisure) demonstrated slight-to-fair interrater agreement.

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Table 2. Distribution of parent-prioritized problems identified during the Arabic version of the Canadian Occupational Performance Measure (COPM) assessment, categorized by main categories, subcategories, and self-care subcomponents, by raters[a].

Categories and subcategories	Rater R, n (%)	Rater S, n (%)	Comparison (percentage points)
Daily activity	380 (82)	383 (85)	+3
Mobility	226 (49)	225 (50)	+1
Self-care	150 (33)	154 (34)	+1
Eating	38 (25)	34 (22)	−3
Dressing	53 (35)	53 (34)	−1
Toileting	22 (15)	33 (21)	+6
Bathing	29 (19)	22 (14)	−5
Hygiene	9 (6)	12 (8)	+2
Communication	4 (1)	4 (1)	0
Productivity	30 (7)	24 (5)	−2
School	30 (7)	24 (5)	−2
Household	0 (0)	0 (0)	0
Community	0 (0)	0 (0)	0
Leisure	50 (11)	43 (10)	−1
Socialization	14 (3)	16 (4)	+1
Community entertainment	13 (3)	10 (2)	−1
Quiet recreation	1 (1)	0 (0)	−1
Physical recreation	22 (5)	17 (4)	−1

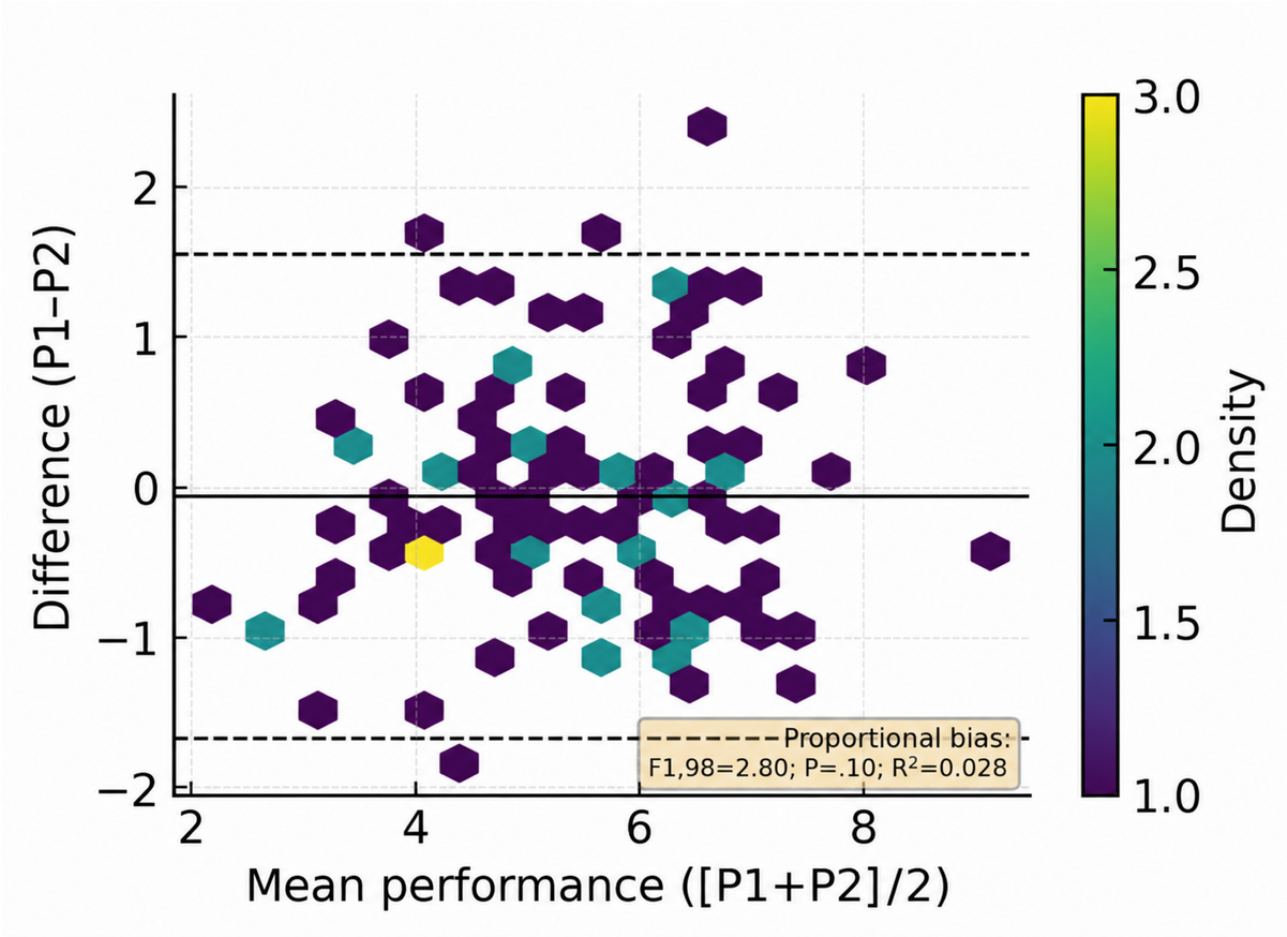
[a]This table summarizes all problems identified by parents during the COPM interview and classified using the standardized COPM coding system. The 3 main categories (daily activity, productivity, and leisure) and their corresponding subcategories are presented alongside detailed self-care subcomponents. For each classification level, the table reports the number and percentage of problems identified independently by rater R and rater S. The comparison column (percentage points) reflects the proportional difference between raters for each subcategory, providing an integrated view of agreement patterns across the full activity and participation domain. Rater R and Rater S were 2 independent raters.

Regarding quantitative interrater agreement, Bland-Altman analysis with hexagonal binning visualization demonstrated strong quantitative agreement between raters for both performance and satisfaction scores. The LOA were narrow, ranging from −1.69 to 1.60 (mean bias −0.048, SD 0.84) for performance scores and from −1.03 to 0.98 (mean bias −0.024, SD 0.51) for satisfaction scores. The corresponding Bland-Altman plots (Figures 2 and 3), enhanced through hexagonal binning to visualize data density, show that most observations were clustered around the mean bias line and fell within the 95% LOA.

Supporting these findings, linear regression analysis revealed no evidence of proportional bias. The relationship between score differences and mean scores was nonsignificant for both performance ($F_{1,98}$=2.80; P=.10; R^2=0.028; Figure 2) and satisfaction scores ($F_{1,98}$=0.83; P=.36; R^2=0.008; Figure 3), indicating consistent agreement across the measurement scale.

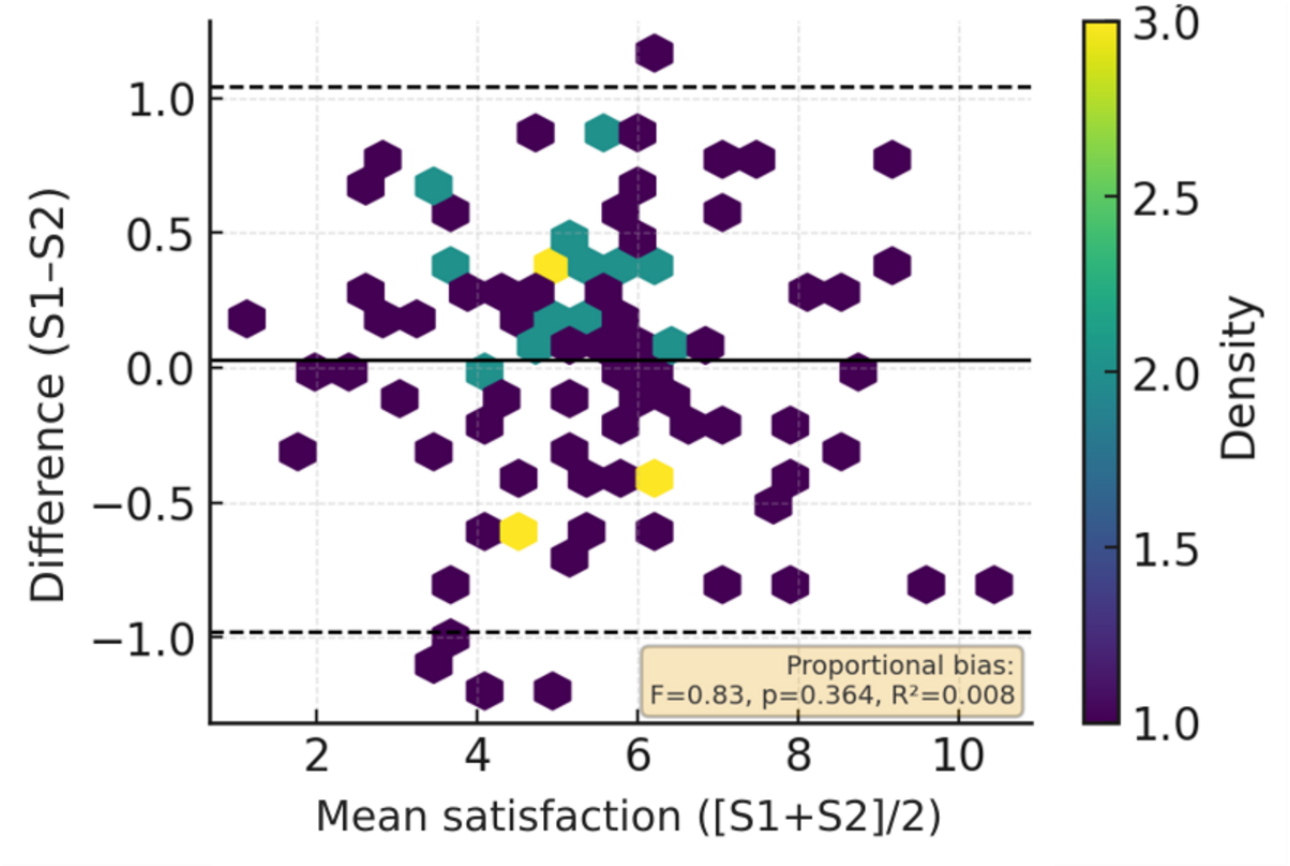
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Figure 2. Hexbin Bland-Altman plot of interrater agreement for Canadian Occupational Performance Measure (COPM) performance scores, with proportional bias analysis. This Hexbin Bland-Altman analytical plot illustrates the agreement between 2 independent raters for COPM performance scores. The mean of the 2 raters' scores is plotted on the x-axis, and the score difference (P1−P2) is plotted on the y-axis. Each hexagonal cell represents the local density of overlapping observations, improving clarity in regions of high point concentration. The solid horizontal line represents the mean bias, while the dashed lines indicate the 95% limits of agreement. Proportional bias was examined using linear regression of score differences on their mean values. The association was nonsignificant (F1,98=2.80; *P*=.10; R2=0.028), demonstrating no systematic proportional bias.



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Figure 3. Hexbin Bland-Altman plot of interrater agreement for Canadian Occupational Performance Measure (COPM) satisfaction scores, with proportional bias analysis. This Hexbin Bland-Altman plot presents the interrater agreement for COPM satisfaction scores. The x-axis shows the mean satisfaction rating between raters, and the y-axis represents the difference (S1−S2). Hexagonal density shading highlights regions where overlapping values occur. The solid line depicts the mean bias, and the dashed lines represent the 95% limits of agreement. Proportional bias was examined using linear regression of score differences on their mean values. The association was nonsignificant (F1,98=0.83; *P*=.36; R2=0.008), demonstrating no systematic proportional bias.



Test-Retest Reliability and Agreement

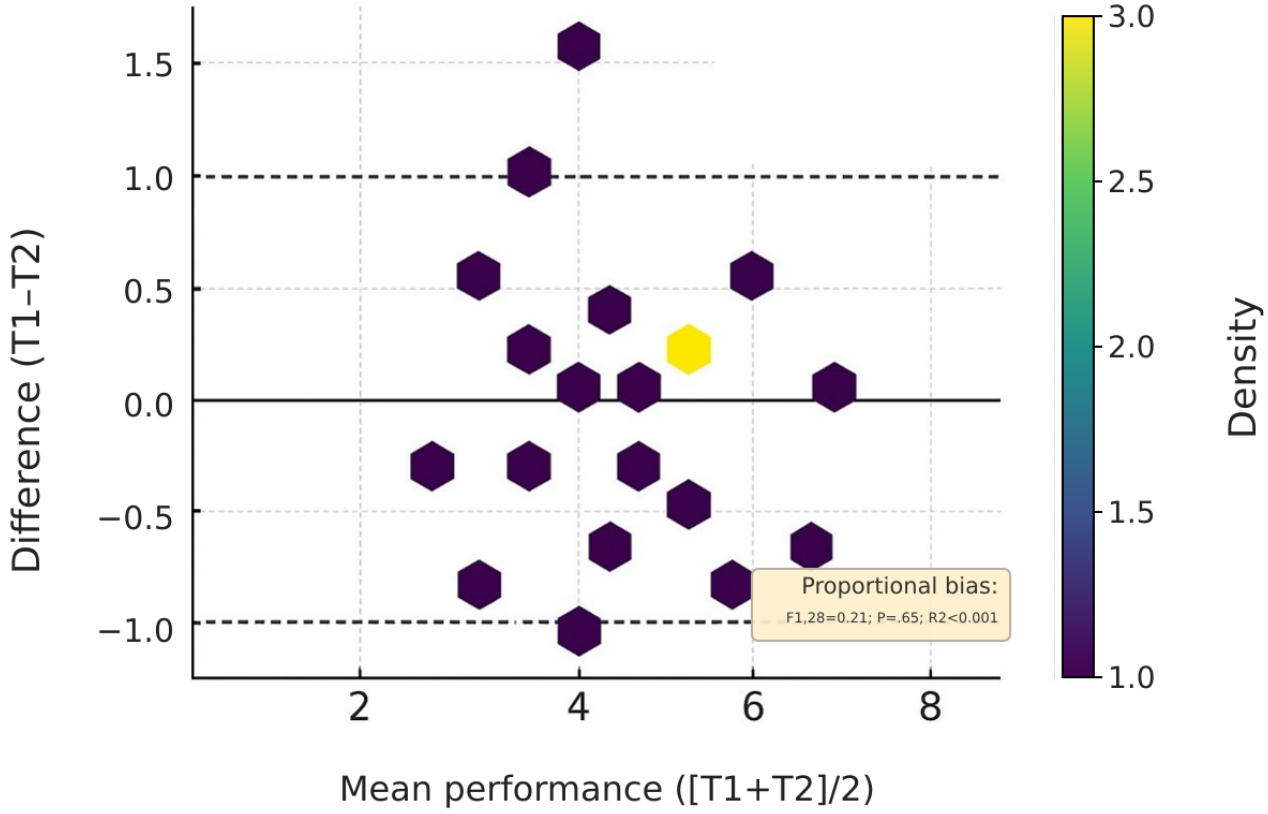
The Arabic-COPM demonstrated excellent temporal stability, with test-retest reliability ICCs of 0.83 (95% CI 0.64-0.92; *P*<.001) for performance scores and 0.91 (95% CI 0.81-0.95; *P*<.001) for satisfaction scores.

In terms of test-retest quantitative agreement, Bland-Altman analysis, visualized through hexagonal binning plots (Figures 4 and 5), demonstrated strong quantitative agreement across the 2-week interval. The LOA were narrow, spanning from −1.43 to 1.51 (mean bias 0.04, SD 0.75) for performance scores and from −0.56 to 0.78 (mean bias 0.11, SD 0.34) for satisfaction scores. The density-based plots show a tight clustering of data points within the LOA, indicating minimal systematic drift and high measurement repeatability over time.

On the other hand, Cohen κ analysis across the COPM main categories (daily activity, productivity, and leisure) demonstrated slight-to-fair interrater agreement.

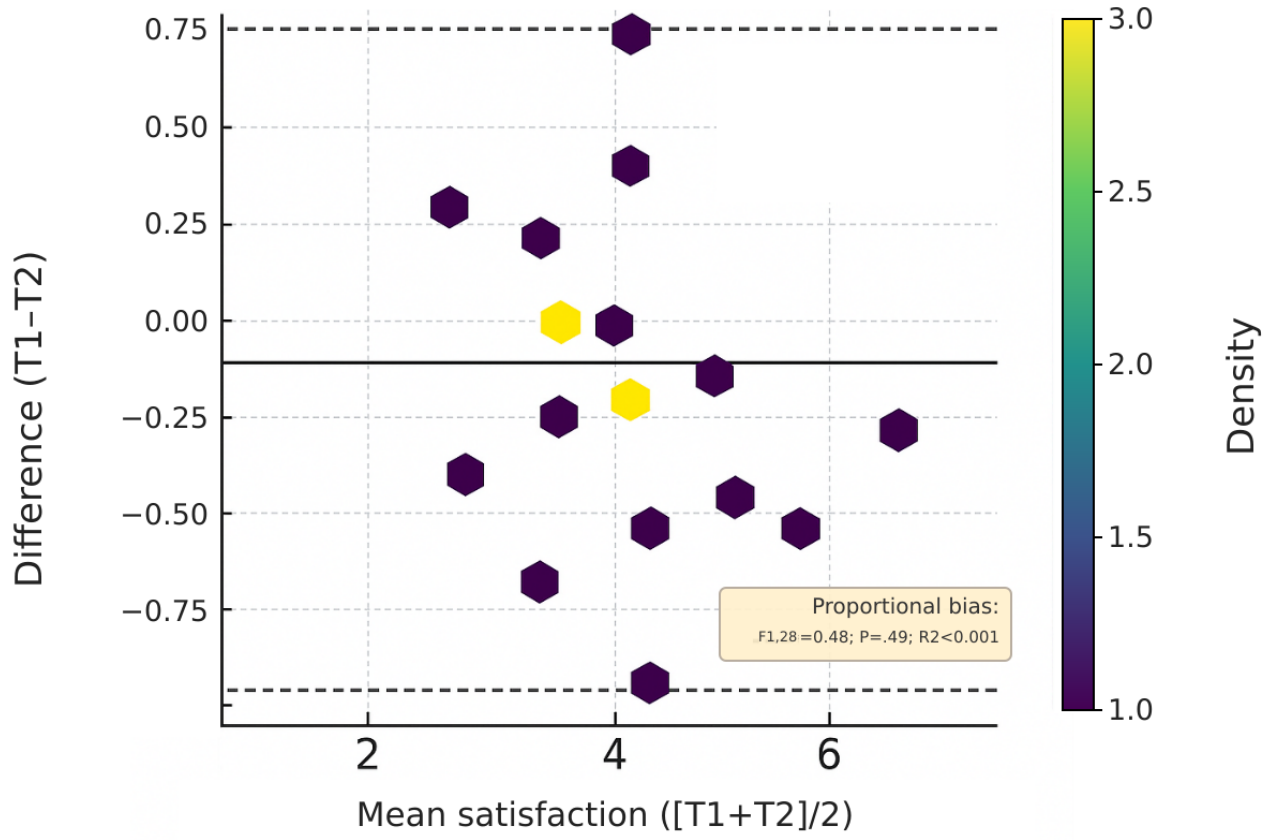
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Figure 4. Hexbin Bland-Altman plot of test-retest agreement for Canadian Occupational Performance Measure (COPM) performance scores (2-week interval), with proportional bias assessment. This Hexbin Bland-Altman analytical plot illustrates the test-retest agreement of COPM performance scores obtained from the same assessor over a 2-week interval. The mean of the 2 performance scores (T1 and T2) is plotted on the x-axis, and their difference (T1−T2) on the y-axis. Density-based hexagonal binning highlights regions of overlapping values, improving interpretability relative to conventional scatter plots. The mean bias is represented by the solid horizontal line, with the 95% limits of agreement shown as dashed lines. Regression analysis demonstrated that the relationship between score differences and their means was nonsignificant, indicating no proportional bias.



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Figure 5. Hexbin Bland-Altman plot of test-retest agreement for Canadian Occupational Performance Measure (COPM) satisfaction scores (2-week interval), with proportional bias assessment. This hexbin Bland-Altman plot displays the test-retest reliability of COPM satisfaction scores across a 2-week interval. The mean satisfaction score is presented on the x-axis, and the difference between sessions (T1−T2) on the y-axis. Density-based hexagonal binning highlights regions of overlapping values, improving interpretability relative to conventional scatter plots. The mean bias is represented by the solid horizontal line, with the 95% limits of agreement shown as dashed lines. Regression analysis demonstrated that the relationship between score differences and their means was nonsignificant, indicating no proportional bias.



Families' Prioritized Concerns

Across both raters, a total of 460 problems were identified by rater R and 450 by rater S (Table 2). The vast majority of parent-prioritized problems fell within the daily activity main category, accounting for 82% to 85% of all reported concerns. Within daily activity, parents expressed the greatest concern for the mobility subcategory, which represented approximately 50% of all identified problems for both raters.

The second most frequently reported main category was leisure (10%-11%), with parents primarily emphasizing difficulties in the physical recreation subcategory (≈5% of all problems). In contrast, productivity concerns were least commonly reported (5%-7%) and were almost exclusively related to the school subcategory, with no meaningful concerns in household or community tasks.

Within the daily activity category, the self-care subcategory represented a substantial proportion of the identified priorities. When examining self-care in more detail, parents reported the highest concern for dressing, followed by eating, with additional—but comparatively fewer—concerns related to toileting, bathing, and hygiene.

Discussion

This study evaluated the interrater and test-retest reliability of the Arabic-COPM in parents of children with physical disabilities. The findings demonstrated strong reliability across both performance and satisfaction scores, supporting the consistency and stability of the Arabic-COPM within pediatric rehabilitation settings.

Psychometric Strength and Cross-Cultural Consistency

The Arabic-COPM exhibited excellent reliability metrics that meet or exceed established standards for outcome measures in rehabilitation. The high ICCs ranging from 0.80 to 0.91 across both interrater and test-retest evaluations indicate remarkable consistency between different clinicians and stability over time. Particularly noteworthy is the exceptional temporal reliability of satisfaction scores (ICC=0.91), suggesting that parental satisfaction with their child's performance represents a particularly stable construct that can be reliably tracked throughout the rehabilitation process.

These reliability findings are generally consistent with several previous COPM studies conducted across different clinical populations and cultural contexts. Similar ICC ranges have been

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reported in patients with chronic obstructive pulmonary disease (approximately 0.90) [14], psychiatric disorders (approximately 0.85) [15], and ankylosing spondylitis (approximately 0.92) [13], supporting the stability of the COPM across diverse rehabilitation settings.

However, reliability findings in the broader COPM literature have not been entirely uniform. Some studies and reviews [28,29] have reported lower or more variable agreement levels depending on the assessed population, administration procedures, and methodological approaches. Such variability may reflect the individualized and semistructured nature of the COPM, in which participant priorities, interviewer interaction, contextual influences, and clinical interpretation can affect scoring consistency. Therefore, the findings of the present study should be interpreted within the context of the heterogeneous reliability literature surrounding the COPM.

These reliability findings demonstrate remarkable consistency with previous COPM validation studies across diverse populations and cultural contexts. The similarity of our ICC values to those reported in patients with chronic obstructive pulmonary disease (approximately 0.90) [14], psychotic disorders (approximately 0.85) [15], and ankylosing spondylitis (approximately 0.92) [13] suggests that the core client-centered methodology of the COPM maintains its measurement properties across linguistic and cultural adaptations. This cross-cultural consistency reinforces the fundamental robustness of the COPM framework while simultaneously validating the quality of the Arabic adaptation.

Comprehensive Agreement Analysis

Beyond conventional reliability coefficients, our implementation of multiple agreement methodologies provides a more nuanced understanding of the measure's performance. The Bland-Altman analyses with hexagonal binning visualization revealed narrow LOA with minimal systematic bias, demonstrating precise measurement characteristics at the individual score level. The 73.5% concordance in problem prioritization between independent raters indicates a moderate level of agreement between assessors. Although this finding supports a reasonable degree of consistency in the Arabic-COPM administration process, the remaining variability highlights the influence of interviewer interaction and individualized problem prioritization inherent in semistructured client-centered assessments.

When contextualized within the broader COPM literature, our interrater agreement rate of 73.5% falls between the agreement rates reported in other populations, reflecting the inherent balance between standardization and individualization in client-centered measures. This rate closely approximates the 80% agreement reported in similar pediatric populations [17] while substantially exceeding the 56% and 66% rates reported in stroke and mixed neurological populations [16,18]. This gradient likely reflects differences in cognitive clarity, goal stability, and the nature of therapeutic relationships across these diverse clinical populations.

Therapeutic Dialogue and Clinical Implementation

The variability observed in qualitative agreement measures should not be interpreted as evidence against standardization or measurement consistency. The COPM combines standardized scoring procedures with a semistructured individualized interview format. Although individualized problem identification and interviewer interaction may introduce some variation in prioritized responses across assessors, the strong quantitative reliability findings observed in the present study suggest that the Arabic-COPM maintains acceptable measurement consistency within a structured client-centered assessment framework.

Cultural and Developmental Priorities in Pediatric Rehabilitation

The pattern of problem prioritization revealed important insights into the concerns of Arabic-speaking families of children with physical disabilities. The overwhelming focus on daily activities (82%-85%), particularly mobility and self-care functions such as dressing and eating, provides empirical support for Maslow hierarchy of needs within this specific cultural and clinical context [30]. As Duncan and Blugis [31] articulated in their pediatric adaptation of this framework, families naturally prioritize fundamental needs related to nourishment, personal care, and basic functioning before addressing higher-order productivity or complex leisure pursuits.

This prioritization pattern reflects both practical caregiving realities and developmental aspirations. Parents intuitively recognize that mastery of basic mobility and self-care skills not only reduces caregiver burden but also serves as the essential foundation for peer socialization, educational participation, and eventual transition toward independent living. The predominance of mobility and self-care concerns identified in the present study suggests that families primarily prioritize essential daily functioning needs when identifying rehabilitation goals for children with physical disabilities. In contrast, productivity-related concerns were less frequently reported. These findings may reflect the central importance of functional independence in early pediatric rehabilitation and emphasize the practical relevance of addressing basic daily activities within family-centered rehabilitation planning.

The consistency of these findings with previous research involving children with cerebral palsy [32] suggests that these fundamental concerns may transcend specific diagnostic categories within the broader population of children with physical disabilities.

Limitations and Future Directions

Although this study establishes the fundamental reliability of the Arabic-COPM, several limitations warrant consideration. The scope of this validation study did not permit exploration of how problem prioritization might vary according to disability severity, socioeconomic factors, or cultural subgroups within the Arabic-speaking population. Another limitation is that absolute reliability indices such as the SE of measurement were not evaluated in the present study. Additionally, CIs for descriptive percentage estimates were not calculated and should be considered in future psychometric studies. Future research should investigate these potential moderating variables to provide more nuanced guidance for clinical implementation. Additionally, the focus on reliability represents only the first

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step in comprehensive instrument validation. Subsequent studies should establish the responsiveness, minimal clinically important differences, and convergent validity of the Arabic-COPM to fully characterize its measurement properties.

Clinical Implications and Conclusions

Notwithstanding these limitations, our findings provide strong evidence supporting the integration of the Arabic-COPM into clinical practice throughout the Arabic-speaking world. The measure offers rehabilitation professionals a reliable, culturally adapted tool to authentically engage families in the goal-setting process. The consistent prioritization of basic daily activities underscores the importance of addressing these fundamental concerns as the foundation of any comprehensive rehabilitation program.

In conclusion, the Arabic-COPM demonstrates excellent reliability and clinical utility for implementing family-centered care in pediatric rehabilitation. Its successful validation opens new possibilities for standardized outcome measurement and culturally responsive service delivery across Arabic-speaking communities, ultimately supporting improved rehabilitation outcomes for children with physical disabilities and their families.

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Generative AI tools (DeepSeek and ChatGPT) were used solely for language editing and to enhance manuscript readability. The authors retained full responsibility for the scientific content, data interpretation, accuracy, and final approval of the manuscript.

Data Availability

The datasets generated and analyzed during the current study are not publicly available due to ethical and privacy restrictions involving pediatric clinical data and family-reported information. Deidentified data may be made available by the corresponding author upon reasonable request.

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Authors' Contributions

HH conceptualized and designed the study, supervised data collection, performed data analysis and interpretation, and drafted and critically revised the manuscript. RS contributed to participant recruitment, data collection, data organization, data analysis and interpretation, and manuscript preparation. NA contributed to study methodology, interpretation of findings, and critical revision of the manuscript. All authors reviewed and approved the final version of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

Arabic-COPM: Arabic version of the Canadian Occupational Performance Measure

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COPM: Canadian Occupational Performance Measure
ICC: intraclass correlation coefficient
LOA: limits of agreement
PROM: patient-reported outcome measure

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Comparison of Capturing Children's Technology Use Using Wearable Camera and Fixed Room Video: Experimental Laboratory Study

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Abstract

Background: Technology use by children has implications for their physical, mental, and social health and development. There are many challenges in measuring modern screen use by children. To better understand the potential impact of technology on children, it is crucial to have robust methods to measure technology use. Visual recording data may be particularly well suited to capture modern digital technology use (eg, rapid transitions, multitasking, and device switching). It would be valuable to directly compare the 2 commonly used methods (wearable camera images and room video frames) to determine what is captured best by each and how they compare when both are coded by human annotation.

Objective: This study aimed to compare wearable camera images and room video frames to understand what can be captured from each source.

Methods: In a laboratory study, children (aged 3 - 14 years) performed various tasks while wearing a wearable camera and being video recorded by room video cameras. Comparisons between the coding of the wearable camera images and room video frames were performed on a second-by-second basis. Confusion matrices were generated to identify patterns of differences in classifications between wearable camera images and room video frame coding. Percent agreement between the wearable camera image and room video frame coding was calculated based on the confusion matrix.

Results: Across 44 participants, 182,451 contemporaneous wearable camera images and room video frames were coded and merged. There were generally low levels of agreement between the codes. The highest agreement was found for "desktop" and "handheld gaming," and the lowest agreement was found for "smartwatch." The wearable camera and room video methods varied in sampling rate, camera movement, and field of view, leading to differences in what was captured.

Conclusions: Room video might better capture technology that is within a set space and the context of the technology use, while wearable cameras could better capture active technology use, the content of technology, and different locations. Capturing technology use by children is difficult, with no gold standard and no one ideal method.

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KEYWORDS

technology use; wearable camera; room video; children; screen use

Introduction

The impact of digital technology use by children is heavily debated, with evidence suggesting that the health effects of digital technology use may be detrimental [1,2], negligible [3], or beneficial [1,4,5]. Similarly, evidence on the educational impact of digital technology use on children is mixed [6].

One important reason for this mixed evidence is that the main measure of technology use by children is through self- or proxy-reported methods, such as questionnaires or diaries [7-9]. These subjective measures may be low cost and generally easy

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to administer but are often imprecise due to reporting bias and recall inaccuracy [7,8,10,11]. Another important reason is that the focus has been on just the duration of technology use (ie, screen time), despite compelling evidence that other aspects, such as device type, content, and context of use, are likely to be critical in determining the impact of technology use on child outcomes [6,12,13].

There are many challenges in measuring modern screen use by children, including children commonly using multiple devices (including those of others and sometimes simultaneously), a variety of software with differing content, for various tasks, and in a variety of contexts and locations [7]. However, to better understand the potential impact of digital technology on children, it is crucial to have robust methods to measure digital technology use. Accurately capturing important aspects of modern digital technology use other than time has been identified as a critical issue in the field [6,7].

Visual recordings have been suggested as an alternative to self- or proxy-reported methods, including the use of still photographs [14-20] or video [21] recorded on cameras worn by the child [18-20] or stationary in a room [14-16,21]. Visual recording data may be particularly well suited to capture modern digital technology use (eg, rapid transitions, multitasking, and device switching).

A camera fixed in one location can capture digital technology use within that local context, for example, within a participant's living room. This was used in a pioneering study by Allen [14] in which time-lapsed cameras were installed in 95 families' homes, recording images of the television 4 times per minute. This early study found differences between the recorded results and the parent-reported results in diaries. Home-based fixed room cameras have subsequently been used in several studies to capture television viewing in young children's homes [15,16,21].

A fixed room camera may be useful if the technology use is mainly in one location (eg, a television or computer in the living room) and may create minimal burden and intrusion for participants. Still photographs (typically automatically set to capture a time-lapse sequence) or video recordings can be made from fixed-position cameras. Furthermore, depending on the camera view as well as the image clarity and resolution, it may or may not be possible to capture screen content, facial expressions, along with local context information such as coviewing [16]. However, information is limited to only activities that appear within the fixed field of view of the camera [22]. Fixed room cameras could also be intrusive to the child and family and may have third-party privacy issues [7].

Wearable cameras can be attached to participants (usually on a chest harness, headband, or a lanyard around the neck). Wearable cameras have been used to investigate different health-related behaviors in adolescents and children [18-20,23-25]. Thomas et al [19] used chest-mounted wearable cameras to capture screen use type and context in a study of 10 adolescents, and Everson et al [20] used cameras worn around the neck on a lanyard to capture screen-based activities (as well as dietary behaviors and physical activity behaviors) in a sample of 14 children.

Wearable cameras obviously move with participants; therefore, they are not restricted to one location and can thus provide location context of the digital technology use [26]. Wearing a camera may influence participant behavior, both by reminding them that their behavior is being recorded (an issue also present with fixed room recording devices) and by participant concern about damaging the device (eg, falling over and breaking the camera) or being injured by the camera (eg, if only secured on a lanyard) [20]. Many devices have limited battery life, with 1 study using wearable cameras to assess children's dietary intake in China reporting that cameras needed to be charged twice per day [27]. Wearable cameras can be set to automatically take still images or video stream. Recordings show the field of view of the participant, which is useful. However, the view and mobility of wearable cameras have raised privacy concerns related to capturing inappropriate or unwanted images and images of third parties [28].

In addition to differences in field of view and camera movement, cameras can also vary in whether still photographs or video are recorded. Still image recording is typically done at 1 image per second or slower [17-19] sampling frequencies, whereas video recording is typically at 30 frames per second or greater [21]. Slower sampling frequencies may miss brief activities performed by children, but they also create less data to be processed. Recorded images or frames are typically coded image or frame by image or frame by humans, which is very labor intensive [7,17-19]. Slower sampling rates may also enable lower storage and battery usage. Cameras also vary in image quality, which is influenced by both resolution (pixels per image) and shutter speed. Higher pixel counts enable more detailed images, although they create larger data files. A slow shutter speed enables more light collection per image but also increases the risk of blurred images from movement of either the camera or an object in the field of view while the shutter is open.

The different aspects of visual recording options for measuring children's use of technology appear to influence the likely information available from each method, with each method potentially being robust and valuable in its own right. Given these differences and the high processing burden in human coding of visual recordings, knowing which method would best suit a particular research project is important. It would therefore be valuable to directly compare the 2 commonly used methods (wearable camera images and room video frames) to determine what is captured best by each and how they compare when both are coded by human annotation. Furthermore, as digital technology engagement has been shown to differ between age groups [29,30] and genders [31], it would be valuable to compare whether there are any age or gender differences in what the 2 methods capture.

To our knowledge, no study has directly compared wearable camera images with room video frames within the same participants. Therefore, the aim of this study was to compare human annotation of wearable camera images and room video frames to understand what can be captured from each data source and to provide examples of issues relating to each, to help health, education, and general child development researchers decide which to use for a particular study. The

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secondary aim was to compare results based on children's gender and age.

Methods

Study Design

An experimental laboratory study was conducted in which children performed a variety of digital technology–related and non–digital technology–related tasks while wearing a wearable camera and being video recorded by 2 room video cameras within a 10-m-diameter laboratory space.

Participants

Typically developing children aged between 3 and 14 years were recruited among university networks and in the community via word of mouth, flyers, and social media advertisements. Recruitment was stratified based on gender and age of the participants, with the aim of recruiting approximately equal numbers of boys and girls and children in 3 age brackets according to Australian school ages (3 - 5 y to represent a preschool-aged population, 6 - 10 y to represent a primary school–aged population, and 11 - 14 y to represent secondary school–aged and early adolescence population). Children were excluded from the study if they had any psychological or physical clinical diagnosis, as reported by their caregiver, which may have influenced their ability to understand and follow instructions or perform requested tasks.

Ethical Considerations

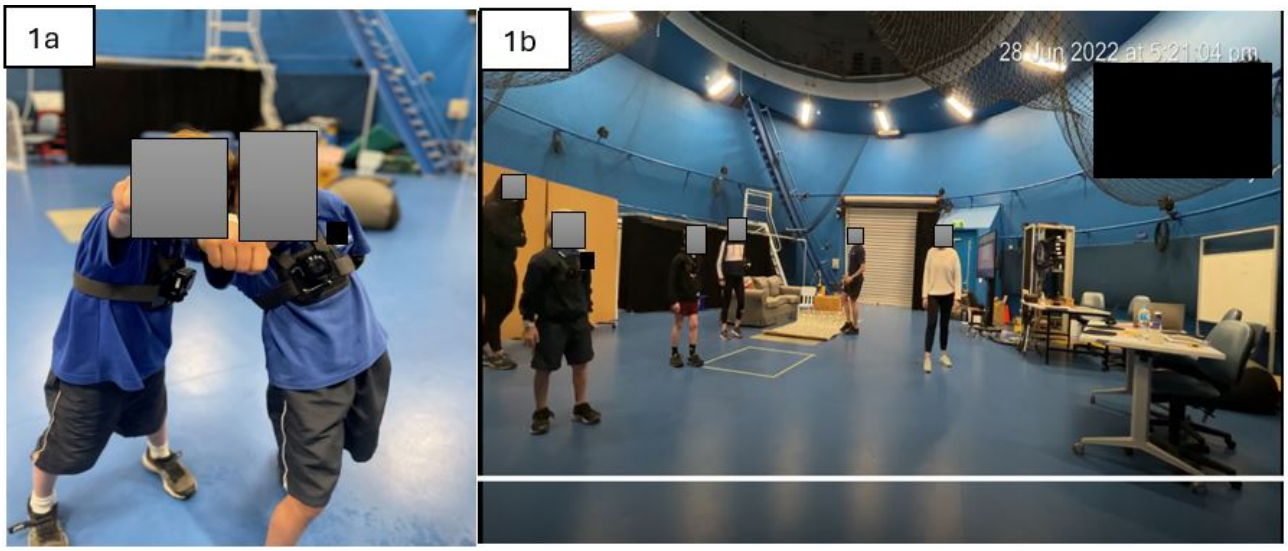
Ethical approval was obtained from the Curtin University Human Ethics Committee (HRE2022-0157). Caregivers provided written informed consent, and children gave verbal or written assent, as appropriate to their age.

Measures

Wearable Camera

One Brinno TLC120 automatic wearable camera operating at a 1-second frequency was fitted to the child's chest (using an adjustable chest-mounted harness to minimize the previously noted issues with lanyards; Figure 1A). The rapid transitions in digital technology use mean longer epochs risk missing brief but meaningful activities. The wearable camera weighed 101 g, was 60×60×35 mm in size, captured a 112° field of view, and did not record audio or video. Images were date- and time-stamped. The wearable camera was used to capture digital technology use during each activity directly from the field of view of the child.

Figure 1. Laboratory space with cameras. (A) Children with wearable cameras. (B) Laboratory space with room video camera on tripod.



Room Video

Room video recording was captured by 2 iPhone 12s (Apple Inc) using a super-wide lens at 30 frames per second. The iPhones were positioned on either side of the laboratory on 1-m-tall tripods approximately 4 m from the center of the room (Figure 1B). One iPhone was classified as the primary video (the most ideal location in the laboratory, providing the best view), and the second iPhone was the secondary video and was only used as a backup (eg, if the primary video battery ran out or the view was blocked by a person). The room videos were used to capture digital technology exposure during each activity by capturing the whole room.

Study Protocol

Children attended a single approximately 1-hour data collection session at a Curtin University laboratory with their caregivers between July and October 2022. Children either participated in the data collection session alone (n=10) or with a friend or sibling (n=38), with a maximum of 2 children participating simultaneously. Two to three researchers, experienced in working with children, were present at each data collection session. After providing informed consent, caregivers completed a brief sociodemographic questionnaire. Subsequently, children were asked for their verbal or written assent, as appropriate to their age, and were then fitted with the wearable camera.

The laboratory was set up to capture different tasks, both with and without digital technology, and involving a range of postures and movements. Following laboratory and equipment

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familiarization, children then completed each task for at least 2 to 3 minutes, allowing for 120 to 180 images to be captured by the wearable camera (based on a 1-s epoch frequency). Tasks were performed in a standardized order where possible. However, flexibility was given in the protocol to ensure the participant's enjoyment. Some tasks were completed with a research assistant, the child's caregiver, or the second child in the session to replicate coviewing tasks (eg, when a child watches a television program with a caregiver or sibling) and to support children in completing the tasks. Tasks included watching programs on a television or laptop, playing on a gaming device (Nintendo Switch), reading a book, drawing on paper, playing with magnetic tiles or Jenga, using a desktop computer, drawing on a tablet, taking photographs with a smartphone, throwing and catching a ball, watching a video on a smartphone, and checking step counts via a smartwatch. Children were instructed on the position or movement to complete the task to allow the capture of images and video from a range of ecologically valid postures and movements. Table 1 provides a full list of tasks completed by the child, with devices used for each task. In total, 9 technologies were included: television, desktop, laptop, tablet, smartphone, smartwatch, handheld gaming console, combined gaming controller, and single gaming controller.

Table . Tasks completed by child.

Device	Position or movement	Details of task
Television	Sitting on bean bag	Watching a program of child's choice on television via laptop (HDMI cable connected to television)
Television	Lying (prone)	Watching a program of child's choice on television via laptop (HDMI cable connected to television)
Laptop	Lying (side lying)	Watching a program of child's choice via laptop
Laptop	Sitting (chair)	Watching a program of child's choice via laptop
Handheld gaming console	Sitting (couch)	Playing Mario Kart via Nintendo Switch using just Switch screen
Handheld gaming console	Standing	Playing Mario Kart via Nintendo Switch using just Switch screen
Book[a]	Lying (prone)	Reading a book
Stationary game (using a controller)	Sitting (couch)	Playing Mario Kart via Nintendo Switch connected to television
Magnetic tiles[a] or Jenga	Sitting (floor)	Playing with magnetic tiles on floor
Active game	Standing while moving or jumping	Playing Just Dance or NS Sports via Nintendo Switch connected to television
Desktop	Sitting (chair)	Drawing or reading on desktop computer
Tablet	Standing	Drawing app
Pencils and crayons[a]	Standing	Drawing and coloring in with paper and colored pencils or crayons
Tablet	Standing while moving	Participating in Cosmic Kids Yoga video or similar age-appropriate movement-based YouTube video
Smartphone	Walking, jumping, running, and skipping	Taking selfies or pictures of posters while walking, jumping, running, or skipping
Ball[a]	Standing while throwing and catching	Throwing and catching a netball or basketball
Smartphone	Lying supine or crook lie (floor)	Watching "Smiling Minds" Sea Creatures video or video of choice
Smartwatch	Jumping, handstands	Jumping and handstands then checking heart rate or steps via smartwatch
Smartwatch	Running, cartwheels	Running and then checking heart rate or steps via smartwatch screen
Smartwatch	Climbing stairs	Climbing stairs and then checking heart rate or steps via smartwatch screen

[a]Nontechnology-based tasks.

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Analysis

Wearable Camera Coding

The wearable camera automatically processed images into a time-lapse video file (.avi), which was later downloaded and converted into single images (.jpg) using the open-source software FFmpeg (version 4.3 FFmpeg Team), which labeled each image with a participant code and image number. Images for each participant were viewed by a member of the research team, who recorded the corresponding technology code (Table 2) for each image recorded in a spreadsheet with image numbers and time stamps. Each image was coded in chronological order as indicated by the image number. The coder first determined if the image was codable or not. Uncodable images were images that could not be confidently annotated due to poor image quality, such as if the image was blurry, had poor lighting, or was obscured. If codable, each image was then coded to determine if any digital technology was visible. If not, then the image was coded as "no digital technology." If a digital technology was visible and active (ie, screen turned on), then the digital technology in the image was coded first for the primary technology device (the technology related to the primary task the child was doing). If there was more than one technology device visible in the image, any other technology was also coded, allowing for up to 3 technologies to be coded for the same image.

Table . Technology code definitions.

Coding options	Definition
Uncodable: blurry	Any image or set of images where the image quality is so poor due to being blurred that the coder is unable to confidently determine what is occurring in all aspects of the image.
Uncodable: obscured images	Any image or set of images where the image quality is so poor due to lighting that the coder is unable to confidently determine what is occurring in all aspects of the image. Poor lighting can include images that are too dark or too overexposed to accurately determine anything.
Uncodable: poor lighting	Images that are completely black or fully blocked by something and cannot be coded as having an active screen-based media device according to the coding rules. Includes completely blacked images.
Unsure	Coder is uncertain what is in the image.
No digital technology	No digital technology is visible (or active for room video).
Television	A device shaped like a box or rectangle with a screen that receives electrical signals and changes them into moving images. Can stand-alone or be mounted to a wall. Can be a smart television (ie, internet connected).
Desktop computer	A computer that fits on a desk but is not easily moved from place to place. Has a monitor, keyboard, mouse, and tower.
Laptop computer	A computer that is small enough to be carried around easily and is flat when closed. Indicated by an inbuilt keyboard.
Smartphone	A handheld device that can be used as a small computer, connect to the internet, and run apps.
Tablet	A small, flat computer that is controlled by touching the screen with one's finger or a special pen. Does not require a keyboard or mouse. Includes e-readers.
Handheld gaming console	Portable, self-contained devices that have a built-in screen, game controls, and speakers.
Combined gaming controller	When the child has the Nintendo Switch controller, which is controlled by 2 hands (ie, it has both the red and the blue parts together or the black controller in their hand).
Single gaming controller	When the child has the controller separated and/or in separate hands.
Smartwatch	A watch that has an electronic screen with features of a smartphone or a computer. Includes fitness trackers, such as a FitBit.

Room Video Coding

Video files were downloaded from the iPhones, with separate files for each participant. The secondary video was used for 4 participants (due to the primary video battery running out). The video frames for each participant were viewed by a member of the research team using QuickTime software (Apple Inc), with the technology code (Table 2) for each frame recorded in a spreadsheet. Video frames were coded in chronological order. To gain an understanding of the context, coders were encouraged to watch several video frames prior to coding. The coder would first determine if a frame was codable using the same codes as those used for the wearable camera images. Next, the coder would determine if any technology was visible and active. The definition of "active" varied from that used for wearable camera images, given the broader field of view of the room video, which

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always included screens not always in use, such as the television screen. To be an active screen, it needed to be (1) within the child's field of view as determined by the child's head position, (2) facing the child, and (3) turned on or the child had active engagement with the screen. For smartwatches or gaming controllers to be coded, the child had to be actively engaging with the device. As with the wearable camera images coding, the primary technology was the technology related to the primary task the child was doing, and up to 2 additional technologies could be coded if they met the abovementioned criteria and were within the video frame. A custom-made Python program was used to generate second-by-second datasets of the video code spreadsheets to enable synchronization with the wearable camera code spreadsheets using a lookup table approach, whereby each time stamp in one dataset was matched to its corresponding time stamp in the other.

Interrater Reliability of Wearable Camera and Fixed Room Video Coding

The wearable camera images and room video frames from 3 participants (one from each age group) were independently coded by a second researcher to determine interrater reliability by assessing percentage agreement and Cohen κ [32]. For the wearable camera images, a very good interrater reliability was observed for all age groups, with an average percentage agreement of 92.5% (range 90.3% - 94.7%) and an average κ of 0.88 (range 0.86 - 0.92). For the room video frames, a good level of interrater reliability was found, with an average percentage agreement of 84.8% (range 72.7% - 98.8%) and an average κ (range 0.66 - 0.98), with the lowest level of agreement found for the youngest participant.

Statistical Analysis

As up to 3 technologies could be coded for each wearable camera image and room video frame, a variable was created to describe all possible combinations of the 9 technologies (television, desktop, laptop, tablet, smartphone, smartwatch, handheld gaming console, combined gaming controller, and single gaming controller), resulting in a total of 50 technology combinations (eg, television and combined gaming controller being used simultaneously when playing a video game). Including "no digital technology," "unsure," and "uncodable" created 53 categories (Table S1 in Multimedia Appendix 1).

An additional "any technology combination" variable was created to describe when each of the technologies was coded either alone or in combination with another technology (eg, "any television" when television was coded either alone or in combination with other technologies). This resulted in a variable with a total of 9 categories: any television, any desktop, any laptop, any tablet, any smartphone, any smartwatch, any handheld gaming console, any combined gaming controller, and any single gaming controller. As the technology types could be used together simultaneously, the 9 "any technology combination" categories were not distinct categories, as each individual image or frame could be coded for a number of these categories.

Comparisons between the coding of the wearable camera images and room video frames were made on a second-by-second basis. Confusion matrices were generated for the 53 categories to identify patterns of differences in classifications between wearable camera image and room video frame coding. Percent agreement between the wearable camera image and room video frame coding was calculated based on the confusion matrix with the 53-category variable.

The 9 "any technology combination" categories were used to determine if a particular technology was coded at the same second by both the wearable camera and room video regardless of whether the technology was coded by itself or with other technologies. Percent agreement between the wearable camera image and the room video frame coding was calculated based on whether either source coded the technology. As percent agreement does not take into account chance agreement, and given the different prevalence of some technologies, prevalence-adjusted bias-adjusted κ (PABAK) was also calculated [32,33]. We interpreted PABAK values using the Landis and Koch [34] classification scale where below-chance agreement <0.00, slight agreement 0.00 to 0.20, fair agreement 0.21 to 0.40, moderate agreement 0.41 to 0.60, substantial agreement 0.61 to 0.80, and almost perfect agreement 0.81 to 1.00. Agreement between the wearable camera and room video was compared between gender and age groups using separate two-way *t* tests or Wilcoxon tests (depending on distribution of data) comparing PABAK between genders and one-way ANOVA or Kruskal-Wallis (depending on distribution of data) comparing PABAK between age groups.

Results

Overview

A total of 48 children completed the study; however, a technical error resulted in some missing wearable camera image time stamps. Therefore, 4 participants were excluded, leaving a sample of 44 participants (girls: n=25, 55%) with a mean age of 8.3 (SD 3.3) years (Multimedia Appendix 2). Eleven children were aged between 3 and 6 years, 22 children were aged between 7 and 10 years, and 11 children were aged between 11 and 14 years. Across the 44 participants, a total of 182,451 contemporaneous wearable camera images and room video frames were coded, which equated to 50.7 hours of observed recording. At an individual participant level, the mean recording duration was 72.5 (SD 11.2, range 39.7-103.0) minutes.

Frequency of Technology Codes for Wearable Camera Images and Room Video Frames

Table 3 presents the frequency distribution of categories with at least 100 images or frames using the 53 categories of possible technology codes based on the wearable camera images and room video frames. Table S2 in Multimedia Appendix 1 contains the distribution of all 53 categories. "No digital technology" was coded for 46% (n=84,178) and 29% (n=52,504) of the wearable camera images and room video frames, respectively. The most frequently coded technologies based on the wearable camera images were "television" (n=21,900, 12%), "laptop" (n=11,596, 6%), and "desktop" (n=9426, 5%). For the room video frames, the most frequently coded technologies were "laptop" (n=19,150, 11%), "television" (n=18,266, 10%), and

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"television & single gaming controller" (n=16,005, 9%). Ten percent (n=17,802) of the wearable camera images were coded as "uncodable" compared to only 3 (0%) room video frames.

Table . Frequency and agreement of 53 category technology coding based on wearable camera and room video recordings.

Technology coded	Wearable camera images (N=182,451), n (%)	Room video frames (N=182,451), n (%)	Agreement, n (%)
Uncodable	17,802 (9.8)	3 (0)	0 (0)
Unsure	234 (0.1)	39 (0.02)	0 (0)
No digital technology	84,178 (46.1)	52,504 (28.8)	41,113 (48.9)
Television	21,900 (12)	18,266 (10)	3825 (17.5)
Desktop	9426 (5.2)	11,893 (6.5)	8759 (73.6)
Laptop	11,596 (6.4)	19,150 (10.5)	10,510 (54.9)
Tablet	7327 (4)	14,565 (8)	5299 (36.4)
Smartphone	4866 (2.7)	9120 (5)	3063 (33.5)
Smartwatch	182 (0.1)	1822 (1)	57 (3.1)
Handheld gaming console	6812 (3.7)	10,758 (5.9)	5988 (55.7)
Combined gaming controller	1922 (1.1)	486 (0.3)	182 (9.4)
Single gaming controller	176 (0.1)	30 (0.02)	0 (0)
Laptop and combined gaming controller	76 (0.04)	0 (0)	0 (0)
Laptop and handheld gaming console	310 (0.2)	113 (0.1)	75 (24.2)
Tablet and smartphone	6 (0)	262 (0.1)	1 (0.4)
Tablet and tablet	1111 (0.6)	0 (0)	0 (0)
Television and combined gaming controller	4142 (2.3)	9346 (5.1)	3028 (32.4)
Television and laptop	6608 (3.6)	9970 (5.5)	4068 (40.8)
Television and single gaming controller	2034 (1.1)	16,005 (8.8)	1559 (9.7)
Television and smartphone	460 (0.3)	4117 (2.3)	150 (3.6)
Television and smartwatch	64 (0.04)	432 (0.2)	8 (1.8)
Television and tablet	389 (0.2)	3147 (1.7)	155 (5)
Television and laptop and smartwatch	0 (0)	171 (0.09)	0 (0)
Television and single gaming controller and single gaming controller	286 (0.2)	0 (0)	0 (0)

Table 4 presents the frequency distribution of categories using the 9 "any technology combination" category codes for both the wearable camera images and room video frames. The most frequently coded technologies based on the wearable camera images were "any television" (36,198/182,451, 19.8%), "any laptop" (n=18,816, 10.3%), and "any desktop" (n=9479, 5.2%). For the room video frames, the most frequently coded technologies were "any television" (n=61,477, 33.7%), "any laptop" (n=29,461, 16.1%), and "any tablet" (n=18,075, 9.9%).

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Table . Frequency and agreement of "any technology combination" coding based on wearable camera images and room video frames.

Technology	Wearable camera images (N=182,451), n (%)	Room video frames (N=182,451), n (%)	Total (N[a])	Agreement, n (%)	PABAK[b]
Any television	36,198 (19.8)	61,477 (33.7)	67,617	30,058 (44.5)	−0.111
Any desktop	9479 (5.2)	11,933 (6.5)	12,628	8784 (69.6)	0.391
Any laptop	18,816 (10.3)	29,461 (16.1)	33,077	15,200 (46)	−0.081
Any tablet	8904 (4.9)	18,075 (9.9)	19,150	7829 (40.9)	−0.182
Any smartphone	5480 (3)	13,564 (7.4)	14,288	4756 (33.3)	−0.334
Any smartwatch	246 (0.1)	2661 (1.5)	2821	86 (3)	−0.939
Any handheld gaming console	7154 (3.9)	10,865 (5.9)	11,705	6314 (53.9)	0.079
Any combined gaming controller	6314 (3.5)	9829 (5.4)	11,155	4988 (44.7)	−0.106
Any single gaming controller	2642 (1.4)	16,033 (8.8)	16,792	1883 (11.2)	−0.776

[a]Coded by either wearable camera and/or room video.

[b]PABAK: prevalence-adjusted bias-adjusted κ.

Comparison of Technology Codes From Wearable Camera Images and Room Video Frames

Overview

Table 3 presents the agreement of the 53-category codes from the wearable camera images and room video frames. Table 4 presents the agreement of all possible classifications for each general technology type combined (ie, the 9 "any technology combination") codes from the wearable camera images and room video frames. Regardless of whether technology was coded uniquely (53 codes) or in any combination (9 codes), there was generally below-chance agreement between the wearable camera image–based and room video frame–based codes. Specifically, for the 9 "any technology combination," the average percent agreement was 38.6% (range 3% - 69.6%), with PABAK scores ranging from −0.939 to 0.391.

While the study did not have an independent reference standard to assess accuracy, it appeared that the wearable camera images provided better information for differentiating background screens from screens being actively engaged with, as well as providing a closer and more detailed image that could enable assessment of content. In contrast, the room video images appeared to provide better information when the child was moving or prone or lying, when the interaction with technology was brief or involved hand controls, the context of use that could include course, and the use of multiple devices.

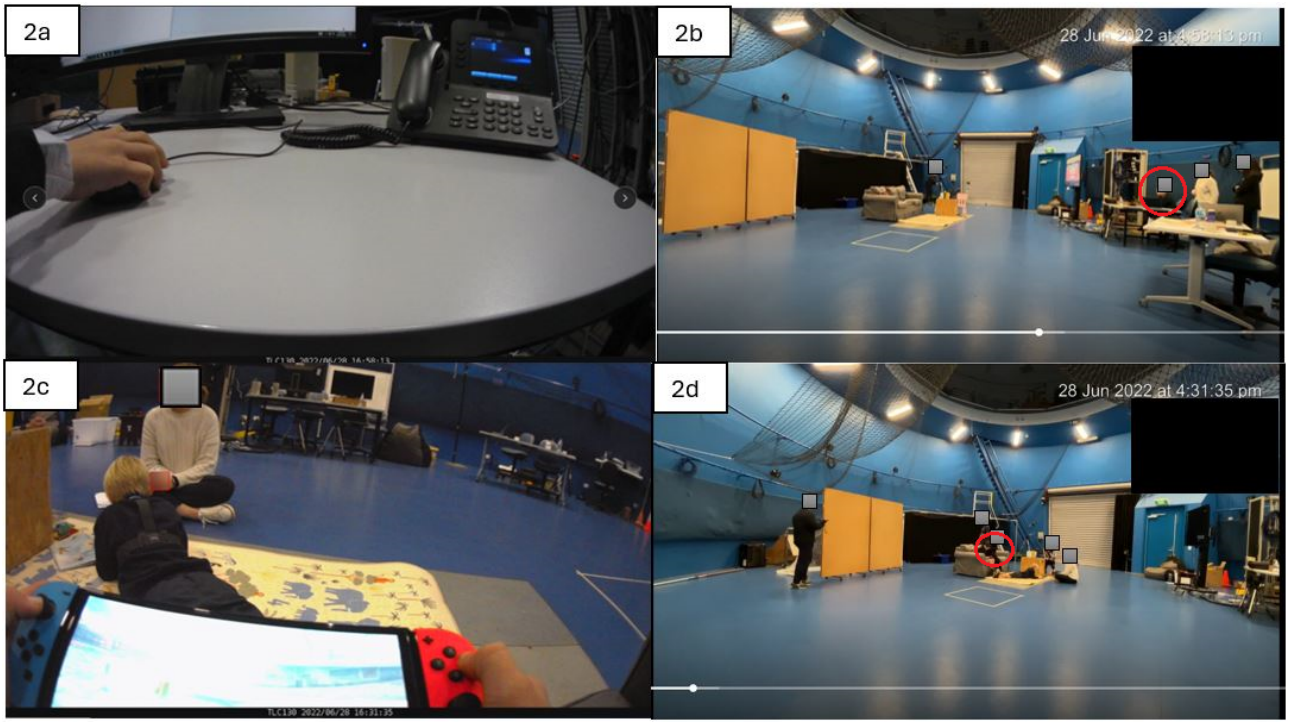
Coding issues were identified related to wearable camera and room video differences, including sampling rate, camera movement, and field of view.

Examples of Coding Issues Related to Differing Sampling Rates

The highest agreement when considering whether a technology was coded was found for more stationary technology use or technology held closer to the child for a longer duration of time; for example, "any desktop" (8784/12,628, 69.6%) had fair agreement (PABAK: 0.391), and "any handheld gaming console" (6314/11,705, 53.9%) had slight agreement (PABAK: 0.079). Figure 2 shows instances where a desktop and a handheld gaming console were coded in agreement based on both the wearable camera image and room video frame.

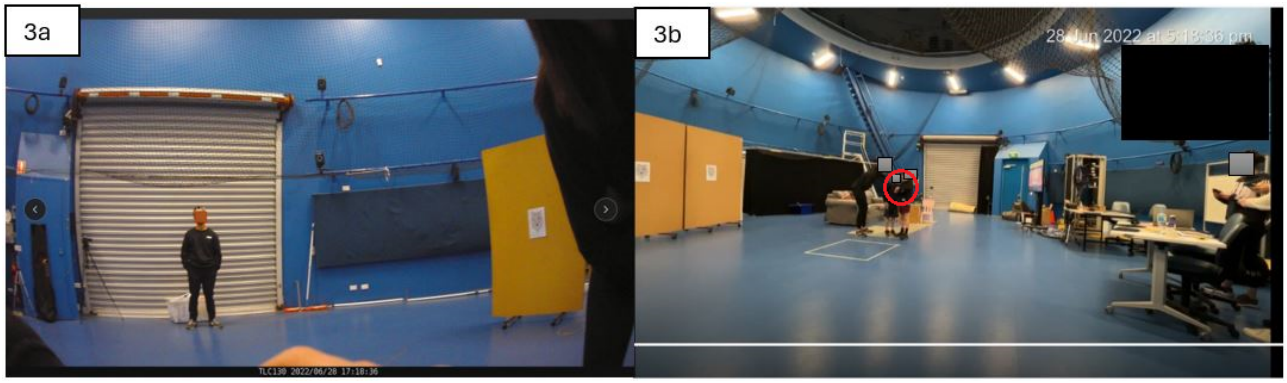
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Figure 2. Impact of sampling rate on coding of longer duration activities. (A) Wearable camera coded desktop, (B) room video coded desktop, (c) wearable camera coded handheld gaming, and (D) room video coded handheld gaming. The red circles indicate the child with the wearable camera.



All other technologies were rated as having below-chance agreement, with the lowest agreement for coding of "any smartwatch" (86/2821, 3%, PABAK: −0.939), which was typically a very brief activity. Smartwatch was coded over an order of magnitude more frequently based on the room video (2661/182,451, 1.5%) compared to the wearable camera image (246/182,451, 0.1%; Table 4). Figure 3 shows an instance when "smartwatch" was coded based on the room video, but "no digital technology" was coded based on the wearable camera.

Figure 3. Impact of sampling rate on coding of brief activity. (A) Wearable camera coded no digital technology. (B) Room video coded smartwatch. Red circle indicates the child with the wearable camera.

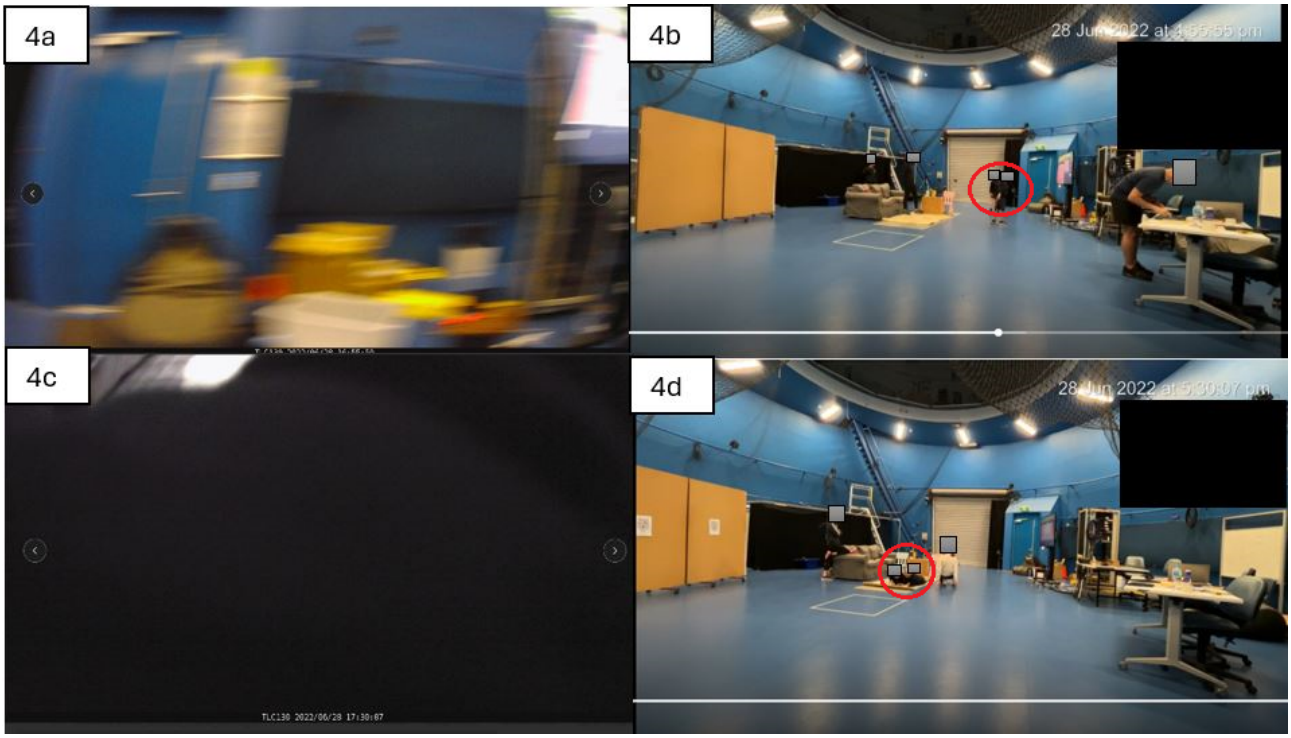


Examples of Coding Issues Related to Camera Movement

"Uncodable" was coded more frequently based on wearable camera images (17,802/182,451, 9.8%) than on room video frames (n=3, 0%). Likewise, more wearable camera images (n=234, 0.1%) than room video frames (n=39, 0.02%) were coded as "unsure." The reason for wearable camera images to be coded as "uncodable" was likely often due to camera movement or a slower shutter speed causing images to be too blurry to code or due to the camera being obscured (eg, child lying on their stomach). Figure 4 shows instances when the wearable camera image was coded as "uncodable" due to being blurry or obscured, but technology was coded based on the room video frame.

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Figure 4. Effect of camera movement or position. (A) Wearable camera uncodable: blurry, (B) room video coded single controller and television, (C) wearable camera uncodable: obscured image, and (D) room video coded smartphone. Red circles indicate the child with the wearable camera.



Examples of Coding Issues Related to Differing Fields of View

Overall, a higher number of frames were coded as "no digital technology" based on the wearable camera images (84,178/182,451, 46.1%) compared to room video frames (52,504/182,451, 28.8%). Accordingly, percent agreement between wearable camera images and room video frames coded as "no digital technology" was only 48.9% (n=41,113). If a wearable camera image was coded as "no digital technology," it was frequently coded as containing a technology based on the room video frame, particularly "television" (8783/84,178, 10.4%), "laptop" (7866/84,178, 9.3%), or "tablet" (6387/84,178, 7.6%). However, if a room video image was coded as "no digital technology," it was only infrequently coded as a technology based on wearable camera images. Figure 5 shows instances when "no digital technology" was coded based on the wearable camera but "television" was coded based on the room video.

Figure 5. Impact of differing fields of view. (A) Wearable camera coded no digital technology and (B) room video coded television. Red circles indicate the child with the wearable camera.



Examples of Coding Issues Related to Technology Device Differences

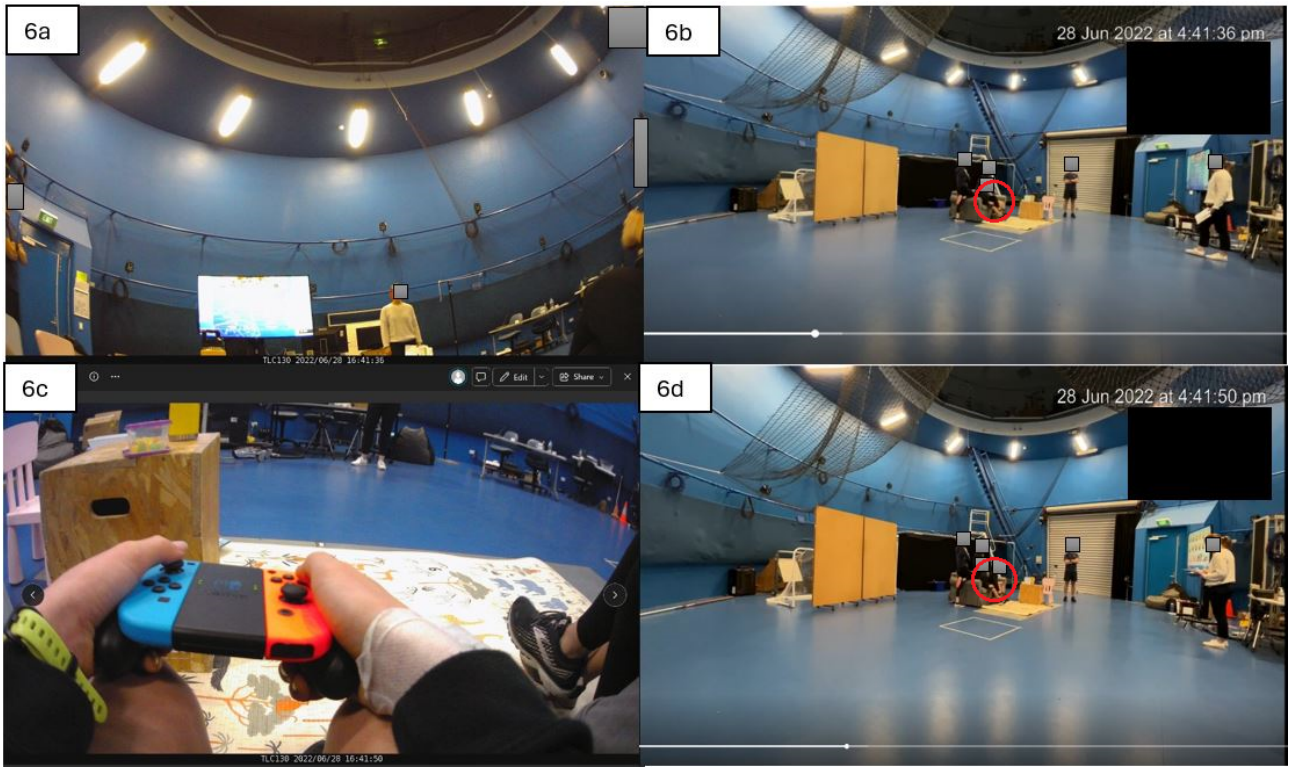
To identify patterns of differences in classifications between wearable camera image and room video frame coding and to determine if a technology (ie, television) was coded as different between the wearable camera and room video or in combination with other technology types, the 53-category confusion matrix can be considered. Multimedia Appendix 3 contains a link to an interactive version of the 53-category confusion matrix, along with an explanation of how to use the interactive figure and clarification of where the link will take the reader.

On the basis of the 53-category confusion matrix, 3825 image and frame were coded as "television" by both the wearable camera and room video (percent agreement: 17.5%). When considering images coded as "television" based on the wearable camera (21,900/182,451, 12%), 8161 (37%) frames were coded as "television & single gaming controller" based on the room video, and 3579 (16%) frames were coded as "television &

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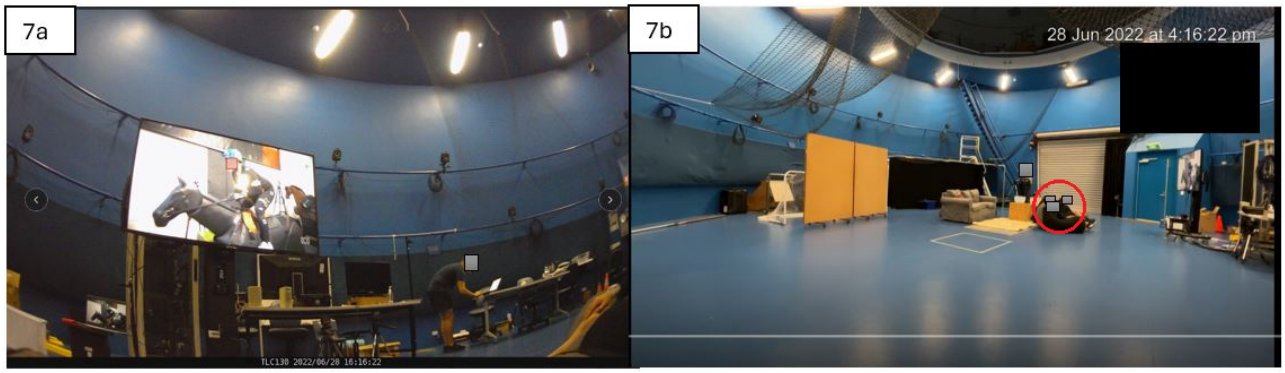
combined gaming controller" based on the room video. When considering frames coded as "television" based on the room video recording (18,266/182,451, 10%), there were low numbers of images coded as "television & single gaming controller" (219/18,266, 1.2%) or "television & combined gaming controller" (206/18,266, 1.1%) based on the wearable camera. A total of 3028 images per frame were coded based on both the wearable camera and room video as "television & combined gaming controller" (percent agreement: 32.4%), and a total of 1559 images per frame were coded based on both the wearable camera and room video as "television & single gaming controller" (percent agreement: 9.7%). Figure 6 shows instances when only "television" or "combined gaming controller" were coded based on the wearable camera image, but "television & combined gaming controller" was coded based on the room video frame.

Figure 6. Impact of field of view and thus ability to code from gaming involving hand controllers and television screen. (A) Wearable camera coded television, (B) room video coded combined controller and television, (C) wearable camera coded combined controller, and (D) room video coded combined controller and television. Red circles indicate the child with the wearable camera.



"Television" as coded based on the room video (18,266/182,451, 10%) was often coded as "television & laptop" (1955/18,266, 10.7%) based on wearable camera. Similarly, "television" as coded based on the wearable camera (21,900/182,451, 12.0%) was also often coded "television & laptop" (1064/21,900, 4.9%) based on the room video. A total of 4068 images per frame were coded based on both the wearable camera and room video as "television & laptop," with a percent agreement of 40.8%. Figure 7 shows an instance when both "television & laptop" were coded based on both the wearable camera image and the room video frames, highlighting the level of detail visible.

Figure 7. Impact of field of view on capturing television and laptop technology. (A) Wearable camera coded television and laptop and (B) room video coded television and laptop. Red circle indicates the child with the wearable camera.



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Gender and Age Group Stratification

There were similar frequencies of codes between genders and age groups for the 9 "any technology combination" coded based on the wearable camera and room video (Table S3 in Multimedia Appendix 1). Overall, there were no significant differences in the PABAK results between either gender or age groups (Table S3 in Multimedia Appendix 1).

Discussion

Summary of Results

Overall, there were generally very low levels of agreement between the codes based on wearable camera images and room video frames for all technology types, as well as for coding whether or not technology was being used. Across all the categories, the highest agreement was found for "desktop" and "handheld gaming console" codes, and the lowest agreement was found for "smartwatch." Differences mostly occurred when multiple technologies were being used or coded or not, as combinations of technology were often captured with the room video but not necessarily with the wearable camera. Similar patterns to those observed in the whole sample were seen when comparing genders and age groups.

Previous literature has compared self-reported and objective measurements of technology use [35,36], with a previous systematic review finding discrepancies between device-logged and self-reported digital media use and reporting that self-reported measures were rarely accurate reflections of device-logged media use [37]. While there are now many studies that have used visual images to measure human behavior, no previous studies that have directly compared wearable camera images and room video frames to understand what can be captured from each of these data sources were identified. The wearable camera and room video varied in aspects such as sampling rate, the ability of the camera to move, and field of view, leading to differences in what was captured by each source. Prior studies have compared different types of cameras and camera views for other outcomes, for example, comparing a head-worn camera with a laptop camera to assess eye tracking [38] and a head-worn camera with an overhead drone camera to assess park quality [39]. The closest identified comparison to this study compared measures of parent-infant behavior using the same head-worn video cameras on the infant, parent, and observing researcher [40]. This study found that both the direction of the field of view (eg, infant's perspective and mother's perspective) and the viewing distance (ie, researcher perspective vs infant and mother) influenced what could be measured. Their findings thus concur with this study that while there was concordance on some outcomes, different camera views provided better options for different outcomes. For example, infant facial expressions were best measured from the mother-worn camera; however, due to the differing visual field, whole-body movements were often missed by the first-person cameras (mother- and infant-worn camera) compared to the third-person cameras (researcher perspective) [40].

The highest agreement for technology types was observed for technology devices that were used when the child was more stationary or when the device was closer to the child (ie, desktop and handheld gaming consoles; Figure 2). Brief technology activities (eg, smartwatch use) were captured better with the room video due to higher sampling rate, resulting in the lowest agreement (Figure 3). Child engagement with a smartwatch tended to occur quickly and was therefore easily missed with the 1-second sampling frequency of camera images and may also have been missed in camera images because of blurring due to the quick movement. Smartwatches are becoming increasingly available to children; therefore, it would be important to capture use effectively [41]. In addition, when a child looked at their wrist, it may not be in view of the wearable camera (eg, the child's arm blocking the camera). Due to these multiple issues, the use of the smartwatch may not have been captured in the wearable camera, which could perhaps be better captured in a room video recording at 30 frames per second.

Activities involving child movement (eg, jumping, running, skipping, and cartwheels) were not captured as well by the wearable camera compared to the room video. A higher percentage of images were coded as *"uncodable"* for the wearable camera images compared to the room video frames. This was often due to movement of the child or camera and a slow shutter speed, leading to blurred images. Furthermore, activities involving prone postures were not captured well by the wearable camera, as the child blocked the wearable camera view (ie, child lying on their stomach; Figure 4).

Owing to the differing fields of view, the wearable camera could miss technology but was more likely to detect active use of technology. It is likely that background use of certain technologies (ie, television and laptop) was coded based on the room video recording but not by the wearable camera images. More frames were coded as "no digital technology" based on the wearable camera images compared to the room video recording. Either the wearable camera missed capturing the technology or the room video "overcaptured" technology use. As captured by the room video, technology devices could still have been used, but due to the field of view of the wearable camera, the technology was missed. However, when determining active technology use based on the room video recording, it was sometimes hard to determine if the child was actively using or engaged with the technology or not, for example, if a technology was in the peripheral vision of the child (Figure 5). Wearable cameras primarily capture first-person, action-proximal engagement, whereas room video captures environmental availability and background exposure.

Technology use involving simultaneous use of hand gaming controllers and a television screen was not captured as well by the wearable cameras due to the field of view missing either the controller or television screen. Single and combined gaming controllers were often coded simultaneously with television for the room video frames but often only coded as "television" based on the wearable camera images (Figure 6). If single and combined gaming controllers were simultaneously coded with television in the wearable camera, then they were likely also simultaneously coded in the room video. The single and combined gaming controllers were often held outside the field of view of the wearable camera and, when within the field of view, could appear blurry in the wearable camera images due to movement of the child and controllers and a slow shutter

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speed. On the basis of the wearable camera, it was sometimes difficult to determine whether the child was simply watching television or gaming using the television, whereas this could be captured within the room video given the different point of view.

Pros and Cons of Each Data Source

Room video data had a wider field of view; therefore, it was able to better capture technology that was in the room and had the ability to capture the context of the technology use. With the ability to capture the whole room, it was clear when the child was passively watching a program on the television compared to actively playing a video game. Additionally, although not an aim of this study, room video would have the ability to capture coviewing and co-use of technology (as seen in Figures 2-7). Borzekowski and Robinson [16] previously used a fixed room camera to capture coviewing of television and behaviors while watching television, such as eating, reading, or doing homework, and playing. On the other hand, the wider field of view of the video recording sometimes limited the quality of the video frames, and therefore, on occasion, it was hard to determine if there was technology present (eg, a laptop in the background). In addition, although not an aim of this study, it would be difficult to determine the content of the technology. For example, on occasion, it was difficult to determine if the television was actively on with a program or just a standby screen; therefore, it would be difficult to determine if the content was a violent movie compared to educational children's content. Furthermore, when determining active technology use based on the room video, it was sometimes difficult to determine if the child was actively using or engaged with the technology or not, for example, capturing technology in the peripheral vision of the child (as seen in Figure 5). Vadathya et al [21] previously attempted to combat this issue by developing a method to determine whether the target child was looking at the television using a home-based fixed room camera. There are also privacy concerns with recording room images.

The wearable camera had a smaller field of view but was closer in proximity and more focused (as seen in Figures 2 and 7). The wearable camera was able to capture active engagement with the technology and, due to the proximity to the technology, would have a greater ability to capture the content on the screen (as seen in Figure 7). Previous studies using wearable cameras to measure device use by adolescents have shown that it is feasible to code multiple screens with details of the screen content (eg, gaming, television viewing, social media, communication, creative content, and internet) as well as the location (eg, bedroom and living room) [18,19]. However, a wearable camera also has limitations. The children were often moving, which led to blurry images (as seen in Figure 4). With the camera mounted on the chest, sometimes some technologies were not visible either due to the position of the child or the placement of the technology (as seen in Figure 6). Particularly for gaming, the controller was frequently not visible in the wearable camera frame due to the child holding the controller out of view or due to movement of the child (such as using the single controller during active play). Therefore, the task may have been missed, with both gaming and television watching activities being coded as "television." Sometimes only a very small part of the screen was visible (eg, the corner of a tablet), therefore potentially missing technology that was out of frame. Moreover, if the engagement with the technology occurred quickly (eg, using a smartwatch), it was easily missed with images only captured every second (as seen in Figure 3). Furthermore, if the child was in certain positions (eg, lying on their stomach), the camera could be blocked, leading to "uncodable" images (as seen in Figure 4). Previous studies have also found that wearable cameras have the ability to capture screen use when the participant is upright or partially upright but capture a high percentage of images of the ceiling or obscure images due to the participants being positioned on their backs or in other positions [18,42,43]. Despite an ethical framework being established for privacy concerns with wearable cameras [28], parents remained concerned, especially with the varied locations of use creating greater potential for capture of nonconsenting third parties. The advantages and challenges of each data source are summarized in Table 5.

Table . Advantages and challenges of fixed room video and wearable cameras.

Method	Advantages	Challenges
Fixed room video	• Can capture technology within the whole space • Can capture the context of the technology, such as passively watching television or actively playing a video game • Can capture coviewing and co-use of technology	• Difficult to determine content on technology device • Difficult to determine active engagement with technology compared to background use • Privacy concerns with recording room images
Wearable camera	• Can capture active engagement with the technology • Has the ability to capture the content on the screen • Has the ability to capture technology use in various locations	• Movement can result in blurry images • Technology may not be visible within field of view • Privacy concerns with the ability to capture content in varied locations

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Strengths and Limitations

A strength of this study was the simultaneous use of both a wearable camera and 2 fixed room video cameras to capture technology use. Another strength was that there was the broad age range from 3 to 14 years and the wide variety of technology devices included in the study. However, there were several limitations. First, the video camera placement at approximately 6 m from the center of the laboratory led to reduced video frame quality. There was also a potential that the time stamp synchronization of the wearable camera images and room video frames was not perfect and that small discrepancies in the time stamp synchronization could result in mismatches, which would affect the agreement of brief activities, such as checking the smartwatch. Finally, as the data were collected in a laboratory setting, the results should be generalized with caution to free-living conditions. We encourage further research in free-living conditions, despite the challenges of such studies.

Implications for Further Research

If future research is continued in free-living conditions, a few considerations should be made. Similar to previous literature [28], caregivers expressed concerns about privacy if the devices were used in a home setting and were worried about other children being captured if the devices were used in a school setting. Caregivers were more comfortable if the recording devices could be turned on and off and if the devices could be smaller. There were also concerns from caregivers about wearing the camera during certain activities, such as contact sports and swimming.

The coding of the wearable camera and fixed video frames was based on decisions made by the coders. In practice, researchers are likely to be able to interpolate coding for some blurred or obscured images, for example, when a screen temporarily moves out of view. This approach was not used in this study to enable clear comparisons of issues, such as movement blurring. Coding of both sources had the potential for human error and was extremely time-consuming (taking ~6 h per hour of recorded data), which suggests that it may be unsuitable for large-scale studies. Machine learning software could potentially be used to reduce the high researcher burden for the analysis of technology use via camera images or video frames [7], and advances in AI should be examined for accuracy in coding child behaviors from images [44].

Given the complexity of modern technology use, future research could usefully evaluate the simultaneous use of several data collection methods to use the relative advantages of different methods [7]. This could include questionnaires to provide some complementary information for image data, such as context or purpose. Images from both the wearable camera and the stationary video camera can capture useful and complementary information and thus could be used together. Similarly, multiple objective measures could be used simultaneously, for example, combining on-device recording of apps used or websites visited to triangulate the classification of content coded from image data.

Conclusions

Overall, there was poor agreement for children's technology use between the wearable camera images and room video frames. The results did not differ based on gender or age of the participants. The wearable camera and room video varied in sampling rate, the ability to move, and perspective, leading to differences in what was captured by each method. Both the room video and wearable camera methods have strengths and limitations due to these differences. Overall, fixed room video might better capture that technology is within a single set space and the context of the technology use, and the view and higher sampling rate of video may be better when child movement or prone lying is involved, handheld devices are used, interactions with technology are brief, or multiple devices are used within a set location. Wearable cameras could better differentiate the active use of technology versus background television, the content of the technology (due to the closer view of screen detail), and different locations of use. Future use of wearable cameras and room video to capture digital technology use should carefully consider the purpose of the study along with the potential limitations of each data source. Capturing digital technology use by children is difficult, with no gold standard and no one ideal method.

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Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

Development of study design: LS, DH, GT, and AC
Data collection: DH, GT

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Data analysis: AB, CLR, and PD
Writing of initial draft: AB, CLR, LS, and AC
Reviewing and editing manuscript: all authors.
All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary tables including technology coding categories, frequency and agreement of technology coding, and gender and age-group stratification.
[DOCX File, 46 KB - pediatrics_v9i1e91113_app1.docx]

Multimedia Appendix 2
Consort style figure of flow of participants and data.
[DOCX File, 39 KB - pediatrics_v9i1e91113_app2.docx]

Multimedia Appendix 3
Interactive confusion matrix: instructions and interpretation.
[DOCX File, 26 KB - pediatrics_v9i1e91113_app3.docx]

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Abbreviations

PABAK: prevalence-adjusted bias-adjusted κ

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Weekend Texting Screen Time and Incident Nicotine Use in Early Adolescents: Longitudinal Analysis of the Adolescent Brain Cognitive Development Study

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Abstract

Background: Adolescent nicotine use initiation remains a significant public health concern. While screen-based behaviors have been linked to substance use, few prospective studies have examined specific forms of interactive screen engagement or tested potential psychological mechanisms underlying this association.

Objective: This study aimed to examine whether weekend texting screen time was prospectively associated with subsequent nicotine use initiation among early adolescents and evaluate whether negative urgency statistically accounted for part of this association.

Methods: We analyzed longitudinal data from a large cohort of adolescents who were nicotine naive at baseline. Weekend texting screen time (hours) was assessed via self-report. Negative urgency, reflecting impulsive action during negative affect, was measured using the UPPS (Urgency, Premeditation, Perseverance, and Sensation Seeking) impulsivity scale. Incident nicotine use initiation was modeled using Cox proportional hazards regression, adjusting for sex, age, race, ethnicity, and household income. We evaluated whether adjustment for negative urgency attenuated the texting-initiation association and conducted a sensitivity analysis restricted to participants for whom texting assessment, negative urgency assessment, and nicotine use initiation were temporally ordered.

Results: Among 5,965 nicotine-naïve adolescents followed prospectively, 239 (4%) initiated nicotine use. Greater weekend texting was associated with increased hazard of nicotine use initiation (per hour: hazard ratio [HR]=1.07, 95% CI 1.04 - 1.11). A 5-hour increase corresponded to an approximately 30% to 40% higher hazard of initiation. Weekend texting was positively associated with negative urgency (β=0.079; *P*<.001), and negative urgency independently predicted nicotine use initiation (per point: HR=1.19, 95% CI 1.13 - 1.25). Inclusion of negative urgency slightly attenuated the texting association (per hour: HR=1.06, 95% CI 1.02 - 1.09), although attenuation was modest. In standardized models, a 1-SD increase in weekend texting was associated with a 21% higher hazard of initiation (HR=1.21, 95% CI 1.10 - 1.31). In a sensitivity analysis restricted to participants with temporally ordered assessments and nicotine use initiation, weekend texting remained associated with nicotine use initiation (HR=1.11, 95% CI 1.06 - 1.16), and negative urgency remained independently associated with use initiation (HR=1.11, 95% CI 1.02 - 1.21). Adjustment for negative urgency attenuated the texting log-hazard coefficient by 6.8%.

Conclusions: Greater weekend texting screen time was prospectively associated with subsequent nicotine use initiation among early adolescents. Negative urgency was independently associated with nicotine use initiation and modestly attenuated the texting-initiation association. These findings are consistent with overlapping contributions of digital engagement and affect-driven impulsivity to early nicotine risk but do not establish a causal mediating pathway.

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KEYWORDS

adolescent nicotine initiation; screen time; SMS text messaging; negative urgency; impulsivity; longitudinal study

Introduction

Adolescent nicotine use initiation remains a major public health concern as early onset of use is associated with increased risk of nicotine dependence, polysubstance use, and long-term adverse health outcomes. Although traditional combustible cigarette use has declined in recent years, the proliferation of electronic nicotine delivery systems and related products has sustained elevated rates of experimentation and initiation during adolescence [1,2]. Longitudinal studies indicate that early e-cigarette use is associated with increased likelihood of subsequent combustible cigarette use initiation [3,4]. Identifying

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modifiable behavioral risk factors that precede nicotine use onset is therefore critical for prevention efforts, particularly given that adolescence is a sensitive developmental period characterized by increased susceptibility to social influence and risk behavior [5].

Screen-based technology use has increased dramatically among youth over the past decade. Adolescents now spend substantial time engaging in texting, messaging, and other forms of digital social interaction [6,7], particularly during weekends, when structured activities are reduced. Prior research has linked greater overall screen time with substance use, including alcohol and nicotine [8,9], but findings have been inconsistent and often limited by cross-sectional designs, aggregation of heterogeneous screen behaviors, or lack of temporal ordering [10]. Importantly, different forms and contexts of screen engagement may not carry equivalent information regarding substance use vulnerability. Texting and messaging are socially interactive behaviors that may capture peer communication and interpersonal engagement more directly than passive screen activities such as television viewing. We focused specifically on weekend texting because weekends are periods with fewer school-related constraints and, therefore, weekend use may more closely reflect discretionary patterns of peer-oriented digital engagement. This distinction does not imply that weekday texting or other interactive screen behaviors are unimportant; rather, weekend texting was examined as a specific, socially interactive exposure that may be particularly informative during periods of relatively unstructured time.

Impulsivity-related traits may represent one individual-level factor associated with both digital engagement and substance use risk. Negative urgency—the tendency to act impulsively during states of negative affect—is a well-established predictor of adolescent substance use initiation and escalation [11,12]. Although negative urgency is conceptualized as an impulsivity-related personality disposition, longitudinal research indicates that negative urgency itself shows meaningful developmental change across adolescence, increasing during early adolescence before leveling off [13]. Thus, negative urgency is not developmentally invariant during this period. Youth with elevated negative urgency are more likely to engage in maladaptive coping behaviors, including nicotine use, particularly in emotionally charged contexts [14]. Interactive digital environments may also involve emotionally salient social feedback, peer reinforcement, and interpersonal stressors [15,16]. Accordingly, greater engagement in these environments and negative urgency may jointly characterize adolescents at elevated risk of substance use initiation. However, whether negative urgency statistically accounts for part of the longitudinal association between digital engagement and subsequent nicotine use initiation remains unclear.

Despite this conceptual overlap, the extent to which impulsivity traits help explain the relationship between screen engagement and nicotine use initiation remains unclear. A key gap in the literature is the lack of longitudinal, prospective investigations testing whether specific forms of screen time are prospectively associated with incident nicotine use initiation among nicotine-naive adolescents and whether negative urgency statistically accounts for part of this longitudinal association. We conceptualized negative urgency as an affect-related impulsivity characteristic associated with vulnerability to risky behavior rather than as evidence that nicotine use initiation occurs during or immediately following texting episodes. Most prior studies have relied on cross-sectional designs, limiting causal inference, or have not examined mediation mechanisms grounded in personality and affect regulation frameworks [17,18]. Clarifying whether impulsivity partially explains this association has implications for both digital health guidance and targeted prevention strategies.

The present study addresses this gap using prospective data from a large cohort followed from early adolescence. We examined whether weekend texting screen time was associated with subsequent nicotine use initiation among youth who were nicotine naive at baseline. We further evaluated whether negative urgency was associated with both texting behavior and nicotine use initiation and whether adjustment for negative urgency attenuated the texting-initiation association.

We tested three primary hypotheses. First, greater weekend texting screen time would be associated with increased risk of incident nicotine use initiation. Second, higher texting screen time would be associated with greater negative urgency. Third, higher negative urgency would be independently associated with nicotine use initiation, and adjustment for negative urgency would partially attenuate the association between texting screen time and use initiation.

By focusing on a specific, socially interactive form of screen engagement and using prospective time-to-event analyses, this study aimed to clarify behavioral and personality mechanisms that may contribute to early nicotine use risk in contemporary digital environments.

Methods

Study Design and Participants

Data were drawn from a large longitudinal cohort of adolescents, the Adolescent Brain Cognitive Development (ABCD) study, assessed at multiple time points [19]. The assessments used in the present analyses took place between 2019 and 2024. Baseline Screen Time Questionnaire (STQ) assessments in the analytic sample were completed between March 2019 and October 2023, with subsequent UPPS (Urgency, Premeditation, Perseverance, and Sensation Seeking) and substance use follow-up assessments extending up to March 2024. The present analyses were restricted to participants with available STQ data [20] and UPPS impulsivity data [21], as well as information regarding nicotine use initiation [22]. To establish temporal ordering, participants who reported nicotine use initiation on or before the STQ assessment were excluded, yielding a nicotine-naive baseline cohort. Participants were further restricted to those with complete covariate data required for multivariable modeling. The final analytic sample consisted of adolescents followed prospectively for incident nicotine use initiation.

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Measures

Weekend Texting Screen Time

Weekend texting screen time at baseline was assessed using a self-report item from the STQ [20] that asked participants to report the number of hours spent texting or messaging on a cell phone, tablet, computer, or similar electronic device during weekends. Responses were recorded in hours. The distribution of texting time was right skewed, with many participants reporting low levels of exposure and a smaller subset reporting higher durations.

Negative Urgency

Impulsivity was assessed using the negative urgency subscale of the UPPS impulsive behavior measure [21]. Negative urgency reflects the tendency to act impulsively during states of negative affect. A summed score was used for analysis, with higher scores indicating greater urgency. The negative urgency score was treated as a continuous variable in all models. For each participant, negative urgency was obtained from the earliest available UPPS assessment taking place on or after the baseline STQ assessment. Eligible assessments were restricted to those taking place within 2500 days after the STQ assessment. In the primary analytic sample, 52.2% of selected UPPS assessments took place within 1 day of the STQ assessment; the median interval was less than 1 day (IQR <1 - 321; range <1 - 590 days).

Nicotine Use Initiation

Incident nicotine use initiation was defined as first reported use of nicotine products occurring after the baseline STQ assessment. Time to event was calculated from the date of the STQ assessment to the reported onset date of nicotine use. Participants who did not initiate nicotine use during follow-up were censored at their last available assessment.

Covariates

All models were adjusted for demographic covariates, including sex, age at baseline assessment, race, ethnicity, and household income. Income was included as a continuous variable. Analyses were conducted using a complete-case approach, with participants missing covariate data excluded from adjusted models.

Statistical Analysis

Descriptive statistics were calculated for weekend texting screen time and negative urgency. Weekend texting screen time was assessed at the baseline STQ assessment. For each participant, negative urgency was obtained from the earliest available UPPS assessment taking place on or after the STQ assessment within the specified 2500-day eligibility window. Because the timing of the selected UPPS assessment varied across participants, including assessments taking place on the same day as the STQ, negative urgency was not treated as a uniformly subsequent assessment. Associations between baseline texting screen time and follow-up negative urgency were evaluated using linear regression models adjusted for demographic covariates.

Prospective associations between baseline texting screen time and incident nicotine use initiation were examined using Cox proportional hazards regression models [23]. The primary model estimated the total association between baseline texting screen time and time to nicotine use initiation, adjusting for demographic covariates. Participants were restricted to those who were nicotine naive at baseline. Time to event was defined as the number of days from the baseline texting assessment to the first recorded nicotine use onset date derived from longitudinal substance use data. Participants without nicotine use initiation were censored at their last available follow-up assessment. Because Cox proportional hazards models explicitly incorporated each participant's observed time-to-event or censoring time, follow-up duration was not included as an additional covariate. We nevertheless examined the association between weekend texting screen time and follow-up duration to assess potential differential observation by exposure. To enhance interpretability, hazard ratios (HRs) were reported per 1-hour increase in weekend texting screen time and were additionally expressed for increases corresponding to 1 SD, 1 IQR, and 5 hours.

To examine whether negative urgency statistically accounted for part of the association between texting screen time and nicotine use initiation, a second Cox model included both texting screen time and negative urgency. Change in the texting coefficient following inclusion of negative urgency was used to quantify attenuation of the association. Because negative urgency was not uniformly assessed after STQ and before nicotine use initiation, these analyses were interpreted as associational rather than as establishing causal mediation.

As a sensitivity analysis addressing temporal ordering, we repeated the Cox analyses after excluding participants whose recorded nicotine use initiation occurred before or on the date of their selected UPPS assessment. This restriction ensured the sequence STQ assessment→UPPS negative urgency assessment→nicotine use initiation among participants experiencing the outcome. The time origin remained the baseline STQ assessment to preserve comparability with the primary survival analysis. Models used the same demographic covariates and family-level clustering as the primary analyses.

An exploratory product-of-coefficients analysis was additionally conducted on the log-hazard scale with nonparametric bootstrap CIs. Because the temporal ordering required for causal mediation was not consistently present in the primary sample, this analysis was interpreted only as a statistical breakdown of associations and not as an estimate of a causal indirect effect or causal proportion mediated.

Cox models incorporated clustering at the family level to account for nonindependence of observations. Proportional hazards assumptions were evaluated using Schoenfeld residual tests [24]. No violations of the proportional hazards assumption were detected. All analyses were conducted in R (R Foundation for Statistical Computing) [25] using the *data.table* and *survival* packages [26,27], along with custom code for bootstrap-based mediation analyses. Statistical significance was evaluated at a 2-sided α level of .05.

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Ethical Considerations

The ABCD study protocol was approved by the centralized Institutional Review Board (IRB) at the University of California, San Diego (160091), with participating study sites obtaining or relying on appropriate local IRB approval. Parents or legal guardians provided written informed consent, and participating youth provided assent. The present study involved secondary analysis of deidentified ABCD study data obtained through the National Institute of Mental Health Data Archive and was determined to be exempt from review by the University of California, San Diego IRB (815599). All study procedures were conducted in accordance with applicable ethical guidelines and the principles of the Declaration of Helsinki.

Results

Sample Characteristics

Of 8048 participants with available STQ and UPPS data, 771 individuals who reported nicotine use initiation on or before the STQ assessment were excluded to ensure a nicotine-naive baseline cohort. This yielded 7277 eligible participants. After restricting to individuals with complete exposure and mediator data and valid follow-up time, 5965 participants were included in the primary Cox proportional hazards analyses, during which 239 incident nicotine use initiation events were observed (Table 1).

Table . Baseline characteristics of participants who did and did not initiate nicotine use during follow-up. *P* values reflect unadjusted comparisons between groups using *t* tests for continuous variables, chi-square tests for categorical variables, and Wilcoxon rank-sum tests for household income.

Characteristics	No nicotine use onset (n=5726)	Nicotine use onset (n=239)	*P* value
Age at STQ[a] (years), mean (SD)	9.92 (0.62)	10.01 (0.61)	.02
Sex, n (%)			<.001
Male	3073 (53.7)	101 (42.3)	—[b]
Female	2653 (46.3)	138 (57.7)	—
Race, n/N (%)			.12
Asian	138/5712 (2.4)	2/239 (0.8)	—
Black	934/5712 (16.4)	33/239 (13.8)	—
Multiracial	612/5712 (10.7)	23/239 (9.6)	—
White	3735/5712 (65.4)	162/239 (67.8)	—
Other	293/5712 (5.1)	19/239 (7.9)	—
Ethnicity, n/N (%)			.13
Not Hispanic or Latino	4648/5647 (82.3)	186/237 (78.5)	—
Hispanic or Latino	999/5647 (17.7)	51/237 (21.5)	—
Household income category score, median (IQR)	8.0 (6.0-9.0)	8.0 (6.0-9.0)	.77
Weekend texting screen time (hours), mean (SD)	1.53 (2.67)	2.20 (2.97)	<.001
UPPS[c] negative urgency (possible range 4-16), mean (SD)	8.36 (2.43)	9.41 (2.45)	<.001
Follow-up time (days), median (IQR)	314.7 (238.8-367.8)	193.5 (102.9-279.3)	<.001

[a]STQ: Screen Time Questionnaire.

[b]Not applicable.

[c]UPPS: Urgency, Premeditation, Perseverance, and Sensation Seeking.

In the primary analytic sample, participants had a median follow-up of 311 (IQR 232-366) days, with a maximum follow-up of 1407 days. A total of 28.7% (2827/9858) of participants had no follow-up Substance Use Interview assessment after the STQ, and 10.9% (1074/9858) had near-immediate follow-up (≤30 days). Follow-up duration was weakly inversely associated with weekend texting screen time (r=−0.044), indicating minimal differential follow-up by exposure (Table 2).

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Table . Summary of follow-up time and observation density after Screen Time Questionnaire (STQ) baseline. Follow-up is defined relative to the baseline STQ assessment using Substance Use Interview (SUI) visit data. Post-STQ visits reflect the number of follow-up assessments per participant.

Characteristics	Values
Participants with baseline STQ, n	9858
No SUI follow-up after STQ, n/N (%)	2827/9858 (28.7)
Number of SUI visits after the STQ, n/N (%)	
0	2827/9858 (28.7)
1	5519/9858 (56.0)
2	1469/9858 (14.9)
≥3	43/9858 (0.4)
Follow-up time (days; after the STQ)	
Median (IQR)	307 (216 - 364)
Mean (SD)	275 (143)
Maximum	1407
Near-immediate follow-up (≤30 days), n/N (%)	1074/9858 (10.9)
Correlation: exposure and follow-up, *r*	−0.044
Slope (days per 1 hour of screen time)	−2.23

Weekend texting screen time and UPPS negative urgency scores were approximately normally distributed after cleaning. The negative urgency score had a mean of 8.36 (SD 2.43).

Association Between Weekend Texting Screen Time and Negative Urgency

In linear regression models, greater weekend texting screen time was significantly associated with higher negative urgency scores (β=0.079; *P*<.001; Tables 3 and 4). Each additional hour of weekend texting screen time was associated with a modest but statistically robust increase in negative urgency, although the overall variance explained was small (R^2=0.008).

Table . Cox proportional hazards models estimating hazard ratios (HRs) for incident nicotine use[a].

Predictor	Model 1 HR (95% CI)	*P* value	Model 2 HR (95% CI)	*P* value
Weekend texting screen time (exposure)	1.07 (1.04 - 1.11)	<.001	1.06 (1.02 - 1.09)	<.001
Negative urgency (mediator)	—[b]	—	1.19 (1.13 - 1.25)	<.001

[a]Model 1 includes weekend texting screen time only; model 2 includes both weekend texting screen time and UPPS negative urgency. HRs represent the change in risk per 1-hour increase in weekend texting screen time and per 1-unit increase in negative urgency score.

[b]The predictor was not included in the model.

Table . Standardized effects per 1-SD increase in exposure and mediator variables, including standardized estimates from models before and after adjustment for negative urgency; the exploratory product-of-coefficients estimate is also shown.

Predictor	Standardized HR[a] (95% CI)
Weekend texting screen time (primary model)	1.21 (1.10 - 1.31)
Weekend texting screen time (adjusted for negative urgency)	1.17 (1.06 - 1.28)
Negative urgency	1.49 (1.29 - 1.73)
Exploratory product-of-coefficients estimate	1.04 (1.02 - 1.06)

[a]HR: hazard ratio.

Models were adjusted for demographic covariates (sex, age, race, ethnicity, and household income); full parameter estimates are provided in Table S1 in Multimedia Appendix 1.

Weekend Texting and Nicotine Use Initiation

In Cox proportional hazards models, greater weekend texting screen time was significantly associated with increased risk of incident nicotine use initiation. Each additional hour of weekend texting screen time was associated with a 7% higher hazard of

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initiation, corresponding to an HR of 1.07 with a 95% CI of 1.04 to 1.11. Model discrimination was modest, with a concordance of 0.617. There was no evidence of violation of the proportional hazards assumption.

The magnitude of this association was clinically meaningful when scaled to larger differences in exposure. A 5-hour increase in weekend texting screen time corresponded to approximately a 40% higher hazard of nicotine use initiation. When standardized, a 1-SD increase in weekend texting screen time was associated with a 21% higher hazard of nicotine use initiation (HR=1.21, 95% CI 1.10 - 1.31).

Association After Adjustment for Negative Urgency

When UPPS negative urgency was included in the model, it independently predicted nicotine use initiation, with each 1-point increase associated with a 19% higher hazard. The association between weekend texting screen time and nicotine use initiation was modestly reduced after adjustment for negative urgency (HR=1.06 per hour), although the magnitude of this attenuation was small. The persistence of the texting association after adjustment indicates that negative urgency statistically accounted for only a portion of the observed association. Because negative urgency was not uniformly assessed before nicotine use initiation, this attenuation should not be interpreted as evidence of a causal indirect effect. In standardized models, the adjusted for negative urgency effect of weekend texting screen time remained statistically significant (HR=1.17, 95% CI 1.06 - 1.28), whereas a 1-SD increase in negative urgency was associated with a 49% higher hazard of nicotine use initiation (HR=1.49, 95% CI 1.29 - 1.73).

Exploratory Bootstrap Statistical Decomposition

Exploratory bootstrap analyses yielded a statistically significant product-of-coefficients estimate for the association involving weekend texting, negative urgency, and nicotine use initiation (Table 5). On the log-hazard scale, the product estimate was 0.014 (95% CI 0.008 - 0.022). The standardized product estimate was 0.0365 (95% CI 0.0201 - 0.0561). Because negative urgency did not uniformly precede nicotine initiation in the primary analytic sample, these estimates are presented as statistical decompositions rather than causal indirect effects, and the corresponding proportion should not be interpreted as the proportion of the total effect causally mediated through negative urgency.

Table . Bootstrap mediation results estimating indirect effects of weekend texting screen time on nicotine use initiation through UPPS negative urgency[a].

Effect	Estimate (95% CI)
Indirect effect—log-hazard	0.014 (0.008-0.022)
Indirect effect—standardized log-hazard	0.0365 (0.0201-0.0561)
Standardized indirect HR[b]	1.04 (1.02-1.06)

[a]Effects are presented on both the log-hazard scale and as hazard ratios. Standardized estimates reflect effects per 1 SD increase in exposure. CIs are derived from bootstrap resampling.

[b]HR: hazard ratio.

Sensitivity Analysis Restricting to Temporally Ordered Assessments

Because negative urgency did not uniformly precede nicotine use initiation in the primary analytic sample, we conducted a sensitivity analysis restricted to participants for whom the temporal sequence of baseline STQ assessment, UPPS negative urgency assessment, and nicotine use initiation was preserved. Of the 239 nicotine use initiators in the primary sample, 109 had their selected UPPS assessment before nicotine use onset, whereas 130 had recorded nicotine use onset before the selected UPPS assessment. Exclusion of the latter participants yielded 5835 participants and 109 events; after restriction to complete covariate data, the adjusted sensitivity models included 5345 participants and 96 events.

Weekend texting remained associated with subsequent nicotine use initiation in the temporally ordered sample (HR=1.11, 95% CI 1.06 - 1.16; P<.001). After adjustment for negative urgency, the association remained significant (HR=1.10, 95% CI 1.05 - 1.16; P<.001), and negative urgency was independently associated with nicotine use initiation (HR=1.11, 95% CI 1.02 - 1.21; P=.01). Inclusion of negative urgency attenuated the weekend texting log-hazard coefficient by 6.8%. There was no evidence of violation of the proportional hazards assumption (global P=.83 for both models).

Sensitivity Analysis Using Visit-Based Nicotine Use

Sensitivity analyses using a fallback definition of nicotine use initiation based on the first observed nicotine use at follow-up visits yielded consistent results with slightly larger effect sizes. In these models, both weekend texting screen time and negative urgency remained strongly associated with nicotine use initiation, and model discrimination was higher, reflecting increased event capture in this framework.

Overall, the association between weekend texting and nicotine use initiation was robust across alternative outcome definitions.

Discussion

Principal Findings

In this longitudinal analysis of nicotine-naive early adolescents, greater weekend texting screen time was associated with increased risk of subsequent nicotine use initiation. This association persisted after adjustment for demographic covariates and remained statistically significant after adjustment for negative urgency. Weekend texting was also positively associated with negative urgency, and negative urgency was independently associated with nicotine use initiation. Adjustment for negative urgency produced modest attenuation of the texting-initiation association, suggesting that the two measures

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capture partially overlapping information relevant to early nicotine use risk.

Importantly, negative urgency was not uniformly measured before nicotine use initiation in the primary analytic sample, precluding a strong temporal or causal mediation interpretation. However, in a sensitivity analysis restricted to participants with temporally ordered STQ, UPPS, and nicotine use onset assessments, both weekend texting and negative urgency remained associated with subsequent nicotine use initiation. These findings support the robustness of the observed associations while indicating that negative urgency accounts for only a modest portion of the texting-initiation relationship.

Interpretation of Effect Sizes

Although the per-hour association was modest, larger exposure differences were associated with clinically meaningful increases in nicotine use initiation risk. A 5-hour increase in weekend texting corresponded to an approximately 30% to 40% higher hazard of initiation, with modest attenuation after accounting for negative urgency. Consistent with this, standardized models indicated that a 1-SD increase in weekend texting screen time was associated with a 21% higher hazard of initiation. Given the highly skewed distribution of texting behavior, such increments represent meaningful shifts in exposure and suggest that high-intensity digital engagement may carry substantive risk.

Negative urgency demonstrated a robust association with use initiation. A 1-SD increase in negative urgency corresponded to approximately 50% higher hazard of nicotine use onset, consistent with extensive literature linking urgency-related impulsivity to early substance use and escalation. These findings reinforce the central role of affect-driven impulsive behavior in adolescent nicotine vulnerability.

Comparison With Existing Literature

Prior research has demonstrated associations between overall screen time and adolescent substance use, including smoking and vaping [8,9]. However, much of this literature has relied on cross-sectional designs, aggregated heterogeneous forms of screen behavior, or failed to establish temporal ordering between exposure and initiation [10,17]. By restricting analyses to nicotine-naive adolescents and using prospective time-to-event modeling, the present study strengthens inference regarding temporal sequencing.

Our focus on weekend texting should not be interpreted as evidence that weekend exposure is uniquely associated with nicotine use initiation or that weekday texting and other interactive digital behaviors are unimportant. Rather, weekend texting represents the specific measure of discretionary, socially interactive digital engagement examined in the present study. Future studies directly comparing weekday and weekend texting and other screen modalities will be necessary to determine whether the observed association is specific to weekend messaging or reflects broader patterns of digital social engagement.

Few studies have examined specific interactive forms of screen engagement such as texting and messaging. Text-based communication may differ from passive screen behaviors (eg, television viewing) in that it involves real-time social interaction, emotional salience, and peer reinforcement [15,28]. Consistent with this distinction, prior literature has suggested that screen time requiring interaction with others, such as texting, may be more strongly associated with vaping than more passive forms of screen use, such as watching videos [29]. Such environments may amplify social contagion effects or increase exposure to peer norms related to substance use [30,31].

The observed role of negative urgency aligns with theoretical models emphasizing affect regulation and impulsivity as key drivers of adolescent risk behavior. Youth high in negative urgency may be more likely to engage in maladaptive coping strategies, including substance use, particularly in emotionally charged contexts [11,12,14]. Digital communication environments may heighten emotional reactivity, social comparison, or interpersonal stress, thereby interacting with urgency-related traits [16,28]. Our findings provide empirical support for this conceptual framework.

Negative Urgency and Potential Mechanisms

The attenuation of the texting coefficient after inclusion of negative urgency suggests that negative urgency statistically accounts for a modest portion of the association between weekend texting and nicotine use initiation. This interpretation was supported by the temporally ordered sensitivity analysis, in which both weekend texting and negative urgency remained associated with subsequent nicotine use initiation. However, these findings should not be interpreted as establishing negative urgency as a causal mediator or as indicating that texting episodes directly provoke nicotine use through acute negative affect. Rather, greater digital social engagement and negative urgency may represent correlated behavioral and individual-level characteristics associated with vulnerability to early nicotine use initiation [32,33].

This pattern suggests that additional mechanisms, as well as sources of residual confounding, likely contribute. These may include peer network exposure and social influence processes [30], digital advertising and product marketing [34,35], sensation-seeking tendencies not fully captured through negative urgency [36], and sleep disruption associated with high digital engagement [37]. Future work should examine these pathways directly, potentially incorporating peer network analyses, ecological momentary assessment, or digital trace data.

Generalizability

The large and diverse ABCD cohort provides an important opportunity to examine risk factors for nicotine use initiation beginning in early adolescence. However, participants were approximately 10 years old at the baseline texting assessment, and nicotine use initiation during the observed follow-up therefore represents relatively early onset. The findings should consequently not be generalized to nicotine use initiation across the full adolescent age range, particularly initiation occurring during mid- or late adolescence, when prevalence is substantially higher. Instead, the present results identify behavioral and individual difference correlates of comparatively early nicotine use initiation. Replication across later developmental periods

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will be important. Because assessments used in the present analyses spanned 2019 to 2024, the observed associations reflect the nicotine product and digital media environments during that period; both environments have continued to evolve.

Limitations

Several limitations warrant consideration. First, texting screen time was self-reported and may be subject to recall bias or social desirability effects. Objective digital use metrics would strengthen future studies. Second, although the prospective design improves temporal inference, residual confounding cannot be excluded. Unmeasured variables such as peer substance use, parental monitoring, or mental health symptoms may partially account for observed associations. Additionally, other screen modalities, particularly social media use, may confound this association as adolescents who text heavily on weekends may also have greater exposure to peer modeling or nicotine-related content online.

Third, the timing of the negative urgency assessment varied across participants. For approximately half of the analytic sample, the UPPS assessment took place within 1 day of the STQ assessment, whereas for others, the selected UPPS assessment took place substantially later. Moreover, among some participants who initiated nicotine use, the selected UPPS assessment took place after the recorded nicotine use onset date. This timing precludes interpretation of the primary negative urgency analyses as demonstrating causal mediation. We therefore interpret negative urgency as statistically accounting for part of the observed association rather than as an established causal intermediary. Reassuringly, sensitivity analyses restricted to participants for whom STQ assessment preceded UPPS assessment and UPPS assessment preceded nicotine use initiation yielded consistent associations for both weekend texting and negative urgency. Nevertheless, studies with prospectively scheduled and clearly separated exposure, mediator, and outcome assessments are needed to establish mediation.

Future Directions

Future research should extend this work in several ways. First, incorporating objective digital use data would allow for more precise quantification of exposure patterns and timing. Second, examining additional impulsivity facets and affect regulation constructs may clarify which personality dimensions most strongly link digital engagement to substance use risk. Third, integrating peer network measures could test whether social contagion mediates part of the association. Fourth, longitudinal models that evaluate reciprocal influences among digital engagement, impulsivity development, and substance experimentation would deepen mechanistic understanding.

From a prevention standpoint, these findings suggest that adolescents with high digital engagement and elevated negative urgency may benefit from interventions targeting emotion regulation and coping skills. Digital literacy efforts may also help reduce exposure to substance-related content in online social environments.

Conclusions

In a longitudinal cohort of nicotine-naive early adolescents, greater weekend texting screen time was associated with a higher hazard of subsequent nicotine use initiation. Negative urgency was independently associated with initiation and modestly attenuated the texting-initiation association. These associations persisted in a sensitivity analysis requiring temporal ordering of texting assessment, negative urgency assessment, and nicotine use initiation. Although these findings do not establish negative urgency as a causal mediator, they suggest that digital engagement and affect-driven impulsivity represent partially overlapping correlates of early nicotine use risk. Future longitudinal studies with clearly separated assessment of exposure, potential mediators, and nicotine use onset are needed to clarify the mechanisms underlying these associations.

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Data Availability

This study used data from the Adolescent Brain Cognitive Development study [38], a longitudinal research initiative funded by the National Institutes of Health. The data analyzed in this research are publicly available through the National Institute of Mental Health Data Archive as part of the Adolescent Brain Cognitive Development study.

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Authors' Contributions

Conceptualization: GZ, ADM
Formal analysis: ADM
Funding acquisition: ADM
Methodology: GZ, MLT
Writing – original draft: ADM
Writing – review & editing: GZ, MLT, ADM

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary materials.
[DOCX File, 17 KB - pediatrics_v9i1e100303_app1.docx]

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Abbreviations

ABCD: Adolescent Brain Cognitive Development
HR: hazard ratio
IRB: institutional review board
STQ: Screen Time Questionnaire
UPPS: Urgency, Premeditation, Perseverance, and Sensation Seeking

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Barriers to Reducing Children's Screen Time and Associated Factors Among Mothers of Under-Five Children in Woliso City Administration, Oromia Ethiopia: Community-Based Cross-Sectional Study

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Abstract

Background: Screen time (ST) is the time spent using screen-based devices and has become a global health concern. Excessive ST negatively impacts children's health and development; however, it has been increasing dramatically among young children. Parents are the primary caregivers responsible for monitoring children's ST. Therefore, identifying potential barriers and their attributes is fundamental to taking early action.

Objective: The study aimed to assess barriers to reducing excessive ST and the factors associated with these barriers among mothers of under-five children in Woliso City Administration, Central Ethiopia.

Methods: A community-based cross-sectional study was conducted from January 10, 2024, through February 29, 2024. A systematic random sampling technique was used to select 423 mothers of under-five children. EpiData (version 3.1) was used for data entry, and SPSS (version 20) was used for analysis. Linear regression analysis was used to identify factors associated with barriers to reducing ST. The multiple linear regression assumptions were checked, and statistical significance was declared at $P<.05$ with 95% CIs.

Results: A total of 423 participants were involved in this study (a 100% response rate). The mean score of barriers among mothers was 4.28 (SD 1.04). Educational status of the mother (β=−0.130, 95% CI −0.255 to −0.004), child's ST (β=0.369, 95% CI 0.328-0.409), parental attitude (β=−0.382, 95% CI 0.264-0.499), parental perceptions of the effect of ST on cognitive well-being (β=0.021, 95% CI 0.009-0.034), parental restrictive practices regarding ST (β=−0.011, 95% CI −0.004 to −0.018), and availability of public facilities (β=0.849, 95% CI 0.759-0.940) were shown to have a significant association with parental barriers.

Conclusions: Most mothers of under-five children experienced 4 barriers to reducing ST. The study also identified 6 factors associated with barriers to reducing ST, including level of education, attitudes toward ST, restrictive practices, perceptions of cognitive effects, children's ST, and lack of public facilities. Enhancing access to public spaces, implementing educational programs, and developing community initiatives are recommended to overcome these barriers and support healthy screen habits.

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KEYWORDS

parental barriers; screen time; predictors; children; mothers; associated factors; under-five children; Woliso City, Ethiopia

Introduction

Screen time (ST) refers to a person's time spent using screens or digital devices such as smartphones, tablets, televisions, video games, computers, or wearable technology [1-3]. According to the World Health Organization (WHO), children under the age of 2 years should not have any ST, whereas those aged 2 to 5 years are recommended to limit their ST to a maximum of 1 hour per day. Individuals exceeding these guidelines are classified as having excessive ST [2].

Recently, ST has emerged as a global health concern [4]. The duration of exposure to screen-based devices has been progressively increasing over time [1]. Notably, a substantial proportion of young children are currently exceeding the WHO's recommendations for ST [5]. For instance, in Singapore, children aged 2 years have an average ST of 2.4 (SD 2.2) hours per day [6]. In Canada, the mean ST for children is 1.4 hours per day at age 5 and 1.5 hours per day at age 3 [7], while in Ontario, 13.6% and 43.5% of children exceed 2 hours per day and 1 hour per day, respectively [8]. Furthermore, in the United Kingdom, 75% of children aged 12 months exceed zero ST [9]. In addition,

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excessive ST is observed in Latin America (47%), Brazil (66.05%), and Malaysia (91.4%), where children spend significant amounts of time on screens [10-12]. Specifically, in Australia, children at 6 months of age are exposed to screens for an average of 1 hour and 16 minutes per day, which increases to 2 hours and 28 minutes by 24 months, with some children exceeding 3 hours per day [13]. Moreover, in Japan, 29.4% of children aged 18 months and 24.5% of children aged 30 months watch television for 4 or more hours per day [14]. In Portugal, about 85% of children under 2 years and 80% of infants aged 6 to 12 months are exposed to screens daily, with 79% spending up to 1 hour per day [15]. Similarly, a recent study in Ethiopia reported that 75.9% of under-five children had excessive ST, underscoring that this global concern is also highly prevalent in local Ethiopian settings [16].

Excessive ST causes various problems in children. It compromises both physical and cognitive development in young children and is positively associated with obesity, sleep problems, depression, and anxiety [17]. It generally leads to delays in all developmental domains, including physical, cognitive, mental, social, and scholastic [18,19]. Physically, it contributes to obesity [3,20,21], a sedentary lifestyle [3], disturbed sleep [22-24], headaches [3], eye strain [3,25], and musculoskeletal pain, such as in the neck, back, and wrists [3]. Mentally, it is linked to communication delays, including expressive speech delay [3,19,26,27], repression or delay in cognitive and motor development [19,27,28], hyperactivity-inattention [3,14], autism spectrum disorder [29], aggressive behavior [3], antisocial behavior [14], a desire for instant gratification [3], and poor concentration [3,7]. Additionally, it leads to fear of missing out, fear of being left out, media addiction, self-harm, anxiety, and depression [3]. Socially, excessive ST causes delays in socioemotional development [19], reduced socialization, and increased social anxiety [3]. Scholastically, it is associated with decreased academic performance [3]. These adverse effects underscore the necessity for parents to limit their children's ST to recommended levels [1-3,23].

Parents play a crucial role in shaping their child's screen usage, as they are their child's first teachers [4,30,31]. They have significant control over their child's health behaviors during the younger years [32], and children tend to adopt habits established in early childhood throughout their lives [22]. Parents should act as role models for healthy screen use, limit their own media use, and model online etiquette. Attentive parenting requires face time away from screens [3,23]. While both parents influence children's screen use, this study focused exclusively on mothers because they are the primary caregivers in most Ethiopian households, particularly during the early years of child development. Mothers typically spend more time with under-five children than fathers. Therefore, examining maternal perspectives provides the most relevant insights into parental barriers to reducing ST in this context.

Parents face multifaceted challenges in monitoring their children's ST. Common barriers include societal pressure to use screens, children's enjoyment of ST, busy family schedules, poor weather limiting outdoor play, and the perceived need for ST for educational purposes [33]. Additionally, parents often face a lack of time, parental fatigue [34], and safety issues [35]. A Reddit content analysis during the COVID-19 pandemic highlighted various barriers, including competing work and in-home obligations, using screens to occupy children during travel, children's screen use with other caregivers, offering ST while parents needed rest, pandemic-related changes in routine, and using screens to encourage necessary behaviors [36]. A study from Selangor, Malaysia, reported an overall mean score of 3.51 (SD 0.83) for parental barriers [37].

Despite rapid urbanization and increasing access to digital devices, there has been limited information about the concept of ST and parental barriers in supervising their children's screen use. Yet there are no national guidelines or structured interventions to help parents manage screen exposure in early childhood. Moreover, caregiving practices, including reliance on screen devices to calm a baby or to complete household chores, may complicate efforts to reduce screen use. Socioeconomic disparities and limited access to public facilities further exacerbate barriers to reducing ST.

Identifying and understanding barriers to reducing ST is crucial for developing effective interventions to promote healthy screen usage among children under-five. However, there has been limited information available about parental barriers to reducing children's ST and associated factors. As this was the first study of its type in Ethiopia, it may shed light on the parental obstacles to monitoring their children's ST, and the information obtained from this study may be used as a foundation for future studies in the field.

Accordingly, this study aimed to answer the following research questions:

1. What is the mean level of barriers to reducing children's ST among mothers of under-five children in Woliso City Administration?
2. What factors are associated with barriers to reducing children's ST?

Methods

Study Design and Setting

A community-based cross-sectional study was conducted from January 10, 2024, through February 29, 2024, in Woliso City Administration. The city is in Oromia Regional State, about 114 km southwest of Addis Ababa, the capital city of Ethiopia. Ethiopia is rapidly shifting from an agrarian lifestyle to urbanization [38]. The country is also undergoing a digital revolution as a result of the national initiative "Digital Ethiopia," which is playing a crucial role in access to digital devices and increased usage [39]. As a result, about 85.4 million and 28.6 million people are actively using mobile phones and the internet, respectively [40]. In particular, about 94.8% of parents in Woliso City had screen devices, of which 99.4% were mobile phones [16].

Regarding ST and the physical environment, about 54.5% of Ethiopian children and adolescents adhere to the sedentary recreational ST guidelines, whereas only 43% of children and adolescents have access to physical activity settings [41,42]. In

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Woliso City, only 26.7% of parents reported having available playgrounds, and about 56.8% of children had outdoor playtime of more than 1 hour [16].

Generally, the study setting (Woliso City) has 4 administrative kebeles (lower administrative units)—namely Ayetu, Egersa, Burka Gudina, and Hora—with an estimated 15,476 households. As of 2014, the estimated total population of the city was 118,000, including 19,389 children under the age of 5 years.

Study Participants and Eligibility Criteria

All mothers of under-five children living in the Woliso City Administration were the source population. All mothers of under-five children who were permanent residents of the city and willing to participate were included in the study. However, mothers who did not have a screen device or whose children were blind were excluded from the study.

Sample Size Determination and Sampling Method

The sample size needed for this study was determined using the single-population proportion formula, considering a 95% CI level, a 5% margin of error, and a 50% proportion of occurrence. After adding a 10% nonresponse rate, a sample size of 423 was obtained and allocated proportionally across kebeles. A systematic random sampling technique was used, targeting every 36th household. The first household was selected by lottery method. In each selected household, mothers or guardians of under-five children were approached and invited to participate. Data collectors explained the study objectives, obtained informed consent, and administered the questionnaire to eligible respondents.

Data Collection Instruments and Techniques

Four data collectors and 1 supervisor conducted the data collection using a validated, structured, and pretested interviewer-administered questionnaire adapted from a previous study [37], after translating it into the local languages (Afan Oromo and Amharic). The questionnaire contained sociodemographic information, child-related factors, parental factors, parental barriers to reducing ST, home environment–related questions, and neighborhood environment–related questions.

Sociodemographic factors include information related to family size, age of the mother, age of the father, marital status, educational status of both parents, occupation of both parents, religion, ethnicity, number of rooms in the house, and monthly income.

Regarding child-related factors, the questionnaire included age, sex, number of children, ST in minutes, and childcare facility. A child's average daily ST, reported by parents, was calculated by multiplying weekday ST by 5 and weekend ST by 2, then dividing the sum by 7 [6].

For parent-related factors, the questionnaire assessed both parents' average daily ST. Parental self-efficacy in reducing their child's ST was evaluated using a single question rated on a 5-point scale, ranging from "not at all confident" to "very confident." Then the scores were divided into 3 categories based on percentiles [8,37]. Parents' attitudes toward ST were evaluated by an 8-item questionnaire on a 5-point Likert scale, ranging from 1 ("strongly disagree") to 5 ("strongly agree"), where scores above 32 indicated a positive attitude [8,10,37]. Additionally, parental perceptions were assessed using 11 questions that examined the effects of ST on their child's physical, cognitive, and social well-being [43]. They rated the influence as 1 ("negative impact"), 2 ("no impact"), or 3 ("positive impact"), with higher scores indicating a more positive effect on their child's specific well-being [37]. Parenting style was assessed using an adapted version of the Steinberg instrument, a widely used tool for measuring parenting style [44]. Two dimensions were measured: involvement (9 items) and strictness (6 items) on a 5-point scale from 1 ("strongly disagree") to 5 ("strongly agree"). Based on the Baumrind classification, parents were categorized into 4 groups according to the median split of involvement and strictness [45]. Furthermore, parental restrictive practices on ST were assessed by 6 sedentary-related restrictive practice questions on a 5-point Likert scale, in which higher scores reflected more restrictive practices [46].

Home environment–related factors include information on the number of screen devices, the presence of screen devices in the child's eating, playing, or sleeping rooms, and the presence of outdoor playthings. The neighborhood environment–related factors include questions about the availability of public facilities or a garden, perceived safety from crime, and perceived pedestrian safety.

Lastly, the outcome variable of this study, parental barriers to reducing a child's excessive ST, was assessed using 6 items adapted from validated instruments [8,37]. Each item was rated on a 5-point Likert scale ranging from 1 ("strongly disagree") to 5 ("strongly agree"). Item scores were averaged to produce a continuous barrier score ranging from 1 to 6, with higher values indicating stronger perceived barriers [8,37]. Internal consistency was confirmed with Cronbach α of 0.82, demonstrating good reliability.

Data Quality Control

The data quality was meticulously ensured from the collection to the analysis stages. The standardized questionnaire was translated into Afan Oromo and Amharic, and then back into English. The researchers and the supervisor conducted regular checks for inconsistencies or missing data, and the data were coded and cleaned before analysis. Moreover, comprehensive training was provided to data collectors and supervisors on data collection tools, procedures, ethics, study aims, and participants' rights.

Data Processing and Analysis

EpiData (version 3.1; EpiData Association) was used for data entry and SPSS (version 20.0; IBM Corp) was used for analysis. All normality assumptions were tested and met for the continuous variables. Descriptive statistics were presented as frequency tables and in-text narratives. Dummy tables were created for all categorical variables, and bivariate linear regression analysis was conducted. All independent variables with $P<.25$ in the bivariate analysis were entered into the multiple linear regression model. Key assumptions were

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assessed and met: linearity was checked using scatterplots, homoscedasticity by examining residual plots, normality of residuals with histograms and the Shapiro-Wilk test, and multicollinearity using variance inflation factors (all <2). Statistical significance was set at $P<.05$, and unstandardized β coefficients with 95% CIs were reported.

Ethical Considerations

The study was conducted in accordance with the Declaration of Helsinki. Accordingly, an ethical approval letter (reference number: IRB/23117/2023) was first obtained from the Arba Minch University Institutional Research Ethics Review Board Office. Then, a letter of support was submitted to the Woliso Town Administration to facilitate cooperation during data collection. After explicitly explaining the study's aim, benefits, and risks, written informed consent was obtained from each participant. To maintain the confidentiality of participants' information, personal identifiers, including names and house numbers, were anonymized.

Results

Sociodemographic Characteristics of Participants

A total of 423 parents took part in this study, resulting in a 100% response rate. The majority of participants were married (n=412, 97.4%), and three-quarters had a moderate (4-6) number of total family members (n=321, 75.9%). The mean ages of mothers and fathers were 31.29 (SD 5.511) and 37.32 (SD 5.939) years, respectively. Approximately half of the mothers (n=223, 52.7%) and the majority of fathers (n=343, 81.1%) completed college or higher education. In terms of employment, 188 (44.4%) mothers were unemployed, while most fathers, 415 (98.1%), were employed. Most participants were identified as Oromo, totaling 374 (88.4%) and 236 (55.8%) of participants reported following the Protestant religion. Around one-third (n=144, 34.0%) of participants earned less than 11,000 Ethiopian Birr (ETB 1=US $0.02 as of February 29, 2024), and one-quarter of participants lived in homes with 2 or fewer rooms (Table 1).

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Table . Distribution of sociodemographic characteristics of under-five children parents in Woliso City Administration, Oromia, Ethiopia, 2024 (N=423).

Variables and category	Value, n (%)
Total family members	
≤3	24 (5.7)
4 - 6	321 (75.9)
≥7	78 (18.4)
Mother's age (y)	
<30	159 (37.6)
≥30	264 (62.4)
Father's age (y)	
<30	44 (10.4)
≥30	379 (89.6)
Marital status	
Married	412 (97.4)
Separated	11 (2.6)
Mother's education status	
No formal education	3 (0.7)
Primary education	42 (9.9)
Secondary education	155 (36.6)
College and above	223 (52.7)
Father's education status	
No formal education	3 (0.7)
Primary education	32 (7.6)
Secondary education	45 (10.6)
College and above	343 (81.8)
Mother's occupation	
Private sector	5 (1.2)
Public sector	155 (36.6)
Self-employed	75 (17.8)
Unemployed/housewife	188 (44.4)
Father's occupation	
Private sector	19 (4.5)
Public sector	266 (62.9)
Self-employed	130 (30.7)
Unemployed	8 (1.9)
Religion	
Protestant	236 (55.8)
Orthodox	150 (35.5)
Muslim	37 (8.7)
Ethnicity	
Oromo	374 (88.4)
Amhara	19 (4.5)
Gurage	30 (7.1)
Number of rooms	

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Variables and category	Value, n (%)
≤2	106 (25.1)
3 - 5	254 (60.0)
≥6	63 (14.9)
Monthly income (ETB[a,b])	
≤11,000	144 (34.0)
11,001 - 20,000	182 (43.1)
≥20,001	97 (22.9)

[a]ETB: Ethiopian Birr.

[b]ETB 1=US $0.02 as of February 29, 2024.

Child-Related Factors

In this study, the mean age of under-five children was 29.1 (SD 14.818) months. More than half of the children were male (n=233, 55.1%), and approximately one-fifth were an only child (n=97, 22.9%). Nearly half, 223 (52.7%), of the children received home care from their parents (Table 2). Additionally, the mean ST of under-five children in this study was 2.268 (SD 1.425) hours per day.

Table . Distribution of child-related characteristics among under-five children in Woliso City Administration, Oromia, Ethiopia, 2024 (N=423).

Variables and category	Value, n (%)
Age (mo)	
<24	156 (36.9)
≥24	267 (63.1)
Sex	
Male	233 (55.1)
Female	190 (44.9)
Number of children	
1	97 (22.9)
≥2	326 (77.1)
Childcare facility	
Home care by parents	223 (52.7)
Home care by other than parents	94 (22.2)
Childcare center	106 (25.1)

Parental-Related Factors

The mean ST of mothers and fathers was 2.39 (SD 1.27) and 3.16 (SD 1.72) hours per day, respectively. In this study, approximately 190 (44.9%) of mothers had low self-efficacy to say no to their child's ST. In addition, about one-third (n=129, 30.5%) of participants held a positive attitude toward their child's ST. Regarding parenting style, approximately 165 (39.0%) participants were identified as neglectful (Table 3). The mean scores for parental perceptions of the effects of ST on children's physical, cognitive, and social well-being were 6.95 (SD 2.31), 8.09 (SD 2.65), and 5.73 (SD 1.92), respectively. Moreover, the mean score of parental restrictive practice concerning ST was 19.74 (SD 6.45).

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Table . Distribution of parental-related factors among parents of under-five children in Woliso City Administration, Oromia, Ethiopia, 2024 (N=423).

Variables and category	Value, n (%)
Mother's ST[a] (h)	
≤2	220 (52.0)
>2	203 (48.0)
Father's ST (h)	
≤2	147 (34.8)
>2	276 (65.2)
Parental SE[b]	
Low	190 (44.9)
Moderate	56 (13.2)
High	177 (41.8)
Parental attitude	
Positive	129 (30.5)
Negative	294 (69.5)
Parenting style	
Authoritative	150 (35.5)
Authoritarian	83 (19.6)
Indulgent	25 (5.9)
Neglectful	165 (39.0)

[a]ST: screen time.

[b]SE: self-efficacy.

Home Environment–Related and Neighborhood Environment–Related Factors

A significant majority of participants (n=401, 94.8%) had at least 3 screen devices in their homes, and approximately 197 (46.6%) parents placed a TV in the room where their child plays, eats, or sleeps. Additionally, 345 (81.6%) parents provided outdoor play equipment for their children, while only 122 (28.8%) parents reported the availability of public facilities, gardens, or playgrounds in their neighborhood (Table 4). Moreover, the mean scores for perceived safety concerning crime and pedestrian issues were 17.50 (SD 6.76) and 17.37 (SD 4.94), respectively.

Table . Distribution of home environment–related and neighborhood environment–related factors among mothers of under-five children in Woliso City Administration, Oromia, Ethiopia, 2024 (N=423).

Variables and category	Value, n (%)
Number of screen gadgets	
<3	22 (5.2)
≥3	401 (94.8)
Presence of screen device in child's playing, eating, or sleeping room	
Yes	197 (46.6)
No	226 (53.4)
Do you provide outdoor plaything?	
Yes	345 (81.6)
No	76 (18.4)
Availability of public facilities	
Yes	122 (28.8)
No	301 (71.2)

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Barrier to Reducing Children's ST

The overall mean score of barriers toward reducing their child's ST was 4.28 (SD 1.04), with the most common challenges including the need for time to complete household chores, poor weather conditions, and the fact that their child enjoys screen-based activities (Table 5).

Table . Distribution of barriers to reducing children's screen time among mothers of under-five children in Woliso City Administration, Oromia, Ethiopia, 2024 (N=423).

Barrier statement	Strongly disagree, n (%)	Disagree, n (%)	Somewhat agree, n (%)	Agree, n (%)	Strongly agree, n (%)	Mean (SD)
There is pressure from society to purchase and use media-related equipment.	112 (26.5)	27 (6.4)	128 (30.3)	40 (9.5)	116 (27.4)	3.05 (1.52)
My neighborhood is not safe for my child to play outdoors.	101 (23.9)	32 (7.6)	97 (22.9)	41 (9.7)	152 (35.9)	3.26 (1.58)
Poor weather limits my child's opportunities to go outside.	35 (8.3)	25 (5.9)	129 (30.5)	54 (12.8)	180 (42.6)	3.75 (1.28)
I need a coping tool to meet demands of a busy day at work or raising multiple children.	76 (18.0)	27 (6.4)	73 (17.3)	46 (10.9)	201 (47.5)	3.64 (1.54)
I need time to do household chores.	62 (14.7)	20 (4.7)	45 (10.6)	47 (11.1)	249 (58.9)	3.95 (1.48)
My child really enjoys screen time activities.	47 (11.1)	31 (7.3)	93 (22.0)	55 (13.0)	197 (46.6)	3.77 (1.38)

Bivariate Analysis of Barriers to Reducing a Child's ST

The bivariate linear relationships between barrier to reducing ST and all independent variables, including sociodemographic, child-related, parental, home environment, and neighborhood environment factors, were illustrated in Table 6.

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Table . Bivariate linear regression analysis of factors associated with barriers to reducing children's screen time among mothers of under-five children in Woliso City Administration, Oromia, Ethiopia, 2024 (N=423).

Variables	β (95% CI)	SE	*P* value
Number of family members	−0.019 (−0.099 to 0.061)	0.041	.64
Mother's age (y)	−0.015 (−0.033 to 0.003)	0.009	.11
Father's age (y)	−0.017 (−0.033 to 0)	0.009	.05
Marital status (reference: married)			
Separated	1.184 (0.565 to 1.802)	0.315	<.001
Religion (reference: Protestant)			
Orthodox	−0.167 (−0.381 to 0.046)	0.109	.12
Muslim	0.264 (−0.098 to 0.626)	0.184	.15
Ethnicity (reference: Oromo)			
Amhara	0.179 (−0.305 to 0.663)	0.246	.47
Gurage	0.170 (−0.220 to 0.561)	0.199	.39
Mother's educational status (reference: secondary school)			
No formal education	−0.188 (−1.379 to 1.004)	0.606	.76
Primary school	−0.416 (−0.772 to −0.060)	0.181	.02
College and above	−0.243 (−0.457 to 0.030)	0.109	.03
Mother's occupation (reference: private sector)			
Public sector	0.165 (−0.764 to 1.095)	0.473	.73
Self-employed	0.339 (−0.606 to 1.284)	0.481	.48
Unemployed	0.456 (−0.471 to 1.383)	0.472	.33
Father's educational status (reference: secondary school)			
No formal education	−0.089 (−1.317 to 1.139)	0.625	.89
Primary school	−0.220 (−0.696 to 0.256)	0.242	.36
College and above	−0.014 (−0.312 to 0.341)	0.166	.93
Father's occupation (reference: private sector)			
Public sector	0.280 (−0.208 to 0.768)	0.248	.26
Self-employed	0.151 (−0.354 to 0.655)	0.257	.56
Unemployed	−0.138 (−1.004 to 0.728)	0.441	.75
Number of rooms in the house	0.006 (−0.057 to 0.068)	0.032	.86
Monthly income (ETB[ab,c]; reference: ≤11,000)			
11,001-20,000	−0.091 (−0.320 to 0.138)	0.117	.44
≥20,001	−0.199 (−0.469 to 0.071)	0.137	.15
Child's age (mo)	0.004 (−0.003 to 0.010)	0.003	.28
Child's sex (reference: male)			
Female	−0.124 (−0.325 to 0.077)	0.102	.22
Number of children	−0.041 (−0.119 to 0.036)	0.039	.29
Childcare setting (reference: home care by parents)			
Home care by others	−0.199 (−0.451 to 0.054)	0.129	.12
Childcare center	−0.021 (−0.264 to 0.221)	0.123	.86
Child's ST[c]	0.650 (0.618 to 0.683)	0.017	<.001
Mother's ST	0.097 (0.019 to 0.174)	0.040	.02
Father's ST	−0.050 (−0.107 to 0.008)	0.029	.09

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Variables	β (95% CI)	SE	*P* value
Self-efficacy to say no for ST (reference: high)			
Moderate	0.361 (0.050 to 0.671)	0.158	.02
Low	0.381 (0.169 to 0.593)	0.108	<.001
Parental attitude (reference: negative)			
Positive	0.451 (0.232 to 0.670)	0.111	<.001
Perception on the influence of ST on child's physical well-being	0.041 (−0.020 to 0.084)	0.022	.06
Perception on the influence of ST on child's cognitive well-being	0.046 (0.009 to 0.084)	0.019	.02
Perception on the influence of ST on child's social well-being	0.029 (−0.023 to 0.081)	0.027	.27
Parenting style (reference: authoritative)			
Authoritarian	−0.035 (−0.315 to 0.246)	0.143	.81
Indulgent	0.344 (−0.099 to 0.787)	0.226	.13
Neglectful	0.158 (−0.073 to 0.390)	0.118	.18
Parental restrictive practices on ST	0.087 (0.074 to 0.101)	0.007	<.001
Number of screen devices at home (reference: <3)			
≥3	0.174 (−0.276 to 0.624)	0.229	.45
Screen device in child's bedroom (reference: yes)			
No	−0.325 (−0.523 to −0.127)	0.101	.001
Outdoor play equipment (reference: yes)			
No	1.523 (1.256 to 1.791)	0.136	<.001
Availability of public facilities (reference: yes)			
No	1.739 (1.594 to 1.884)	0.074	<.001
Perceived safety related to crime	0.035 (0.021 to 0.049)	0.007	<.001
Perceived safety related to pedestrian	0.032 (0.012 to 0.052)	0.010	.002

[a]ETB: Ethiopian Birr.

[b]ETB 1=US $0.02 as of February 29, 2024.

[c]ST: screen time.

In the bivariate analysis, educational status of mothers and the availability of screen devices in the child's bedroom were identified as having a negative association with parental barriers to reducing ST. Accordingly, mothers of under-five children who had primary education (β=−0.416, 95% CI −0.772 to −0.060; *P*=.02), mothers of under-five children with college education or above (β=−0.243, 95% CI −0.457 to −0.030; *P*=.03), and not having screen devices in the bedroom (β=−0.325, 95% CI −0.523 to −0.127; *P*=.001) were associated with fewer barriers.

On the other hand, factors found to be positively associated with parental barriers to reducing ST included marital separation (β=1.184, 95% CI 0.565 to 1.802; *P*<.001), child's ST (β=0.650, 95% CI 0.618-0.683; *P*=.02), mother's ST (β=0.097, 95% CI 0.019-0.174; *P*=.02), moderate maternal self-efficacy to say no to ST (β=0.361, 95% CI 0.050-0.671; *P*=.02), low maternal self-efficacy to say no to ST (β=0.381, 95% CI 0.169-0.593; *P*<.001), positive maternal attitude (β=0.451, 95% CI 0.232-0.670; *P*<.001), perception of the influence of ST on the child's cognitive well-being (β=0.046, 95% CI 0.009-0.084; *P*=.02), restrictive practices regarding ST (β=0.087, 95% CI 0.074-0.101; *P*<.001), providing outdoor playthings (β=1.523, 95% CI 1.256-1.791; *P*<.001), presence of public facilities such as gardens and playgrounds (β=1.739, 95% CI 1.594-1.884; *P*<.001), perceived crime safety (β=0.035, 95% CI 0.021-0.049; *P*<.001), and perceived pedestrian safety (β=0.032, 95% CI 0.012-0.052; *P*=.002).

Factors Associated With Barriers to Reducing a Child's ST

In the simple linear regression analysis, 22 variables with a *P*<.25 were identified and included in the multiple linear regression models. All assumptions for multiple linear regression were met, and the explanatory variables in the final models explained about 89.4% of the variation in barriers to reducing ST (R^2=0.894 and adjusted R^2=0.892). The multiple linear regression analysis revealed that educational status of the

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mother, the child's ST, attitude, perceptions of the effect of ST on cognitive well-being, restrictive practices regarding ST, and the availability of public facilities were significantly associated with barriers to reducing their under-five children's ST.

In this study, mothers of under-five children with only a primary school education faced fewer barriers compared to those with a secondary school education (adjusted β=−0.130, 95% CI −0.255 to −0.004; *P*=.04). Additionally, participants with a positive attitude toward child ST were more likely to encounter higher barriers in reducing ST than those with a negative attitude (adjusted β=0.382, 95% CI 0.264-0.499; *P*<.001). For each unit increase in perceptions of the effect of ST on a child's cognitive well-being, the mean score of barriers was increased by 0.021 (adjusted β=0.021, 95% CI 0.009-0.034; *P*=.001). Moreover, for a 1-unit increase in restrictive practices regarding ST, the mean score of barriers decreased by 0.011 (adjusted β=−0.011, 95% CI −0.004 to −0.018; *P*=.001). The only child-related factor that was significantly associated with parental barriers was the child's ST. Accordingly, parents whose children spent more hours on screens faced greater barriers to reducing ST (adjusted β=0.369, 95% CI 0.328-0.409; *P*<.001). Lastly, parents who indicated a lack of public facilities, gardens, or playgrounds in their area were more likely to experience higher barriers to reducing ST than their counterparts (adjusted β=0.849, 95% CI 0.759-0.940; *P*<.001) (Table 7).

Table . Factors associated with barriers to reducing children's screen time among mothers of under-five children in Woliso City Administration, Oromia, Ethiopia, 2024 (N=423).

Variables	Adjusted β (95% CI)	SE	*P* value
Mother's educational status (reference: secondary school)			
Primary school	−0.130 (−0.255 to −0.004)	0.064	.04
Parental attitude toward ST[a] (reference: negative)			
Positive	0.382 (0.264 to 0.499)	0.060	<.001
Parental perceptions of influence of ST on child's cognitive well-being	0.021 (0.009 to 0.034)	0.006	.001
Parental restrictive practice on ST	−0.011 (−0.004 to −0.018)	0.003	.001
Child's ST	0.369 (0.328 to 0.409)	0.021	<.001
Availability of public facilities, garden, and playthings (reference: yes)			
No	0.849 (0.759 to 0.940)	0.046	<.001

[a]ST: screen time.

Discussion

Principal Findings

This study assessed barriers to reducing ST and its associated factors among mothers of under-five children in the Woliso City Administration. Accordingly, the study found that the mean barrier score was 4.28 (SD 1.04). Factors significantly associated with barriers to reducing ST included mother's educational status, child's ST, attitudes, perceptions of the effect of ST on cognitive well-being, restrictive practices regarding ST, and the availability of public facilities.

In this study, the mean score for barriers was found to be 4.28 (SD 1.04), which is notably higher than the mean score 3.51 (SD 0.83) reported in a previous Malaysian study [37]. The variation in scores could be attributed to differences in study populations, as this study focused solely on mothers, while the Malaysian study included both parents [37]. Research indicates that mothers often bear a larger share of managing children's routines and ST [47], and a recent systematic review also confirms that maternal caregiving roles remain central in moderating child ST [48]. Additionally, the difference in study settings may account for this variation. The nature of community-based studies, which reach a diverse population, often allows them to capture a broader range of everyday challenges and barriers experienced by parents. Socioeconomic status [37], cultural norms, and parenting practices [49] also likely contribute to these differences.

According to this study, mothers of under-five children with only a primary school education faced fewer parental barriers to reducing their children's ST compared with those with a secondary school education. This finding may be because mothers with higher education levels may have greater access to resources, support systems, and outdoor employment status, which can influence their ability to manage their children's ST effectively. This finding is congruent with research indicating that higher educational attainment often correlates with increased awareness of the potential negative impacts of ST, leading to more restrictive practices and fewer perceived barriers [50].

Additionally, mothers with a positive attitude toward ST were more likely to encounter higher barriers in reducing ST. This finding is supported by a study from Australia [49] and Malaysia [37]. Research indicates that parents' positive attitudes toward ST can lead to more permissive practices and a lower perceived need to restrict ST, thereby increasing the barriers they face in attempting to reduce it [49]. Conversely, parents with negative attitudes are more likely to implement stricter controls and face fewer barriers. Recent reviews also highlight similar findings, noting that parental attitudes and self-efficacy strongly influence barriers to ST reduction [49].

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Furthermore, our study reported that there was a positive association between parental perceptions of the effects of ST on their child's cognitive well-being and barriers. This finding is supported by research indicating that parents who perceive ST as having a positive impact on cognitive development may face greater barriers [49]. When parents perceived ST to be beneficial to their child or themselves, it became a barrier for them to place necessary restrictions on ST activity [50,51]. This aligns with updated evidence showing that parental confusion and mixed perceptions about ST benefits remain a major barrier [48].

Apart from that, parental restrictive practices regarding ST were negatively associated with barriers to reducing ST. Parents who monitor and employ greater restrictions on ST may face fewer challenges in managing their child's ST due to the consistent enforcement of ST rules [49,52]. This finding is congruent with recent intervention studies that report that restrictive practices are effective strategies for reducing barriers [53].

Furthermore, our study reported that mothers whose children spent more time on screens faced greater barriers to reducing ST. This was supported by previous studies [8,37,54]. Increased ST can lead to more ingrained habits and screen addiction [3], making it extremely hard for parents to enforce restrictions, which can increase parental barriers [55].

Finally, our study reported that parents who indicated a lack of public facilities, gardens, or playgrounds in their area faced greater barriers to reducing ST. The absence of accessible outdoor spaces limits children's opportunity for physical activity, making it more challenging for parents to encourage alternatives to ST, thereby increasing barriers to reducing ST [56]. The UNESCO MGIEP (United Nations Educational, Scientific, and Cultural Organization—Mahatma Gandhi Institute of Education for Peace and Sustainable Development) highlighted that equitable access to green spaces is crucial for promoting healthy behaviors and reducing ST among children [57]. Additionally, community programs aimed at reducing ST were less successful in neighborhoods with limited green spaces, as children had fewer options for outdoor play [56].

These findings should be understood within Ethiopia's social environment, where childcare facilities such as kindergartens and nursery schools are limited, and playgrounds and safe outdoor spaces are scarce. Such contextual realities restrict opportunities for alternative activities and create barriers to reducing screen use. The broader social environment, including limited facilities and cultural caregiving practices, remains crucial for interpreting and designing locally tailored interventions.

Strengths and Limitations of the Study

To the best of our knowledge, this is a pioneering study in Ethiopia that identified barriers to reducing ST. Thus, it can be used as a baseline for future studies. Its community-based design ensured that diverse real-life challenges were captured. Comprehensive data collection through a validated questionnaire and a multilingual approach (Afan Oromo and Amharic) facilitated accurate responses. However, several limitations should be noted. First, the cross-sectional design limits causal inference. Second, reliance on self-reported ST may introduce recall bias, as parents may not accurately remember or estimate their child's daily screen use. Third, social desirability bias may have influenced responses, with some parents underreporting ST or overstating restrictive practices to align with perceived norms. The reliance on maternal reports of their partner's ST is also a limitation. Fourth, although we adjusted for multiple covariates, residual confounding cannot be ruled out, as unmeasured factors (eg, parental mental health) may also influence barriers. These limitations should be considered when interpreting the findings, and future longitudinal studies using objective measures of ST are recommended.

Implications for Practice

The findings from this study underscore the need for targeted interventions to reduce ST among young children. Health care providers, educators, and policymakers should prioritize enhancing access to public facilities, gardens, and playgrounds as alternatives to ST. Additionally, implementing educational programs for parents can raise awareness of the negative impacts of excessive ST and provide strategies for effective management. Community-based initiatives that create screen-free zones and organize family-friendly events can foster environments that support healthy screen habits. Health care professionals should integrate ST management guidelines into routine pediatric care, offering parents consistent support and personalized recommendations. Providing parents with practical tools and resources for monitoring and restricting ST can help to overcome identified barriers and promote healthier screen habits among children.

For the scientific community, this study highlights the importance of further research on the barriers and predictors of parental efforts to reduce ST in various cultural and socioeconomic settings. It encourages the development and testing of community-based initiatives and interventions that create supportive environments for reducing children's ST. Additionally, it advocates for policies that enhance access to public facilities, gardens, and playgrounds to promote healthy child development. By addressing a significant research gap, this pioneering study in Ethiopia provides valuable insights and potential solutions for both clinical practice and the scientific community, ultimately contributing to the global effort to manage and reduce children's ST.

Conclusions

Most mothers with a child aged younger than 5 years experienced 4 barriers in their efforts to reduce ST. In addition, this study identified several associated factors with barriers to reducing ST, including maternal education, parental attitudes, restrictive practices, perceptions of ST's cognitive effects, the child's ST, and lack of public facilities such as gardens and playgrounds. Based on these findings, we recommend that relevant bodies enhance access to public facilities and playgrounds to provide alternatives to screen use, implement educational programs for parents to raise awareness about the negative impacts of excessive ST, and develop community-based initiatives that support screen-free activities. Interventions should also address parental attitudes and misconceptions, promote balanced and evidence-based perspectives, and support

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consistent restrictive practices such as monitoring and removing screens from children's bedrooms. Furthermore, community-based initiatives that encourage screen-free activities can complement household efforts, and integrating ST management guidelines into routine pediatric care will ensure that parents receive culturally appropriate support. Together, these measures can reduce barriers and foster healthier screen habits among young children.

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Data Availability

The data used in this study are available from the corresponding author upon reasonable request.

Authors' Contributions

AD contributed to conceptualization, methodology, analysis, and preparing the manuscript. WG contributed to supervision, methodology, analysis, and editing the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

ETB: Ethiopian Birr
ST: screen time
UNESCO MGIEP: United Nations Educational, Scientific, and Cultural Organization—Mahatma Gandhi Institute of Education for Peace and Sustainable Development
WHO: World Health Organization

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Relationship Among Internet Use, eHealth Literacy, Internet Addiction, and Physical Activity Among Adolescents: Cross-Sectional Study

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Abstract

Background: The internet is highly convenient and has become an indispensable part of daily life. However, its widespread use also has notable disadvantages, such as the risk of internet addiction. Still, increased internet use may enhance eHealth literacy, and online health information seeking may contribute to health promotion. In Hong Kong, internet addiction and low physical activity among adolescents are growing concerns, underscoring the need to address internet use to better support the health and well-being of youth.

Objective: This study aimed to investigate the effects of internet use, eHealth literacy, and internet addiction on adolescents' physical activity in Hong Kong.

Methods: An online cross-sectional study was conducted in Hong Kong between June 2023 and August 2023. Secondary school students aged 12 to 18 years were recruited. Data were collected using the eHealth Literacy Scale, the International Physical Activity Questionnaire, the Chen Internet Addiction Scale, and a questionnaire assessing demographic characteristics and the use of eHealth technologies. Spearman ρ correlation and mediation analyses were performed to examine the relationships among variables.

Results: A total of 117 participants were included. Participants reported an average internet use of 5.28 (SD 3.50) hours per day, and the mean eHealth literacy score was 31.15 (SD 4.04). Correlation analyses revealed that internet use was positively correlated with internet addiction (r=0.33; P<.001) but negatively correlated with physical activity (r=−0.21; P=.02), and internet addiction was negatively correlated with physical activity (r=−0.26; P=.005). In addition, the mediation analysis demonstrated that both internet use and eHealth literacy had a direct effect on internet addiction (B=1.53, P<.001 and B=−0.91, P=.002, respectively). Internet addiction had a direct effect on physical activity (B=−43.94, P=.02). In contrast, eHealth literacy had no significant direct effect on physical activity and did not mediate the relationship between internet use and physical activity.

Conclusions: The findings highlight the importance of eHealth literacy in reducing internet addiction. However, future research should further examine factors that mediate the relationship between eHealth literacy and physical activity or other health-related behaviors. This study sheds light on the benefits of promoting eHealth literacy among adolescents to prevent internet addiction and offers practical insights for teachers and parents.

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KEYWORDS

eHealth literacy; internet use; internet addiction; physical activity; adolescents

Introduction

The internet has transformed modern life and has become an integral part of our daily activities by providing widespread access to information and connectivity [1]. However, these benefits are accompanied by potential drawbacks, including the risk of addiction. Internet addiction is a growing global concern, and a substantial body of research suggests that excessive internet use can lead to various adverse health outcomes, including distress and impairment in daily functioning [2].

In Hong Kong, the prevalence of internet addiction among adolescents ranged from 17% to 26.8% over the 6-year longitudinal study from the 2009 to 2010 to 2015 to 2016 school years [3]. A review by Chung et al [4] found an increasing prevalence, consistent with the upward trend in internet use

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among adolescents over the past decade. Moreover, internet-related behaviors, including excessive smartphone use, have intensified since the COVID-19 pandemic disrupted daily routines [5]. Adolescents who spend more time using the internet have an increased risk of adverse outcomes, such as decreased physical activity and poor physical development [2]. Overall, these findings highlight the importance of addressing internet and smartphone use among adolescents to support their health and well-being.

The potential impact of internet addiction on physical activity and cardiovascular health has elicited concern [6-9]. Problematic internet use has been associated with physical inactivity among high school students [10,11]. Physical inactivity and sedentary behavior can lead to adverse health problems, such as obesity and cardiovascular disease [12]. For instance, children who engage in sedentary behaviors, such as screen viewing, were found to be approximately 5.68 times more likely to become overweight [13]. Furthermore, adolescents with low physical activity levels were reported to be 7.69 times more likely to have high blood pressure [14]. These findings indicate the need to identify potential protective factors that might reduce internet addiction and promote physical activity.

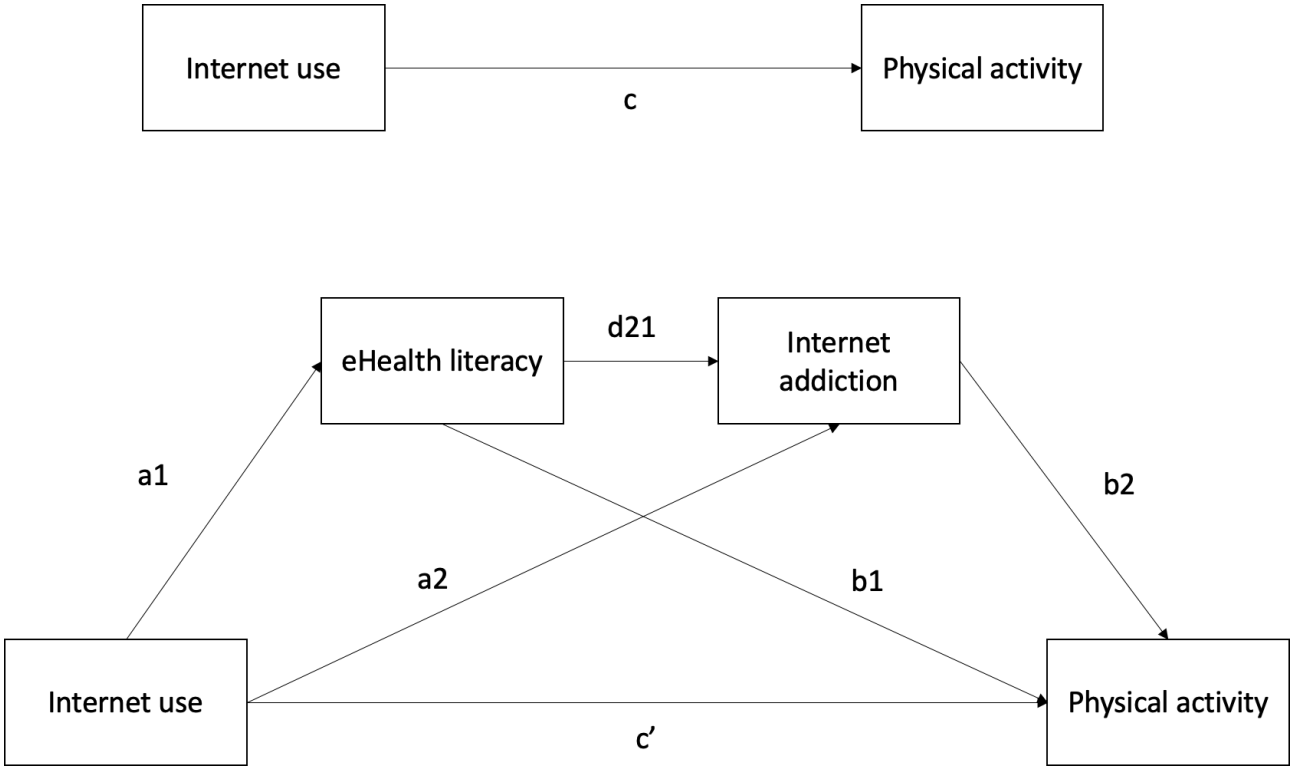
Longer time spent using the internet may facilitate health information seeking online [15]. eHealth literacy is defined as the ability to seek, find, understand, and appraise health information from electronic sources and to apply the knowledge gained to address or solve health problems [16]. This concept has become increasingly important because the internet has become a major source of health information, and digital health interventions have become more common [17]. Studies have reported that eHealth literacy is a significant predictor of health-promoting behaviors, including physical activity, nutritional behaviors, life appreciation, social support, stress management, and health responsibility, among adolescents [18,19]. These findings highlight the benefits of promoting eHealth literacy among young individuals. Evidence suggests that a poor health status and unhealthy lifestyle during adolescence are associated with poor health in adulthood [20,21]. Thus, eHealth literacy appears to be a protective factor worthy of further investigation. Furthermore, a study reported a negative association between health literacy and internet addiction [22]. To further explain the potential relationships among internet use, eHealth literacy, internet addiction, and physical activity, social cognitive theory provides a useful theoretical framework [23]. This theory emphasizes the dynamic interactions among personal, environmental, and behavioral factors [23]. Within this framework, internet use may function as an environmental factor by providing access to public information and shaping attitudes and norms related to physical activity. Personal factors may be represented by eHealth literacy, which can influence personal beliefs and foster self-efficacy related to adopting physical activity, and by internet addiction, which may reflect low self-efficacy in regulating online behavior and serve as a maladaptive coping strategy that undermines physical activity. Physical activity, in turn, is the behavioral outcome.

Internet addiction and low physical activity levels among adolescents in Hong Kong have become growing concerns [3,24,25]. For instance, the Student Health Service Annual Health Report for the 2023 to 2024 school year reported that 96.1% of secondary school students did not meet the recommended physical activity levels [26]. Furthermore, the proportion of secondary school students engaging in recreational screen time for 2 or more hours per day increased from 78% in the 2022 to 2023 school year to 80.9% in the 2023 to 2024 school year [26]. Enhancing eHealth literacy can help address internet addiction and insufficient physical activity among adolescents. However, although studies on eHealth literacy have been conducted in Hong Kong, they have mainly focused on adults [27,28]. Thus, little is known about eHealth literacy among Hong Kong adolescents. Furthermore, to the best of our knowledge, no study has examined the relationships among eHealth literacy, internet addiction, and physical activity in this population. This gap in the literature warrants further investigation. Evidence indicates that eHealth can positively affect health behaviors, and this potential should be specifically examined in relation to internet addiction and physical activity.

This study investigated the effects of internet use, eHealth literacy, and internet addiction on physical activity levels among adolescents in Hong Kong. In addition, this study examined the mediating role of eHealth literacy in mitigating the negative effects of internet use and internet addiction on physical activity (Figure 1). Specifically, we hypothesized that (1) internet use is positively associated with eHealth literacy, (2) eHealth literacy is negatively associated with internet addiction, (3) eHealth literacy is positively associated with physical activity, and (4) eHealth literacy and internet addiction mediate the relationship between internet use and physical activity.

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Figure 1. The proposed mediation model for internet use, eHealth literacy, internet addiction, and physical activity.



Methods

Participants

A total of 7 secondary school students who participated in a research internship program at The Hong Kong Polytechnic University assisted with participant recruitment for this study after receiving approval from their respective schools. As the participating secondary schools did not have their own ethics review bodies, ethics approval for the study was obtained from the study institution. Participants were recruited through convenience sampling from the secondary schools attended by the student interns. After the study details were explained to students and their parents, students were invited to complete a set of questionnaires administered through Google Forms. Upon selecting "agree" on the Google Form, participants were directed to the questionnaire section. To minimize duplicate responses, participants were instructed to complete the questionnaire only once using their Google account. Data were collected between June 2023 and August 2023, which coincided with the summer school holiday period in Hong Kong. As students generally have more free time to use digital devices during the holiday, this period was selected for data collection.

The eligibility criteria for participation were as follows: (1) an age of 12 to 18 years, (2) status as a full-time secondary school student in Hong Kong, (3) ability to understand traditional Chinese, and (4) ability to use electronic devices to access the online survey. Individuals who self-reported neurological illnesses (eg, stroke and autism), functional disabilities (eg, blindness), or any form of psychosis or intellectual disability that could hinder completion of the online survey were excluded from participation.

A total of 123 responses were received. Of these, 5 respondents did not provide informed consent, and one did not meet the inclusion criteria. Therefore, 117 responses were included in the analysis. For sample size estimation, a confidence level of 95% was applied, with the margin of error set at 10% because of the relatively short data collection period and the estimated proportion was set to 0.5. On the basis of these parameters, the estimated required sample size was 96.

Outcome Measures

Demographic Information and eHealth Technology Use

Demographic information was collected, including participants' age, sex, grade, height, and weight. Furthermore, a set of questions was used to evaluate participants' use of technology and health-related applications, including (1) the amount of time spent on the internet per day and (2) whether technologies were used for health monitoring. The measured domains and the validity and localization testing of the instruments used are summarized in Table 1.

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Table . Summary of instruments used in the test: domains measured and reference on validity testing or translation.

Instruments	Domains measured	Validity test and translation studies
eHealth Literacy Scale	Consumer's integrative knowledge, comfort, and perceived skills at searching, and evaluation and application of electronic information to address health-related problems	Koo et al [29]
International Physical Activity Questionnaire	Monitor activity habits over the previous 7 days, with focus on leisure, domestic, work, and transport	Macfarlane et al [30]
Chen Internet Addiction Scale	Compulsive use, withdrawal, tolerance, problems in interpersonal relationships, as well as health and time management	Chen et al [31]

eHealth Literacy Scale

The eHealth Literacy Scale (eHEALS) is a questionnaire designed to evaluate individuals' eHealth literacy. It includes items that measure self-perceived competence and confidence in finding, evaluating, and applying health information obtained from electronic sources [16]. This scale comprises 8 items, which are rated on a 5-point Likert scale. This study used the Chinese version of the eHEALS (C-eHEALS) [29]. Koo et al [29] examined the psychometric properties of the C-eHEALS. Additionally, the C-eHEALS was used in a study of adolescents in Hong Kong and demonstrated excellent internal consistency (Cronbach α=0.95) [32]. In this study, the C-eHEALS similarly exhibited high internal consistency (Cronbach α=0.92).

International Physical Activity Questionnaire

The Chinese version of the International Physical Activity Questionnaire (IPAQ)–Short Form (IPAQ-C) was used in this study [30]. This self-reported questionnaire assesses the amount of physical activity individuals engaged in during the past week [30]. An example item is as follows: "During the last seven days, on how many days did you participate in vigorous physical activities?" [30]. Responses are converted into metabolic equivalent of task (MET) values based on the duration and intensity of physical activity (MET=3.3 for walking, 4 for moderate physical activity, and 8 for vigorous physical activity) [30]. For example, if an individual walks for 60 minutes per day over 7 days, their MET score is calculated by multiplying 3.3 by 60 minutes and 7 days, yielding a total of 1386 METs. A higher MET score indicates a higher level of physical activity. The IPAQ-C demonstrated satisfactory psychometric properties and was validated among adolescents in Hong Kong [30].

Chen Internet Addiction Scale

The Chen Internet Addiction Scale (CIAS) is a self-reported instrument consisting of 26 items designed to assess various symptoms and problems related to internet use [31]. The scale covers 4 main dimensions: compulsive use, withdrawal, tolerance, and problems related to interpersonal relationships, health, and time management. The total CIAS score ranges from 26 to 104. Established cutoff points for screening (57/58) and diagnosis (63/64) are available to classify the severity of internet addiction. In addition, the total score can be used to assess the tendency toward internet addiction, with higher scores indicating greater severity [33]. In this study, only the total CIAS score was used for analysis. The Cronbach α for the CIAS was 0.95 in a previous study conducted in Hong Kong [34] and 0.95 in this study.

Data Analysis

Data are presented as mean (SD), unless otherwise indicated. After examining the distributional assumption, the normality assumption was found to be violated. Therefore, Spearman ρ correlation was used to examine the relationships between internet addiction, physical activity, eHealth literacy, and internet use among adolescents. A mediation model was then used to examine the role of eHealth literacy as a mediator in the relationships between internet use, internet addiction, and physical activity. The mediation analysis was conducted using model 6 of Hayes PROCESS macro in SPSS (IBM Corp). Specifically, internet use served as the independent variable, physical activity level (ie, the MET score derived from the IPAQ) served as the dependent variable, and eHealth literacy and internet addiction were specified as mediators of the relationship between internet use and physical activity (Figure 1). In addition, age, sex, and BMI were included as control variables. Bootstrapping with 5000 resamples was performed [35]. The 95% CI was defined by the lower limit CI and upper limit CI. Mediation effects were considered statistically significant if the CI did not include zero. All statistical analyses were conducted using SPSS (version 29.0.2), and a *P* value of<.05 was considered statistically significant.

Ethical Considerations

Ethics approval was obtained from the Institutional Review Board of The Hong Kong Polytechnic University (HSEARS20230701001). Before participation, parents were asked to provide electronic informed consent, and both students and their parents had to indicate agreement to participate. No compensation was provided to participants. All data collected were anonymized and stored in a password-encrypted database.

Results

A total of 117 participants completed the survey. Of these, 61.5% (72/117) were girls. The mean age of the participants was 15.9 (SD 1.29) years. The majority (n=50, 42.7%) of the participants were secondary school year 5 students. On average, the participants reported spending 5.28 (SD 3.50) hours per day using the internet, and the mean eHealth literacy score was 31.15 (SD 4.04). Table 2 presents the characteristics and scores of the participants.

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Table . Participant characteristics and scores of questionnaires (N=117).

	Values
Sex, n (%)	
Female	72 (61.5)
Male	45 (38.5)
Age (y), mean (SD)	15.9 (1.29)
BMI (kg/m^2), mean (SD)	20.2 (3.05)
Form, n (%)	
1	7 (6)
2	2 (1.7)
3	11 (9.4)
4	35 (29.9)
5	50 (42.7)
6	11 (9.4)
Missing	1 (0.9)
Internet use per day (h), mean (SD)	5.28 (3.50)
Use technology to monitor health, n (%)	
Yes	36 (30.8)
No	81 (69.2)
Physical activity, mean (SD)	2667.65 (2657.73)
Internet addiction (possible range 26 - 104), mean (SD)	63.00 (13.83)
eHealth literacy (possible range 8 - 40), mean (SD)	31.15 (4.04)

Correlations between internet use, internet addiction, eHealth literacy, and physical activity are presented in Table 3. Internet use was significantly and positively correlated with internet addiction (r=0.33; P<.001) and negatively correlated with physical activity (r=−0.22; P=.02). eHealth literacy was negatively correlated with internet addiction (r=−0.26; P=.005) but was not correlated with internet use or physical activity. Internet addiction was negatively correlated with physical activity (r=−0.25; P=.006).

Table . Spearman ρ correlation between internet use, internet addiction, eHealth literacy, and physical activity.

	1	2	3	4
Internet use	—[a]	—	—	—
Internet addiction	0.33[b]	—	—	—
eHealth literacy	0.06	−0.12	—	—
Physical activity	−0.21[c]	−0.26[d]	−0.05	—

[a]Not applicable.
[b]P<.001.
[c]P<.05.
[d]P<.01.

The results of the mediation analysis are presented in Table 4 and Figure 2. Internet use had a direct effect on internet addiction (B=1.53; P<.001). eHealth literacy also had a direct effect on internet addiction (B=−0.91; P=.002). Internet addiction had a direct effect on physical activity (B=−43.94; P=.02). The findings revealed neither a direct effect of internet use on physical activity or eHealth literacy nor a direct effect of eHealth literacy on physical activity. Only one significant indirect effect was observed: internet use was indirectly associated with physical activity through internet addiction (B=−67.19, 95% CI −148.17 to −9.45).

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Table . Mediation analysis of the relationship between internet use on physical activity via eHealth literacy and internet addiction[a].

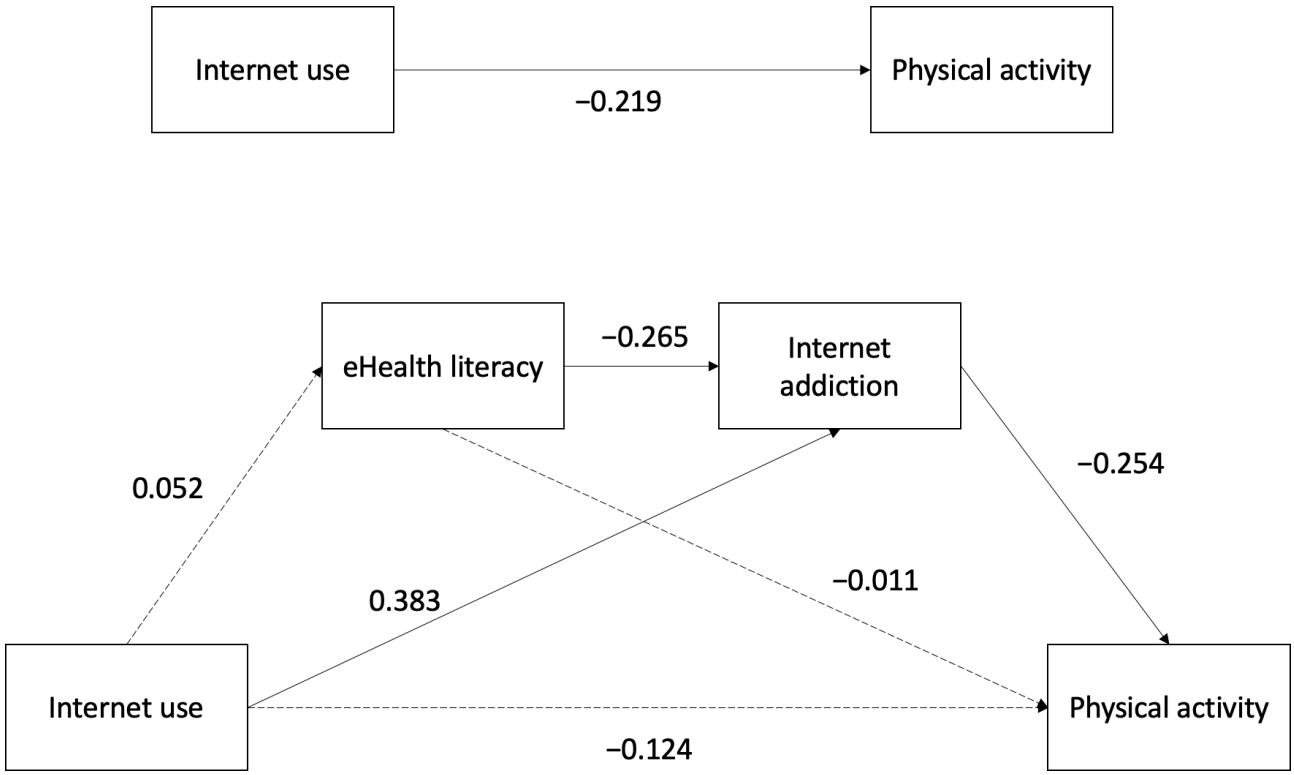
	Unstandardized coefficients, *B* (SE)	*t* test (*df*)	*P* value	95% CI
Direct effect				
Internet use on physical activity	−85.81 (70.27)	−1.22 (105)	.23	−225.14 to 53.52
Internet use on eHealth literacy	0.052 (0.11)	0.46 (107)	.65	−0.17 to 0.27
Internet use on internet addiction	1.53 (0.35)	4.43 (106)	<.001	0.84 to 2.21
eHealth literacy on Internet addiction	−0.91 (0.29)	−3.12 (106)	.002	−1.50 to −0.33
eHealth literacy on physical activity	−6.47 (57.30)	−0.11 (105)	.91	−120.08 to 107.14
Internet addiction on physical activity	−43.94 (18.15)	−2.42 (105)	.02	−79.93 to −7.95
Indirect effect				
Internet use → eHealth literacy → physical activity	−0.3393 (6.74)	—[b]	—	−10.67 to 17.79
Internet use → internet addiction → physical activity	−67.19 (35.96)	—	—	−148.17 to −9.45
Internet use → eHealth literacy → internet addiction → physical activity	2.11 (5.36)	—	—	−10.05 to 13.16
Total effect				
Internet use on physical activity	−151.23 (65.76)	−2.30 (107)	.02	−281.58 to −20.88

[a]The model controlled for age, gender, and BMI. Analysis was based on 112 participants after listwise deletion of cases with missing data.

[b]Not applicable.

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Figure 2. The mediation model's results for internet use, eHealth literacy, internet addiction, and physical activity. All effect coefficients are reported using standardized coefficients. The solid line indicates a significant path; the dotted line indicates an insignificant path.



Discussion

Principal Findings

This study examined the relationships between internet use, eHealth literacy, internet addiction, and physical activity. In particular, we hypothesized that eHealth literacy and internet addiction mediate the relationship between internet use and physical activity. The results indicated that internet addiction was the only significant mediator in this relationship. Although our findings revealed that eHealth literacy was not associated with internet use and physical activity, it had a direct effect in reducing internet addiction.

Our results revealed no significant association between time spent on the internet and eHealth literacy. This finding suggests that spending more time online does not necessarily improve individuals' ability to understand and use health-related information available online. This result contrasts with the findings of some previous studies. For instance, one study reported that more frequent use of information and communication technology was associated with a higher level of eHealth literacy [36]. Various factors may explain this discrepancy, including a lower level of trust in online health information than in information provided by clinicians [37] and the nature of online activities, which may be primarily entertainment oriented rather than health related [38]. In addition, experiences during the COVID-19 pandemic may have contributed to increased health awareness and, consequently, increased eHealth literacy [39]. Thus, the effect of recent internet use on eHealth literacy might be less pronounced than before. Overall, these findings indicate that although internet use is widespread, it does not automatically translate into improved eHealth literacy.

A significant negative relationship was observed between eHealth literacy and internet addiction, which supports one of our hypotheses. This finding indicates that a higher level of eHealth literacy is associated with a lower level of internet addiction. Individuals who are more familiar with searching for and understanding online health information might be more aware of the potential drawbacks of excessive internet use and thus may be better able to avoid behaviors that contribute to addiction [40]. This finding underscores the importance of enhancing eHealth literacy as a potential strategy for mitigating internet addiction and identifies a critical target for future intervention programs.

This study also examined the relationship between eHealth literacy and physical activity and found no significant relationship in either the correlation or the mediation analysis. Although previous studies have reported a positive relationship between eHealth literacy and physical activity [18,40], our results suggest that being literate in eHealth does not necessarily translate into increased engagement in healthy behaviors, such as physical activity. The lack of a significant relationship might be due to various external factors such as personal motivation, social influence, limited resources, academic demands, or other daily life commitments, which may play a more prominent role in affecting adolescents' willingness and opportunities to engage in physical activity [41,42]. Therefore, although eHealth literacy is an important ability in terms of accessing and understanding health information, it does not appear to affect physical activity behaviors directly; it may thus reflect a gap between health-related intentions and actual behavior [43]. Moreover, the perceived need to engage in health-promoting behaviors

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might be another variable contributing to the nonsignificant results [44,45]. For instance, a study on the use of mobile health applications reported that individuals with severe obesity were more likely to use health applications to engage in health behaviors than individuals who were underweight [44]. In addition, a study by Weaver et al [45] examining the types of health information searching (wellness, illness, or mixed information) found that individuals who searched only for wellness-related information reported a better health status and a higher level of physical activity than those in other groups [45]. These findings indicate that although individuals may be confident in their ability to search for and use online health resources, not all individuals are motivated to change their lifestyle in favor of wellness. Some may consider themselves as healthy or may not prioritize health behavior changes at their current life stage. Individuals may possess eHealth literacy but engage with health information only when they perceive a need, such as searching for illness-related information when experiencing symptoms. The nonsignificant relationship between eHealth literacy and physical activity observed in this study might indicate that adolescents with eHealth literacy place less emphasis on promoting their wellness.

This study provides preliminary results regarding the use of health information from electronic sources among adolescents in Hong Kong. The level of eHealth literacy observed in our sample (mean 31.15, SD 4.04) was comparable to that reported in other countries, such as the mean score of 28.4 (SD 7.6) reported by Koo et al [29]. Although no official cutoff score exists for the eHEALS to define adequate eHealth literacy, a recent study on adults in China suggested a cutoff of 29.5 [46]. On the basis of this reference value, only 19.7% (23/117) of adolescents in this study scored below the suggested cutoff value, indicating that 80.3% (94/117) of our participants had adequate eHealth literacy. Furthermore, our results suggest that internet addiction could be reduced by increasing eHealth literacy. In addition to seeking health information online, adolescents also obtain health advice from school [47]. Thus, educators should consider incorporating electronic health information sources into classroom instruction or extracurricular activities. However, eHealth literacy was not associated with physical activity in this study. Future studies should examine the factors mediating the relationship between eHealth literacy and health-promoting behaviors. In particular, further investigation is needed to understand how eHealth literacy can be translated into actual health-related behaviors among adolescents.

This study has several limitations. First, all the measures were self-reported; therefore, the participants' responses may have been influenced by social desirability bias or inaccurate due to recall bias regarding, for example, the time spent on the internet and physical activity. Second, this study included a relatively small sample from a few secondary schools in Hong Kong. Thus, its generalizability is limited. Future studies with larger and more diverse samples are recommended to increase representativeness among Hong Kong adolescents.

Conclusions

This study investigated the relationships among internet use, eHealth literacy, internet addiction, and physical activity. The results provided preliminary evidence regarding the level of eHealth literacy among adolescents in Hong Kong. Furthermore, the results highlight the significant role of eHealth literacy in reducing internet addiction; however, eHealth literacy was not found to be associated with physical activity. Teachers and parents should promote adolescents' eHealth literacy as a strategy to support health and prevent internet addiction.

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Authors' Contributions

XCCF was responsible for study design, data collection, data analysis, and manuscript writing. JSCC was responsible for manuscript writing, editing, and revision. FFW and BWML were involved in manuscript writing and revision. SPCN was involved in study design and manuscript writing and revision. All authors reviewed the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

CIAS : Chen Internet Addiction Scale
eHEALS : eHealth Literacy Scale
IPAQ : International Physical Activity Questionnaire
MET: metabolic equivalent of task

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Original Paper

Screen Exposure and Childhood Adiposity in Socially Vulnerable Settings: Cross-Sectional Study

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Abstract

Background: Screen-based media use among children has been increasing, particularly in lower socioeconomic groups. As this behavior is linked to obesogenic habits, it is crucial to examine the associations between screen-based media use and adiposity in primary schoolchildren, particularly those from socially vulnerable contexts, such as children from the Educational Territories of Priority Intervention program.

Objective: This study aimed to examine the associations between screen-based media use and adiposity in primary schoolchildren from socially vulnerable contexts.

Methods: This study, part of the BeE-school Project, included 735 children (mean age 7.7, SD 1.2 years; n=380, 51.7% boys and n=355, 48.3% girls) from 10 primary schools located in vulnerable contexts in northern Portugal. Researchers recorded weight, height, and waist circumference and calculated BMI *z* scores and the waist-to-height ratio (WHtR). Screen-based media use was reported by parents using the ScreenQ tool, which includes 4 domains (screen access, frequency of use, media content, and caregiver-child coviewing). Sociodemographic and anthropometric data of parents were obtained via a questionnaire. Generalized linear models were applied.

Results: A higher screen-based media use score was associated with higher BMI *z* scores and WHtR (b=0.064, 95% CI 0.034-0.094 and b=0.002, 95% CI 0.001-0.003, respectively) even after adjusting for children's sex and age and parents' education and BMI. Significant associations (P<.05) were also observed for the domains of screen access, frequency of use, and media content.

Conclusions: Screen-based media use is linked to higher BMI and WHtR in vulnerable children. Reducing screen access, limiting use frequency, and curating media content could improve health outcomes. Interventions for obesity prevention should consider these factors.

Trial Registration: ClinicalTrials.gov NCT05395364; https://clinicaltrials.gov/study/NCT05395364

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KEYWORDS

screen-based media use; screen time; children; adiposity; obesity

Introduction

Children are now growing up in a technological society, with the use of electronic devices being an essential part of their lives [1]. This has led to an increase in personal screen media device use among children and adolescents, providing numerous entertainment options, such as watching videos, gaming, using social media, and communicating with family and friends [2]. This use encompasses both active and passive engagement with various devices and content [1,3].

From a very early age, screen-based media use is a reality, with children spending many more hours per day in screen time than the international recommendation of no more than 2 hours per day for children and adolescents aged 5 to 17 years [4,5].

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According to the American Academy of Pediatrics (AAP), for children aged 6 years and older, healthy habits should be encouraged, and screen-based activities should be limited [6]. It is also recommended to turn off all screens during family meals and outings and to turn off and remove screens from bedrooms 30 to 60 minutes before bedtime [6].

In Portugal, the percentage of children aged 6 to 9 years who spend more than 2 hours per day engaging in screen time on weekdays is around 35%, increasing significantly on weekends to approximately 78% [7]. Also, this prevalence tends to decrease in families with higher levels of parental education, in contrast to an increase in families with lower levels of parental education. In the latter group, children spend around 45% of weekdays and 77% of weekend days exceeding 2 hours of screen time per day [7].

On the other hand, the prevalence of overweight and obesity among school-aged children is 25.7% and 12.5%, respectively, with higher rates observed in families with lower levels of education [7]. This highlights the need to understand the associations between screen-based media use and adiposity in socioeconomically vulnerable contexts.

The associations between excessive screen time and behaviors that promote obesity are well-established [1,8]. For example, obesogenic behaviors (including physical inactivity, increased sedentary behavior, poor dietary habits, and disrupted sleep patterns) [5] have been associated with excessive screen time and childhood obesity [4,5,9]. Additionally, excessive screen time can lead to depression, anxiety, and poor school performance in children [4]. Despite this, there remains controversy over studies' findings that balance the benefits and harms of screen-based media use, taking into account the type of media and how it is used [4,10]. In addition, although the association between screen use and adiposity has already been studied [8], this relationship remains unclear in the context of primary schoolchildren from socially vulnerable backgrounds.

In Portugal, a school is considered vulnerable if it belongs to the Educational Territories of Priority Intervention. These schools are located in areas characterized by socioeconomic vulnerability, where poverty and social exclusion are prevalent [11,12].

Previous studies examining the relationship between screen-based media use and adiposity in children have shown mixed results. While some report positive associations [1,5,8], others find weaker or inconsistent links depending on factors such as the type of media used and children's daily contexts [4]. Furthermore, most research focuses on general population samples, leaving limited evidence on how these associations operate among socially vulnerable groups. As a result, important gaps remain in understanding how screen use relates to adiposity in children living in disadvantaged settings.

To address this, the objective of this study was to analyze the associations between screen-based media use and adiposity in primary schoolchildren from socially vulnerable contexts.

Methods

Study Design and Participants

This study is part of the broader BeE-school Project, a trial conducted in primary schools that are part of the Educational Territories of Priority Intervention project, which covers territories characterized by social vulnerabilities. For this cross-sectional study, a total of 735 children from 10 primary schools participated with parental consent. The inclusion criteria required that children be from 10 primary schools located in economically and socially disadvantaged areas marked by poverty and social exclusion. Children with cognitive or physical impairments that could compromise data collection were excluded from the study.

Anthropometrics

Children's weight and height were measured at school by trained researchers using standardized procedures. Measurements were taken with a pediatric scale and stadiometer (SECA 799; SECA GmbH & Co KG), with weight rounded to the nearest 100 g. Height was measured with the head positioned in the Frankfort plane and recorded to the nearest 0.1 cm. Waist circumference was measured directly on the skin, 1 cm above the uppermost lateral border of the right ilium, at the end of normal expiration, and recorded to the nearest 0.1 cm [13]. Children were measured while at school, lightly dressed and without shoes. If there was any doubt about the measurement, the procedure was repeated.

The BMI was calculated as the ratio of body weight to height squared (kg/m^2) and converted into SD scores (BMI *z* score [BMIz]) adjusted for specific age and sex categories using the World Health Organization (WHO) growth reference [14]. The waist-to-height ratio (WHtR) was calculated by dividing waist circumference by height.

Weight status was defined according to WHO cutoff points of BMI and categorized into 3 groups: normal and underweight (SD ≤1), overweight (1< SD ≤2), and obesity (SD >2). Normal and underweight were grouped together due to the low number of underweight cases in our sample.

Parents self-reported their height and weight, from which BMI was calculated. Parental BMI was categorized according to WHO guidelines into 3 categories: normal and underweight (BMI ≤24.9 kg/m^2), overweight (BMI 25-29.9 kg/m^2), and obesity (BMI ≥30 kg/m^2). Due to the small number of underweight parents (8 mothers and 2 fathers), they were grouped with normal weight cases.

BMI and WHtR were used as indirect anthropometric indicators commonly used to estimate general and central adiposity, acknowledging that they do not represent direct measures of body fat.

Sociodemographic Information

Parents' education levels were collected through a questionnaire and categorized into 3 groups: "less than secondary level," "secondary educational level," and "university studies." These variables (mothers' and fathers' education levels) were

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considered as covariates in the fully adjusted model of the analysis.

Screen-Based Media Use

Children's screen-based media use was assessed through the ScreenQ questionnaire, filled out by parents. This 16-item questionnaire included 4 domains derived from aspects of media use cited in AAP recommendations: access to screens, frequency of use, media content, and caregiver-child coviewing [15,16].

The evaluation of screen media access includes questions about screen use during meals, in the bedroom, while waiting, ownership of media devices, and screen use at night during the school period (questions 1 to 5). Frequency of use is assessed not only by the number of screen-time hours per day but also by factors such as the age at which children first had contact with screens, whether they use screens to fall asleep, and whether they frequently use screens to calm down (questions 6 to 9). Media content is evaluated through items that assess exposure to violent content, content pacing, and whether children independently choose what to view (questions 10 to 12). Finally, caregiver-child coviewing considers not only the presence of an adult but also the nature of interaction between the adult and the child during screen use (questions 13 to 15) [16].

The 16 items of ScreenQ are summed for a total score ranging from 0 (perfect adherence with AAP recommendations) to 27 points (extreme nonadherence—a major risk for adverse effects). The score for each dimension was calculated by summing the scores of the corresponding questions.

Internal consistency of the scale for children aged >5 years is 0.64 (Cronbach α), which indicates a good internal consistency [15]. In our sample, Cronbach α was also calculated, and a value of 0.61 was obtained, indicating good internal consistency. The total score and the scores for each domain were analyzed as predictors of adiposity in the statistical analysis.

Statistical Analysis

Descriptive analysis encompassed measures of central tendency and dispersion tailored to each variable type. Quantitative variables were summarized using mean and SD, while categorical variables were described using counts (n) and percentages (%). Proportions of categorical variables were compared using chi-square tests for contingency tables, and a 2-tailed Student *t* test was applied for quantitative variables.

Generalized linear models were used to assess the associations between children's screen-based media use (predictor) and children's adiposity (BMI and WHtR) as dependent variables, with a significance level set at .05.

Three models were used. Model 1 was the unadjusted model, model 2 incorporated children's sex and age as covariates, and model 3 represented the fully adjusted model, including children's sex and age, as well as mothers' and fathers' education levels, and mothers' and fathers' BMI as covariates. Data analysis was conducted using SPSS (version 29.0.1; IBM Corp).

Ethical Considerations

This study was approved by the Ethics Committee for Life and Health Sciences (CEICVS 009/2022) of the University of Minho and registered on the ClinicalTrials database (NCT05395364). The research adhered to the Code of Ethics of the World Medical Association (Declaration of Helsinki). All participants, including parents or caregivers, signed informed consent forms, and children were asked for their assent to participate before any procedures were conducted.

Results

Descriptive data for the participants are presented in Table 1. In a sample of 735 school-aged children, 380 (51.7%) were boys and 355 (48.3%) were girls, with a mean age of 7.7 (SD 1.2) years. Most of the children had normal weight (448/728, 61.5%), 22.7% (165/728) were overweight, and 15.8% (115/728) had obesity. Around half of the mothers (305/552, 55.3%) had normal weight, whereas 37.8% (191/505) of fathers fell into this category. Nearly half of fathers were overweight (237/505, 46.9%).

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Table 1. Descriptive analysis[a].

	All (n=735)	Boys (n=380)	Girls (n=355)	*P* value
Age (years), mean (SD)	7.7 (1.2)	7.7 (1.2)	7.7 (1.2)	.67
BMI *z* score	0.69 (1.30)	0.76 (1.36)	0.62 (1.23)	.15
BMI category, n (%)				.16
Normal and underweight	448 (61.5)	234 (62.2)	214 (60.8)	
Overweight	165 (22.7)	76 (20.2)	89 (25.3)	
Obesity	115 (15.8)	66 (17.6)	49 (13.9)	
Waist-to-height ratio, mean (SD)	0.47 (0.05)	0.47 (0.05)	0.47 (0.05)	.58
ScreenQ total score, mean (SD)	10.27 (4.02)	10.64 (3.94)	9.88 (4.09)	.04
Mothers' education, n (%)				.25
Less than secondary level	105 (17.3)	46 (15)	59 (19.6)	
Secondary educational level	234 (38.6)	117 (38.2)	117 (38.9)	
University studies	268 (44.2)	143 (46.7)	125 (41.5)	
Fathers' education, n (%)				.03
Less than secondary level	168 (29.1)	75 (26.2)	93 (32)	
Secondary educational level	223 (38.6)	104 (36.4)	119 (40.9)	
University studies	186 (32.2)	107 (37.4)	79 (27.1)	
Mothers' BMI category, n (%)				.75
Normal and underweight	305 (55.3)	155 (56.6)	150 (54)	
Overweight	169 (30.6)	83 (30.3)	86 (30.9)	
Obesity	78 (14.1)	36 (13.1)	42 (15.1)	
Fathers' BMI category, n (%)				.62
Normal and underweight	191 (37.8)	95 (37.8)	96 (37.8)	
Overweight	237 (46.9)	114 (45.4)	123 (48.4)	
Obesity	77 (15.2)	42 (16.7)	35 (13.8)	

[a]Percentages were calculated using the available data for each variable; therefore, denominators may vary across categories due to missing data.

Tables 2 and 3 present the associations between children's screen-based media use and adiposity (with BMIz as the surrogate measure of adiposity in Table 2 and WHtR in Table 3). We conducted the analysis using 3 models to explore these associations.

Table 2. Association between children's screen-based media use and their BMI z score[a].

	Model 1[b], B (95% CI)	Model 2[c], B (95% CI)	Model 3[d], B (95% CI)
ScreenQ total score	0.064 (0.034 to 0.094)[e]	0.059 (0.029 to 0.089)[e]	0.053 (0.023 to 0.083)[e]
Access	0.105 (0.048 to 0.163)[e]	0.097 (0.040 to 0.155)[e]	0.064 (0.005 to 0.122)[e]
Frequency	0.098 (0.027 to 0.169)[e]	0.095 (0.024 to 0.166)[e]	0.078 (0.004 to 0.151)[e]
Content	0.140 (0.059 to 0.221)[e]	0.117 (0.032 to 0.203)[e]	0.119 (0.034 to 0.204)[e]
Coviewing	0.002 (–0.081 to 0.085)	–0.007 (–0.090 to 0.076)	0.008 (–0.075 to 0.092)

[a]Values are presented as unstandardized regression coefficients (B) with corresponding 95% CI.

[b]Model 1: unadjusted model.

[c]Model 2: adjusted model for children's sex and age.

[d]Model 3: adjusted model for children's sex and age, mothers' and fathers' education level, and mothers' and fathers' BMI.

[e]*P* value<.05.

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Table 3. Association between children's screen-based media use and waist-to-height ratioa.

	Model 1[b], b (95% CI)	Model 2[c], b (95% CI)	Model 3[d], b (95% CI)
ScreenQ total score	0.002 (0.001 to 0.003)[e]	0.002 (0.001 to 0.003)[e]	0.002 (0.001 to 0.003)[e]
Access	0.004 (0.002 to 0.006)[e]	0.004 (0.002 to 0.006)[e]	0.004 (0.002 to 0.006)[e]
Frequency	0.004 (0.001 to 0.006)[e]	0.004 (0.001 to 0.006)[e]	0.004 (0.001 to 0.006)[e]
Content	0.005 (0.002 to 0.009)[e]	0.005 (0.002 to 0.009)[e]	0.005 (0.002 to 0.009)[e]
Coviewing	–0.0004 (–0.004 to 0.003)	–0.0004 (–0.004 to 0.003)	–0.0004 (–0.004 to 0.003)

[a]Values are presented as unstandardized regression coefficients (B) with corresponding 95% CI.

[b]Model 1: unadjusted model.

[c]Model 2: adjusted model for children's sex and age.

[d]Model 3: adjusted model for children's sex and age, mothers' and fathers' education level, and mothers' and fathers' BMI.

[e]*P* value<.05.

A higher screen-based media use score was significantly associated with higher BMIz (b=0.053, 95% CI 0.023-0.083) and WHtR (b=0.002, 95% CI 0.001-0.003) in the fully adjusted model. Similar associations were observed for the domains of screen access, frequency of use, and media content. Caregiver-child coviewing was not significantly associated with BMIz (b=0.008, 95% CI –0.075 to 0.092) or WHtR (b=–0.0004, 95% CI –0.004 to 0.003).

Discussion

Principal Results

We found that children with higher ScreenQ scores—reflecting screen media use that does not align with AAP recommendations—tended to have higher BMIz and WHtR values. We also found that specific characteristics of screen media use—such as screen access, frequency of use, and media content—were significantly associated with both measures.

Comparison With Prior Work

Our findings indicate that children with nonadherence to AAP recommendations had a higher risk of adverse effects concerning surrogates of obesity. This is in accordance with existing evidence that identifies overweight and obesity as one of the first health consequences of excessive screen time in children [1,4,17,18]. Since 1985, when the first paper about the effects of media use on children's adiposity was published by Dietz and Gortmaker [19], the scientific community has observed the negative consequences of excessive media use by children. Additionally, the frequency of media use has been increasing in recent years, particularly during successive lockdowns when screen use significantly surged in many regions worldwide [20]. The long-term effects of the COVID-19 pandemic lockdowns remain unclear [21], and it is possible they have influenced the frequency of postpandemic screen viewing.

According to Hutton et al [16], screen media use could pose potential neurobiological risks. Furthermore, the AAP has cited language delay, poor sleep, impaired executive function and general cognition, and decreased parent-child engagement as some of the other consequences of screen-based media use by children [16,22].

Screen time is typically associated with sedentary behavior and linked to a higher consumption of energy-dense foods, promoting an energy imbalance [23-25]. Children who increased or consistently maintained high screen time from preschool to school age were more likely to adopt unhealthier dietary patterns, such as frequent snacking or consuming energy-dense foods [26]. Media can act as a trigger or prompt for eating, extend the duration of eating, or distract from feelings of satiety [8]. Another growing concern is the presence of food marketing in digital media, especially targeted at children, which can explain the link between screen-based media use and higher energy consumption [8]. Marketing and the commercial determinants of health have the power to shape children's food preferences, purchasing behaviors, and consumption patterns. Because the most commonly promoted food products to children are sugary breakfast cereals, soft drinks, savory snacks, confectionery, and fast food, accounting for about 60% to 90% of all food marketing [27], it is possible that their consumption might increase. Screen-based media use is also linked to poorer sleep, which can cause changes in appetite-regulating hormones such as ghrelin and leptin, leading to increased hunger and decreased satiety [8].

Concerning screen access, children now have a wide variety of screen media devices available to them, such as smartphones, tablets, laptops, desktops, gaming consoles, and televisions. According to Dy et al [28], the devices that children have the most access to are televisions, followed by smartphones and tablets. With all these access opportunities, screen time during important periods such as mealtimes and bedtimes has emerged, with screen use during meals becoming increasingly common among children and adolescents [29]. This has a significant impact on child health, as screen use during meals has been linked to increased consumption of snacks, including high-calorie and low-nutrient products [29].

The type of content is another important aspect to discuss. Screen media content available to children varies widely, differing in aspects such as target audience, educational value, and language used [30]. These factors have been linked to cognitive and learning outcomes [28,30,31]. Content can also influence diet, particularly through the promotion of unhealthy eating behaviors via junk food marketing [17]. Children are

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exposed to marketing of unhealthy foods and are considered a vulnerable group for this type of digital content [17,30]. However, depending on the content, media use can also have a significantly positive impact on children's health, and interventions that use media to promote the adoption of healthy lifestyles should be considered [1,31].

Despite some studies identifying coviewing screen media as having a positive impact on health outcomes [28], in our study, this dimension did not appear to be significantly associated with adiposity. According to Dy et al [28], children are nearly 9 times more likely to have excessive screen time when watching alone compared to watching with an adult, and excessive screen use has been linked to worse health outcomes, as mentioned earlier. However, our findings regarding this specific domain could be related to the type of coviewing, such as interactive or passive coviewing. Alroqi et al [30], who investigated the influence of the quantity, content, and context of screen media use on the language development of 85 Saudi children aged 1 to 3 years, reported that passive coviewing of television was more common than interactive coviewing, with the latter appearing to have a positive effect on children's development and health. It is noteworthy that despite the nonsignificant result, the association between coviewing and BMIz is positive, and a higher screen use without adult supervision is associated with a higher BMIz.

Apart from health consequences, media use by children was also identified by Priftis and Panagiotakos [4], in a review documenting the health effects of excessive screen viewing on children and adolescents, as potentially having a socioeconomic impact as well. Moreover, lower maternal education levels and lower household income were linked to higher odds of increased screen time [26]. Moreover, some parents seem to believe that screen time increases children's creativity and imagination [28], while others reported having strict rules concerning screen-based media use in their homes [10].

This study was conducted with a specific group of children from primary schools located in socially vulnerable territories. However, not all families had a very low socioeconomic status, which may explain the relatively higher rates of mothers (268/607, 44.2%) and fathers (186/577, 32.2%) with a university education level. Nevertheless, as educational level is considered an important surrogate variable for socioeconomic status [32], we accounted for it as a potential confounder in our analysis.

This study has several strengths that should be emphasized. First, we used trained researchers to collect the anthropometric measures, and we included both BMIz and WHtR as measures of adiposity, thereby enhancing the validity of our findings. To assess adiposity, BMI has been widely used as a surrogate measure; however, WHtR has recently been identified as a potentially better surrogate measure for adiposity. It predicts total and trunk fat mass more accurately and can discriminate lean mass in the pediatric population, unaffected by children's age and sex [33]. Second, we used the ScreenQ as a measure of screen-based media use, an instrument that has already been validated for Portuguese children. ScreenQ evaluates not only the screen time but also other dimensions of screen-based media use: access to screens, frequency of use, media content, and caregiver-child coviewing [15,16], allowing a more comprehensive analysis. Third, the analysis considered potential confounders such as children's characteristics and parents' sociodemographic and weight status. Finally, this study was conducted in a specific context of vulnerability, which has not yet been extensively studied in Portugal.

Limitations

We recognize that this study has some limitations. First, the cross-sectional design did not allow us to identify a causal relationship. Second, the data on ScreenQ, sociodemographic factors, and parents' anthropometrics were self-reported by parents, potentially introducing social desirability bias. To minimize the impact of these limitations on the credibility of the findings, we used validated instruments (such as the ScreenQ) and ensured anonymity in participation to reduce potential response bias. We also interpreted the results cautiously, clearly acknowledging the direction of the associations without implying causality. These measures help safeguard the trustworthiness and robustness of the study's conclusions.

Finally, the use of BMI and WHtR as surrogate indicators of adiposity represents a limitation, as these measures may not fully capture body fat distribution and can be influenced by factors such as muscle mass. Although BMI and WHtR likely capture relevant population-level variation in body shape [34], future studies should consider incorporating objective measures of adiposity to provide more precise assessments.

Conclusions

Screen-based media use was significantly associated with higher BMI and WHtR among primary schoolchildren from socially vulnerable contexts. Future school-based interventions should emphasize the substantial impact of screen use on children's adiposity, particularly in light of their socioeconomic circumstances.

Data Availability

The datasets generated and/or analyzed during this study are available from the corresponding author on reasonable request.

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Authors' Contributions

Conceptualization: AD, JM
Formal analysis: AD, JM

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Funding acquisition: RR
Investigation: AD, JM, MJS, CA, RR
Methodology: AD, JM
Supervision: RR
Writing—original draft preparation: AD
Writing—review and editing: AD, JM, MJS, CA, RR

Conflicts of Interest

None declared.

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Abbreviations

AAP: American Academy of Pediatrics
BMIz: BMI z score
WHO: World Health Organization
WHtR: waist-to-height ratio

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Original Paper

Exposure to e-Cigarette Posts Across Social Media Platforms and Its Associations With Susceptibility and e-Cigarette Use: Comparative Cross-Sectional Study of High Schoolers in Jalisco (Mexico) and Southern California (United States)

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Abstract

Background: Adolescents' exposure to electronic cigarette (e-cigarette) content through social media platforms influences their perceptions and behaviors, although cross-country analyses in different regulatory environments are scarce.

Objective: This study evaluated the association between e-cigarette exposure on social media platforms and e-cigarette susceptibility and use in Jalisco (Mexico) and Southern California (United States).

Methods: In 2022-2023, students from 23 high schools in Jalisco (n=1418) and 11 in Southern California (n=2953) were surveyed with harmonized measures on past-month frequency of social media platform use (ie, YouTube [Google], Instagram [Meta], TikTok [ByteDance], Snapchat [Snap Inc], WhatsApp [Meta], Facebook [Meta], Twitter (now "X"), and Twitch [Twitch Interactive]) and seeing e-cigarette posts on each social media platform used; which were recoded to 5-point scores (range 0-4) for social media platforms use and e-cigarette post exposure. Country-stratified logistic models regressed e-cigarette susceptibility (among noncurrent users) and past-month use on social media platform scores, adjusting for age, sex, family affluence, and friends' e-cigarette use.

Results: Past-month e-cigarette use was higher in Jalisco (248/1418, 17.5%) than Southern California (139/2953, 4.7%; *P*<.001). Social media use and e-cigarette exposure on each social media platform differed across samples (*P* values<.001). In Southern California, more frequent social media use was positively associated with e-cigarette susceptibility (adjusted odds ratio [AOR] 1.83, 95% CI 1.48-2.25), whereas in Jalisco, higher frequency of exposure to e-cigarette content was associated with susceptibility (AOR 1.21, 95% CI 1.02-1.43). Higher frequency of social media use and exposure to e-cigarette content were both positively associated with past-month e-cigarette use in Southern California; in Jalisco, greater exposure to social media platforms and e-cigarette content was associated with past-month use.

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Conclusions: Frequent social media platform use and e-cigarette exposure through social media platforms appear to be associated with e-cigarette susceptibility and use across contexts. Stronger policies to limit and enforce online exposures are needed.

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KEYWORDS

social media use; e-cigarette use; e-cigarette susceptibility survey research; adolescents; vaping

Introduction

Over the last decade, adolescent cigarette use has significantly decreased in many countries around the world that have adopted strong tobacco control policies, including bans on cigarette advertising through traditional media channels [1,2]. In contrast, adolescents' use of electronic cigarettes (e-cigarettes) has increased as countries have been slower to adopt and enforce strong e-cigarette regulations. Moreover, increases in e-cigarette use have coincided with and appear to be partly explained by the growing and widespread use of social media platforms, which is often the primary means of adolescent exposure to e-cigarette marketing [3].

e-Cigarettes were first marketed as a harm reduction product to help adult smokers quit [4], yet they have become increasingly popular among adolescents in both high and middle-income countries with different regulatory frameworks. In the United States, for example, adolescent e-cigarette use rapidly increased in 2017-2018, which prompted policy actions, including federal prohibition of e-cigarette sales to anyone younger than 21 years in December 2019 [5]. Furthermore, in 2020, the US Food and Drug Administration (FDA) banned cartridge-based e-cigarettes with any flavors except tobacco or menthol, and the FDA has also denied marketing requests for most e-cigarette products [6]. Despite enforcement issues and loopholes for some e-cigarette types (eg, disposables), these measures have been accompanied by decreased current e-cigarette use among high schoolers from 20.8% in 2018 to 10% in 2023 [7,8]. However, e-cigarettes remain the most commonly used tobacco product among US adolescents [7]. These trends generally characterize adolescents in California (United States), although the prevalence of e-cigarette use is lower there than in other states [9].

In Mexico, the 2008 General Tobacco Control Law stipulated that no new tobacco products or any products that resemble tobacco products could be introduced or sold in the country [10]. Regulators interpreted this legislation as a de facto ban on e-cigarette marketing and sales, with a 2020 Presidential Decree specifically banning their importation and clarifying that the General Tobacco Control Law banned e-cigarette marketing and sales [11]. However, the national prevalence of past-month e-cigarette use among 15- to 18-year-olds increased from 2% in 2021 to 3.3% in 2022 [12]. Even though the prevalence is relatively low compared with the United States, the increase from 2021 to 2022 represents a 65% growth in use. Furthermore, representative data from urban public schools in large Mexican cities suggest that e-cigarette use is substantially higher than these estimates [13], perhaps due to reduced bias from adolescents' self-administering surveys in schools compared with the national surveys that involve survey administration in households. Importantly, despite Mexico's e-cigarette ban, e-cigarettes are accessible through a variety of venues in both the formal and informal economy due to a lack of enforcement [14,15]. Illegal marketing through social media platforms—which is particularly challenging to enforce—may also contribute to Mexican adolescents' e-cigarette use.

The growth in internet access has been accompanied by increasing use of social media platforms worldwide [16]. In Mexico, 96% of adolescents and young adults reported using social media platforms in 2021 [17], and in 2022, 97% of US adolescents aged between 13 and 17 years reported using them [18]. Furthermore, in 2023, it was estimated that 77% of US high-school students used social media platforms several times a day [19]. Among youth in Canada, England, and the United States, those in the United States reported the greatest increase in noticing e-cigarette marketing from 2017 to 2019, with "websites or social media" being the second most reported channel of marketing exposure [20]. Additionally, a 2021 survey among middle- and high-school students in the United States found that 73.5% of social media users reported having ever seen e-cigarette–related content on social media platforms [21]. To our knowledge, there are no studies in Mexico or other Latin American countries where e-cigarettes are banned that have assessed exposure to e-cigarette content across social media platforms and its associations with susceptibility or use of these products.

e-Cigarette advertisements on social media platforms usually portray the devices and their use as desirable, trendy, and fashionable, which likely appeals to adolescents [22]. Indeed, exposure to e-cigarette advertisements has been associated with more positive perceptions of vaping, lower harm perception, change in perceived acceptability among peers [23], as well as with greater susceptibility to and current use of e-cigarettes among both adolescents and young adults [24,25]. To maximize attention and engagement, many e-cigarette brands use social media *influencers* or celebrities to promote their products [22]. Even though advertisements on social media platforms can be targeted to specific population groups (ie, >18 y), 1 study found that more than 60% of the e-cigarette brands and *influencers* on Instagram [Meta] had no age-gating restrictions for followers, although their posts were intended only for adult users [26]. A key feature of social media concerns its transnational reach across jurisdictional borders, making it possible for adolescents in one country to access content from other countries, even if the content contains marketing that is illegal in their home countries.

This study examined similarities and differences in the use of social media platforms, exposure to e-cigarette posts on social media platforms, and their associations with e-cigarette susceptibility and use among high schoolers from the southern

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part of Jalisco in Mexico and Southern California in the United States. As described above, tobacco regulations and adolescent e-cigarette use prevalence differ between Mexico and the United States, with potential consequences for adolescents' exposure to e-cigarette content via social media platforms. Furthermore, a higher proportion of the Mexican American population live in Southern California [27], which may help reduce differences in the study populations due to cultural background. We expected lower exposure and use among Mexican adolescents due to the national e-cigarette ban. Nevertheless, in both countries, we expected that greater exposure to e-cigarette posts on social media platforms would be positively associated with susceptibility and use, even after adjusting for overall social media platform use. To our knowledge, this is the first study of adolescent exposure to e-cigarette content across specific social media platforms and the association with susceptibility and use across countries.

Methods

Population

Data for Mexico come from the 2022-2023 Mental Health, Addiction, and Violence Survey in the state of Jalisco. A convenience sample of high schools (n=23) in 16 municipalities of the Southern part of Jalisco answered an online, self-administered survey from November 2022 to February 2023. A total of 1557 students were invited to participate, 131 (8.4% approximately) refused, yielding a sample of n=1426. US data come from the Assessing Developmental Patterns of Vaping, Alcohol, Nicotine, and Cannabis Use and Emotional Wellbeing (ADVANCE) cohort [27] in Southern California; participants were recruited as ninth-grade students in either 2020 (class of 2024) or 2021 (class of 2025) from 11 high schools. To harmonize survey timing with Mexico, we analyzed data only from the February to June 2023 survey, when the Southern California students were in 10th or 11th grade. A total of 4206 students were invited to participate, 631 (15% approximately) refused, yielding a sample of 3575. Participants with missing data were dropped from analyses (Jalisco final sample, n=1418, vs Southern California final sample, n=2953).

Ethical Considerations

Before survey administration, both studies obtained students' assent, and ADVANCE also obtained parental consent. For the Mental Health, Addiction, and Violence Survey in the state of Jalisco, active parental consent was not required from the ethics committee; parents were informed about the study and could request that their child be excluded. Protocols were approved by the Institutional Review Board and Ethics Committee of the Ministry of Health of Ciudad Guzmán, Jalisco, Mexico (103/RVI/2021), and for Southern California, by the Institutional Review Board of University of Southern California (HS-19-00682). Participants in ADVANCE received a small token of appreciation (eg, stickers or a pen). Absentee and transfer students were offered a US $10 gift card to complete the survey independently. No incentives were provided for participants in Jalisco. Projects are hosted on secure servers. To protect participants' privacy, data were deidentified before sharing. When data transfer was required, a 2-step secure procedure was used. First, a password-protected link to the REDCap (Research Electronic Data Capture; Vanderbilt University) server was sent to the authorized recipient. The password was then transmitted separately in a second email. The download link was single-use and remained active for a limited time to further enhance security.

Measurements

Social Media Platforms–Related Variables

To assess general social media engagement, students were asked, "How often do you visit the following social media sites?" for each of the following social media platforms—Facebook [Meta], Instagram, WhatsApp [Meta; Jalisco only], Snapchat [Snap Inc; Southern California only], Twitter (now "X" [X Corp] as of July 24, 2023), YouTube [Google], TikTok [ByteDance], and Twitch [Twitch Interactive]. Response options in both surveys were (1) 0="I don't use this social media," (2) 1="once a month or less," (3) 2="weekly," (4) 3="daily," (5) 4="several times a day," and (6) 5="I don't know."

Next, to assess exposure to e-cigarette content on social media, students were asked, "How often do you see posts about e-cigarettes and nicotine vaping products on the following social media sites (same as above)?" In Jalisco responses were "I don't use this social media," "never," "once a month or less," "weekly," "daily," and "several times a day" while in Southern California responses were "never," "monthly or less," "weekly," "daily," "several times a day," and " I don't know". To harmonize responses across samples, first we recoded "I don't use this social media" (Jalisco) and "don't know" (Southern California) along with "never" as 0, indicating no exposure; then we rescaled all remaining responses to a 0-4 scale for comparability (0="I don't use this social media, never, or I don't know," 1="once a month or less," 2="weekly," 3="once a day," and 4="several times a day"). Finally, we calculated 2 continuous scores, that is, social media use score and e-cigarette postexposure score by averaging responses across platforms (range=0-4) to reflect students' average frequency of social media use and exposure to e-cigarette–related content, respectively.

e-Cigarette Use and Susceptibility

Students reported their frequency of using e-cigarettes in the previous 30 days ("In the last 30 days, how many total days have you used any electronic cigarette with nicotine?"). Responses were recoded into a dichotomous variable (0="No use in the past 30 days" [noncurrent users], and 1="any use in the past 30 days"). Susceptibility to use e-cigarettes was assessed with the question "Do you think that at some point during the next 12 months, you will use an e-cigarette?" with responses recoded as a dichotomous variable based on previous research on susceptibility among youth [28] (0="definitely not, 1="probably not," "probably yes," or "definitely yes").

Covariates

Sociodemographic variables included age (12 y, 13 y, 14 y, 15 y, 16 y, 17 y, 18 y, 19 y or older), sex (female and male), and household wealth, using the Family Affluence Scale (FAS). The FAS includes the following questions, (1) how many cars

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or trucks does your family own (0, 1, 2 or more); (2) do you have a room for yourself? (0 or 1); (3) during the last 12 months, how many times did you go on vacation with your family? (0, 1, 2, 3 or more); (4) how many computers does your family have? (0, 1, 2, 3 or more). The FAS has shown reliability and validity as a measure of socioeconomic status [29], in both the United States [30] and Mexico [31]. As is standard practice, the FAS items were summed (range=0-9), with higher scores indicating higher family affluence. Use of e-cigarettes by friends was also assessed (Jalisco: "Of your five best friends, how many use electronic cigarettes?" and Southern California: "How many of your five (5) closest friends use electronic cigarettes for vaping nicotine?") with responses dichotomized to indicate having any friends who use (0=none, and 1=1-5).

Analyses

For descriptive analyses, datasets were combined to allow comparison of sample characteristics using Pearson chi-square tests for categorical variables and independent sample *t* tests for the continuous variables. We used Pearson chi-square tests to assess if there were any differences in the frequency of social media platform use and frequency of exposure to e-cigarette content through social media platforms across countries. Then, for each country, we conducted crude and adjusted logistic regression models with Standard Errors (SEs) clustered by school to account for intragroup correlation among students within schools were estimated for each of two outcomes, (1) susceptibility to use e-cigarettes (analytic sample=noncurrent users [n=1170 for Jalisco, and n=2695 for Southern California]) and (2) current e-cigarette use (analytic sample=entire sample [n=1418 for Jalisco, and n=2953 for Southern California]). Independent variables included the index of frequency of exposure to e-cigarette posts on social media, as well as the frequency of social media use index and other covariates. Due to potential different effects per social media platform [28], sensitivity analyses were conducted by analyzing one social media platform at a time, adjusted by the frequency of social media use (Multimedia Appendix 1). To further assess the robustness of findings to alternative methods for handling within-school correlation, additional sensitivity analyses were conducted using multilevel logistic regression models with school specified as a random effect. Results from multilevel models were consistent in direction, magnitude, and statistical significance with those from the clustered SE approach; therefore, clustered models were retained as the primary analyses (Multimedia Appendix 2). Finally, pooled analyses across countries were conducted using adjusted models for susceptibility and use that included an interaction between country and exposure to e-cigarette content via social media. These pooled models were treated as supplementary to country-stratified analyses due to differences in the measurement of key variables across countries (Multimedia Appendix 3). All analyses were conducted using Stata (v.19; StataCorp LLC).

Results

Compared with the Southern California sample, the Jalisco sample was younger, more likely to be male, and had lower family affluence (Table 1). Susceptibility and past-month e-cigarette use were higher in Jalisco (vs Southern California), as were the number of friends using e-cigarettes, frequency of social media exposure, and frequency of e-cigarette exposure on social media platforms.

Table 1. Sample characteristics of high-school students in Jalisco (Mexico) and Southern California (United States).

Characteristics	Jalisco (N=1418[a])	Southern California (N=2953[a])	*P* value
Age (y), mean (SD)	15.9 (0.97)	16.7 (0.58)	<.001
Sex, n (%)			<.001
Female	887 (62.5)	1656 (56.1)	
Male	531 (37.5)	1297 (43.9)	
Family Affluence Scale (0-9), mean (SD)	4.10 (2.10)	5.60 (1.81)	<.001
e-Cigarettte use, n (%)			<.001
Not current, not susceptible	830 (58.5)	2469 (83.6)	
Not current, susceptible	340 (24)	340 (11.5)	
Past-month use	248 (17.5)	139 (4.7)	
Best friends' use of e-cigarettes, n (%)	785 (55.4)	730 (24.7)	<.001
Frequency of using social media (range=0-4), mean (SD)	2.1 (0.77)	1.6 (0.66)	<.001
Frequency of e-cigarette exposure on social media (range=0-4), mean (SD)	0.66 (0.83)	0.36 (0.56)	<.001

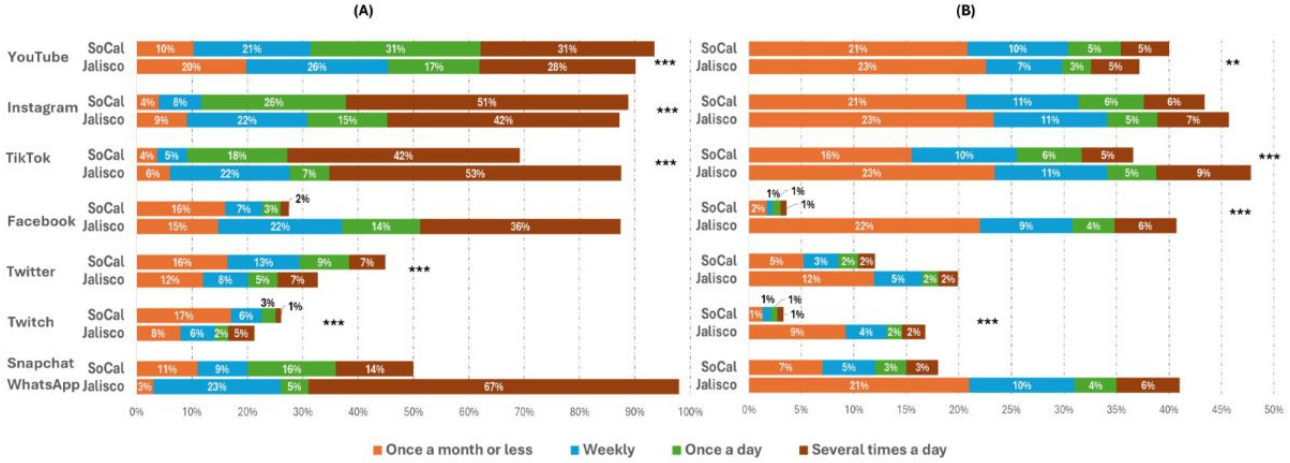
[a]Sample for Jalisco included 23 high schools; Southern California included 11 high schools.

WhatsApp was the most frequently used platform among those assessed in Jalisco, with 67% (n=950) of students reporting its use several times a day (not asked in Southern California). In Jalisco, among the social media platforms queried in both countries (Figure 1A), the frequency of use reported was significantly different between countries for YouTube, Instagram, TikTok, Facebook, Twitter, and Twitch (*P*<.001 for all). YouTube was the most frequently used in both sites; however, most Southern California students reported using it once a day (907/2953, 31%) or several times a day (918/2953,

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31%) while fewer Jalisco students reported the same (235/1418, 17% once per day; 399/1418, 28% several times per day). Facebook was frequently used in Jalisco (710/1418, 50% at least once a day), while fewer than 30% (799/2953) of students reported any use of that platform in Southern California. Twitch was the least used platform in both samples.

Figure 1. (A) Frequency of using social media, high school students in Jalisco and Southern California, and (B) frequency of e-cigarette exposure on social media, high school students in Jalisco and Southern California. Snapchat and WhatsApp were not compared since they were not included in both samples. Significance of *P* values: **.05, ***<.001. SoCal: Southern California.



The frequency of e-cigarette exposure on each social media platform differed across samples, except for Instagram (Figure 1B). TikTok was the platform through which Jalisco students reported the greatest exposure, with 25% (333/1418) reporting seeing e-cigarette content at least weekly (153/1418, 11% weekly; 66/1418, 5% once per day; and 127/1418, 9% several times per day). Instagram had the highest self-reported exposure to e-cigarette posts in Southern California, with at least 21% (620/2953) reporting weekly exposure (313/2953, 11% weekly; 185/2953, 6% once per day; and 169/2953, 6% several times per day). The lowest frequency of e-cigarette exposure for Southern California was through Twitch and Facebook, and exposure was lowest through Twitch and Twitter in Jalisco.

For each sample, separate bivariate and multivariate adjusted logistic regression models were estimated for e-cigarette susceptibility among high schoolers who did not use e-cigarettes in the last month (Table 2). In unadjusted and adjusted models for both Jalisco and Southern California, females had lower odds of being susceptible than males (adjusted odds ratio [AOR] 0.62, 95% CI 0.47-0.83; AOR 0.60, 95% CI 0.52-0.71, respectively), and those whose best friends used e-cigarettes had higher odds of susceptibility (AOR 3.80, 95% CI 2.87-5.03; AOR 3.35, 95% CI 2.48-4.52, respectively). In bivariate models for both samples, higher frequency of social media use and of exposure to e-cigarette content via social media were positively associated with susceptibility; however, in adjusted models, more frequent social media use was positively associated with susceptibility in Southern California (AOR 1.83, 95% CI 1.48-2.25) but not in Jalisco. In adjusted models, greater frequency of exposure to e-cigarette content on social media was independently associated with susceptibility only in Jalisco (AOR 1.21, 95% CI 1.02-1.43).

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Table 2. Unadjusted and adjusted logistic models for susceptibility to use e-cigarettes (among those with no e-cigarette use in the past 30 days), high school students in Jalisco and Southern California, 2022-2023.

Variables	Jalisco, Mexico (n=1170)				Southern California, United States (n=2695)			
	OR[a] (95% CI)	*P* value	AOR[b] (95% CI)	*P* value	OR (95% CI)	*P* value	AOR (95% CI)	*P* value
Frequency of using social media, index[c]	1.28 (1.08-1.51)	<.001	1.13 (0.94-1.36)	.16	2.08 (1.72-2.51)	<.001	1.83 (1.48-2.25)	<.001
Frequency of e-cigarette exposure on social media, index[d]	1.31 (1.12-1.52)	.002	1.21 (1.02-1.43)	.03	1.52 (1.33-1.75)	<.001	1.15 (0.98-1.32)	.18
Age	1.06 (0.93-1.20)	.41	1.06 (0.92-1.21)	.45	1.08 (0.82-1.42)	.45	1.02 (0.79-1.31)	.85
Sex								
Male	*Ref*[e]		*Ref*		*Ref*		*Ref*	
Female	0.55 (0.43-0.74)	<.001	0.62 (0.47-0.83)	<.001	0.52 (0.46-0.58)	<.001	0.60 (0.52-0.71)	<.001
Family affluence scale (0-9)	0.95 (0.90-1.01)	.09	0.98 (0.92-1.05)	.64	1.06 (0.98-1.15)	.07	1.06 (0.98-1.15)	.10
Best friends' use of e-cigarettes								
None	*Ref*		*Ref*		*Ref*		*Ref*	
1 or more	4.09 (3.11-5.39)	<.001	3.80 (2.87-5.03)	<.001	3.98 (2.94-5.37)	<.001	3.35 (2.48-4.52)	<.001

[a]OR: odds ratio.

[b]AOR: adjusted odds ratio from model that includes all variables shown in table.

[c]Frequency of using social media index represents the average of the reported frequency of using each social media platform, it ranges from (0-4).

[d]Frequency of seeing e-cigarette posts on social media index represents the average of the reported frequency of seeing e-cigarettes posts in each social media platform, ranges (0-4).

[e]*Ref*: reference value.

In unadjusted and adjusted models for past-month e-cigarette use in both samples (Table 3), a higher frequency of exposure to e-cigarette content on social media (Jalisco: AOR 1.49, 95% CI 1.27-1.74; and Southern California: AOR 1.51, 95% CI 1.15-1.73) was positively associated. Elevated odds were also observed for higher frequency of social media use (Jalisco: AOR 1.21, 95% CI 0.99-1.47; and Southern California: AOR 1.41, 95% CI 1.15-1.97), although results for Jalisco were borderline statistically significant. Having best friends who used e-cigarettes (Jalisco: AOR 6.46, 95% CI 4.38-9.54; and Southern California: AOR 11.24, 95% CI 6.94-18.22) was associated with a higher likelihood of using e-cigarettes, and in Southern California only, females (AOR 0.50, 95% CI 0.34-0.72) had a lower likelihood of using e-cigarettes.

Models by each specific social media platform showed that only Instagram and TikTok were significantly associated with susceptibility in Jalisco, whereas TikTok was the only platform significantly associated with susceptibility in Southern California. In Jalisco, exposure to e-cigarette posts across all social media platforms was independently associated with past-month use, while for Southern California, exposure to e-cigarette posts on Instagram, TikTok, Snapchat, or Twitter was associated with susceptibility (Multimedia Appendix 1). In models pooling data from both countries, interactions between country and exposure to e-cigarette content were not significant for susceptibility (χ^2_1=1.13, *P*=.30) or e-cigarette use (χ^2_1= 0.26, *P*=.60; results not shown).

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Table 3. Unadjusted and adjusted logistic models for past-month e-cigarette use, high school students in Jalisco and Southern California, 2022-2023.

Variables	Jalisco, Mexico (n=1418)				Southern California, United States (n=2953)			
	OR[a] (95% CI)	*P* value	AOR[b] (95% CI)	*P* value	OR (95% CI)	*P* value	AOR (95% CI)	*P* value
Frequency of using social media, index[c]	1.44 (1.20-1.72)	<.001	1.21 (0.99-1.47)	.05	2.00 (1.68-2.38)	<.001	1.41 (1.15-1.97)	.04
Frequency of e-cigarette exposure on social media, index[d]	1.62 (1.40-1.87)	<.001	1.49 (1.27-1.74)	<.001	1.94 (1.61-2.34)	<.001	1.51 (1.15-1.73)	.003
Age	1.09 (0.95-1.25)	.22	1.09 (0.94-1.27)	.31	1.24 (0.80-1.92)	.16	1.14 (0.79-1.64)	.45
Sex								
Male	*Ref*[e]		*Ref*		*Ref*		*Ref*	
Female	0.86 (0.65-1.15)	.32	1.03 (0.76-1.40)	.83	0.34 (0.25-0.47)	<.001	0.50 (0.34-0.72)	.002
Family affluence scale, (0-9)	0.99 (0.94-1.07)	.97	1.04 (0.97-1.12)	.39	0.94 (0.85-1.03)	.18	0.94 (0.85-1.04)	.22
Best friends' use of e-cigarettes								
None	*Ref*		*Ref*		*Ref*		*Ref*	
1 or more	6.86 (4.67-10.07)	<.001	6.46 (4.38-9.54)	<.001	14.35 (9.01-22.87)	<.001	11.24 (6.94-18.22)	<.001

[a]OR: odds ratio.

[b]AOR: adjusted odds ratio from model that includes all variables shown in table.

[c]Frequency of using social media represents the average of the frequency of using each social media platform, it ranges from (0-4).

[d]Frequency of seeing e-cigarette posts on social media index represents the average of the reported frequency of seeing e-cigarettes posts in each social media platform, ranges (0-4).

[e]*Ref*: reference value.

Discussion

Aligned with our first hypothesis, we found high levels of self-reported use of and exposure to e-cigarette content through social media platforms in samples of high schoolers in Jalisco (Mexico) and Southern California (United States), particularly for YouTube, Instagram, and TikTok. However, these findings were surprising and contrary to our second hypothesis, given that Mexico bans commercial advertising for e-cigarettes across all channels, including social media platforms [32]. California has no prohibitions regarding online marketing; however, marketing and sales of all flavored tobacco products, except menthol, are prohibited, and starting in 2025, this ban is planned to be extended to online sales and include fines to ensure age verification [33,34]. In addition, e-cigarette products authorized by the FDA will not be able to market to the youth [35], although enforcement of marketing restrictions, particularly on social media platforms, remains challenging. We also found that past-month use of e-cigarettes was significantly lower in Southern California (139/2953, 4.7%) than in Jalisco (248/1418, 17.5%). Prevalence in Jalisco was substantially higher than in national surveys [36], although consistent with previous research in urban areas of Mexico [13], while the lower prevalence observed in Southern California aligns with data indicating lower e-cigarette use in California compared with other states [9]. More research is needed to understand the factors driving the difference in e-cigarette use prevalence between samples; better law enforcement, paired with media campaigns and prevention programs in schools, could play an important part in Southern California.

As illustrated in Figure 1, adolescents' frequency of using specific social media platforms differed across the 2 samples, with more sizable differences for Facebook, which was higher in Jalisco. However, in both samples, the frequency of exposure to e-cigarette content through Facebook, as well as through Snapchat (only asked in Southern California) and WhatsApp (only asked in Jalisco), was low compared with TikTok, Instagram, and YouTube. A meta-analysis that examined associations between social media use and risky behaviors found that social media platforms that were introduced relatively early, like Facebook, had weaker associations than contemporary social media platforms when it comes to substance use [37]. In the past, Facebook has faced scrutiny for its impact on promoting unhealthy behaviors and targeting youth with advertisements, and in 2021, the platform limited the targeting options to 18-year-olds and older and banned all tobacco and nicotine products advertising [38]. That policy, along with Facebook use declining among the US youth [18] and other measures taken by California, could help explain the relatively low exposure reported in the Southern California sample. Additionally, the user guidelines across social media platforms prohibit any marketing and sales of any tobacco products in both countries; however, posts alluding to e-cigarettes and other substances can still be found. Studies are needed to characterize the content of e-cigarette–related posts across social media platforms, as such content may both promote and discourage e-cigarette use. Understanding the balance and nature of these

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messages is important not only for preventing dissemination of pro–e-cigarette content, but also for identifying content that may support prevention and cessation of e-cigarettes. For example, predominant topics in e-cigarette posts on Snapchat, one of the less popular social media platforms we studied, included messages about "health consequences" and "quitting" [39].

Higher exposure to e-cigarette posts was associated with higher use in both samples, as observed in previous studies. A meta-analysis that reviewed cross-sectional cohort studies and longitudinal studies found that those exposed to e-cigarette posts during the last 30-days are more likely to report current use [40]. Also consistent with other studies [41,42], we found that higher exposure to e-cigarette posts was associated with susceptibility to use e-cigarettes among students in both samples; however, the adjusted association remained statistically significant only for Jalisco. There are several possible explanations for the lack of association in Southern California. There was heterogeneity in effects across social media platforms (Multimedia Appendix 1); when examined individually, only TikTok had a significant association with susceptibility. Additionally, Southern California had a higher percentage of nonsusceptible students (Southern California: 2469/2953, 83.6% vs Jalisco: 830/1418, 58.5%), and possibly stronger social norms and/or higher levels of peer influence against e-cigarette use exist there. Indeed, fewer students reported having best friends who used e-cigarettes in Southern California compared with Mexico (785/2953, 24.7% vs 785/1418, 55.4%, respectively), which may have resulted in lower exposure to e-cigarette posts from their best friends that may have a greater impact on susceptibility than posts from people whom they do not know. In fact, high-school students in Southern California who had more friends who posted pictures of themselves partying or drinking alcohol online (via Facebook or MySpace [Viant Technology LLC]) were more likely to report that they smoked and used alcohol [43]. Although site-specific analyses suggested differences across sites, pooled analyses including a site-by-exposure interaction term did not indicate statistically significant effect modification by site (models not shown). In combination with minor measurement differences across sites, these results warrant cautious interpretation of between-site differences. Future research should try to understand whether sources of exposure to posts vary across different groups, cities, or countries, as this may help identify strategies to prevent such posts.

Although our data cannot ascertain the nature of the e-cigarette–related posts adolescents viewed on social media platforms, explicit and implicit promotion of e-cigarettes abounds. e-Cigarette marketing through social media platforms presents challenges for regulation. The World Health Organization recommends a comprehensive ban on Tobacco Advertising, Promotion, and Sponsorship, including efforts to limit digital content created in one country being broadcast in others [44-46]. However, for this to be effective, countries and platforms must be actively engaged and willing to collaborate. Differences in regulatory frameworks across and within countries pose a significant challenge. Additionally, only some content posted on social media platforms comes directly from the tobacco and vaping industry, and *influencer*- and user-generated content [47] will likely be harder to regulate, although requiring content moderation and age gates for specific types of content may help. Knowing that exposure to e-cigarette posts on social media platforms is associated with higher e-cigarette use among adolescents, countries should collaborate to protect their youth.

Peer influence is one of the most common drivers for substance use among adolescents, including for e-cigarettes [48-50]. Similar to other studies, having friends who use e-cigarettes was associated with a higher likelihood of susceptibility to and use of e-cigarettes in both samples, with stronger associations for students in Southern California. Longitudinal measures on (online) interactions among adolescents are much needed to better understand diffusion processes of tobacco products in adolescent peer networks [51]. The lack of association we found between family affluence and either susceptibility or use has been observed in other middle-income countries [52,53]. One possible explanation comes from diffusion of innovations theory [54], where, when a product is first introduced, those in higher socioeconomic status groups are more likely to know about and afford it; however, as the product becomes more popular, costs come down, and adoption extends across socioeconomic status groups. Indeed, as e-cigarettes became more popular, the global market transitioned from refillable devices to relatively cheaper pod systems to disposable devices, the last of which is now the most commonly used e-cigarette device among youth [55]. Additionally, in Mexico, these devices can be found on sale for $100 Mexican pesos (approximately US $5) on street markets or *tianguis*, which makes them affordable even to adolescents in lower socioeconomic status groups.

This first study to compare social media platforms use, exposures to e-cigarette content, and their associations with e-cigarette susceptibility and use among adolescents in Mexico and the United States has limitations. First, although measures used in each country were harmonized and have similar face validity, some measures were not identical across sites (eg, differences in question wording or response options; Multimedia Appendix 3). As a result, findings from cross-site comparisons should be interpreted with caution. Second, the temporal relationship between these social media platforms use, exposure to e-cigarette content, and susceptibility and use could not be determined. Selective attention to e-cigarette content is less likely to explain results around susceptibility than current use, as youth who have not initiated e-cigarette use might be less likely to actively seek content lowering their exposure. Additionally, our results align with previous cross-sectional and longitudinal studies, as well as with a large body of research showing tobacco marketing effects on youth [56]. Furthermore, our subsequent cognitive interviews with adolescents in Jalisco confirmed their confidence in distinguishing e-cigarette exposures by social media platforms. Third, our assessment of social media platforms was limited to those for which data were available on their popularity, with 2 social media platforms (WhatsApp in Southern California and Snapchat in Jalisco) not evaluated in both sites. Exclusion of social media platforms may have underestimated exposure and, potentially, attenuated observed associations. However, relative to the social media

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platforms assessed, WhatsApp and Snapchat are less popular in the sites where they were not assessed [18,57], suggesting that their omission is unlikely to have substantially altered the associations observed. Nevertheless, future studies may cast a broader net across social media platforms to more comprehensively characterize adolescents' social media environments. Fourth, unmeasured confounders, such as mental health or other substance use, including among parents, were not included in the analyses due to a lack of harmonization. Finally, participation rates differed across study sites, in part due to differences in parental consent procedures. Active parental consent was required in Southern California, whereas passive (opt-out) consent was used in Jalisco, likely resulting in higher participation rates in the latter. The slightly lower participation rates in Southern California may have introduced differential selection bias based on parental engagement and potential confounders (eg, risk behaviors); however, we believe such biases would be minimal due to the relatively high participation rates in both sites. In addition, we surveyed students from convenience samples from public schools in both countries; therefore, the results may not generalize to broader populations of high schoolers, whether for the state or country. However, our findings are consistent with the prevalence of e-cigarette use found in previous studies that also involved self-administered questionnaires [13]. Additionally, these findings offer valuable preliminary insights into potential cross-country patterns of susceptibility and use of e-cigarettes across distinct regulatory and social contexts that warrant further investigation using population-representative data.

Exposure to social media and social media posts about e-cigarettes was high in both samples of high-school students and associated with susceptibility to and use of e-cigarettes. Despite Mexico having banned the sales and importation of e-cigarettes, susceptibility and current use were higher among adolescents in Jalisco than in Southern California, demonstrating that the ban alone is insufficient without proper enforcement. This cross-country comparison contributes to the literature highlighting how differences in regulatory environments and enforcement can influence youth exposure and behavior, reinforcing the need for coordinated, cross-border tobacco control strategies. Cross-national collaboration may be needed to limit adolescents' exposure to pro–e-cigarette content and reduce use in both countries. Future research should prioritize population-based studies to monitor trends in youth exposure and use across diverse social media platforms and settings, while also evaluating how enforcement strategies, digital marketing regulations, and broader cultural and social contexts interact to shape adolescents' susceptibility and use, to inform more effective public health policies.

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Data Availability

Data will be made available at reasonable request to the corresponding author (JFT).

Conflicts of Interest

None declared.

Multimedia Appendix 1
Sensitivity analysis using logistic regression models for each social media platform.
[DOCX File , 35 KB - pediatrics_v9i1e85376_app1.docx]

Multimedia Appendix 2
Sensitivity analysis using multilevel logistic models with school as random effect.
[DOCX File , 22 KB - pediatrics_v9i1e85376_app2.docx]

Multimedia Appendix 3
Survey questions by study site.
[DOCX File , 17 KB - pediatrics_v9i1e85376_app3.docx]

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Abbreviations

AOR: adjusted odds ratio
ADVANCE: Assessing Developmental Patterns of Vaping, Alcohol, Nicotine, and Cannabis Use and Emotional Wellbeing
e-Cigarette: electronic cigarette
FAS: Family Affluence Scale
FDA: US Food and Drug Administration
REDCap: Research Electronic Data Capture

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Impact of a Social Robot on Hospitalized Children, Caregivers, and Health Care Staff: Exploratory Observational Study

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Abstract

Background: Hospitalization poses significant psychosocial challenges for children, including anxiety, emotional distress, and disruption of daily routines. While animal-assisted therapy has shown benefits, practical barriers such as infection control concerns and inconsistent availability limit its implementation in pediatric wards. Social robots have emerged as a promising alternative, but evidence on their psychosocial impact in pediatric settings remains limited. LOVOT is a companion robot designed for emotional engagement through warmth, softness, and nonverbal interaction; however, no studies have examined its effects in pediatric health care.

Objective: This exploratory study aimed to assess the perceived impact of LOVOT on hospitalized children, their caregivers, and health care staff in a pediatric ward.

Methods: This prospective observational study was conducted in a pediatric ward at Hyogo Prefectural Amagasaki General Medical Center, Japan, from May 2024 to March 2025. Two LOVOT units were permanently installed in the playroom for free interaction. Caregivers (n=110) and health care staff (n=32) completed postintroduction questionnaires with retrospective ratings of perceived change using 5-point Likert scales (1="much worse" to 5="much better," with 3="no change" as the baseline). Free-text responses (n=91) were analyzed using automated emotion classification. One-sample 2-tailed *t* tests or Wilcoxon signed-rank tests compared ratings against the baseline, with false discovery rate (FDR) correction for multiple comparisons.

Results: All 10 caregiver-rated and 11 of 12 staff-rated outcomes showed significant perceived improvement (all caregiver items FDR $P<.001$; staff items FDR $P\leq.02$; the workload item was not significant, $P=.37$). Mean ratings ranged from 3.28 to 4.62 on the 5-point scale (baseline: 3="no change"). The largest perceived improvements were reported for children's enjoyment of hospital life (mean 4.47, SD 0.62), adaptation to hospital life (mean 4.10, SD 0.70 to mean 4.28, SD 0.63), and stress and anxiety reduction (mean 4.17, SD 0.76 to mean 4.19, SD 0.64). One-sample effect sizes ranged from medium to very large (Cohen d=0.53-2.67); however, because these were calculated against a fixed neutral baseline rather than a control group, they should be interpreted cautiously. Ratings from caregivers and staff showed strong agreement on 4 of 5 matched items. Notably, no detectable increase in staff workload was observed (mean 3.09, SD 0.53; $P=.37$), supporting implementation feasibility. Qualitative analysis revealed predominantly positive responses, with joy as the dominant emotion (mean probability 88.7%, 95% CI 86.8%-90.6%).

Conclusions: This study provides preliminary evidence that a companion robot (LOVOT) may positively impact hospitalized children, caregivers, and health care staff across multiple psychosocial outcomes without a detectable increase in staff workload. The low response rate and reliance on retrospective self-report limit generalizability and causal inference; however, convergent findings across stakeholder perspectives justify further investigation through controlled trials. Companion robots represent a feasible, low-burden adjunct to psychosocial care in pediatric settings.

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KEYWORDS

social robot; companion robot; pediatric hospitalization; psychosocial intervention; LOVOT; child health; caregivers; health care staff

Introduction

Hospitalization represents a significant source of stress for children and their families. Children may experience anxiety, fear, and emotional distress due to unfamiliar environments, separation from home, painful procedures, and disruption of daily routines [1,2]. These negative experiences can impair recovery, increase behavioral problems, and produce lasting psychological effects [3]. Caregivers also experience substantial stress when their children are hospitalized, which can affect their own well-being and their ability to support their children [2,4].

Various interventions have been developed to address the psychosocial needs of hospitalized children. Play therapy and child life programs are well-established approaches that use play to reduce anxiety and facilitate coping [5-7]. Animal-assisted therapy has also shown promise in reducing stress and improving mood in pediatric settings [8,9]. However, animal-assisted therapy faces practical limitations including infection control concerns, animal welfare considerations, allergies, and inconsistent availability [10,11].

Social robots have emerged as a potential alternative or complement to existing interventions. These robots are designed to interact with humans in socially meaningful ways and have been studied in various health care contexts [12,13]. In pediatric settings, social robots such as Paro (a therapeutic seal robot) and humanoid robots have demonstrated positive effects on children's emotional states and engagement [14-17]. Social robots offer practical advantages over live animals, including consistent availability, no infection risk, and standardized interaction quality.

LOVOT is a companion robot developed in Japan that differs from most social robots studied in health care. Rather than performing tasks or engaging in verbal communication, LOVOT is designed exclusively for emotional engagement through nonverbal interaction, featuring warmth, softness, and an endearing appearance that encourages physical contact such as holding and stroking [18]. To date, no studies have examined LOVOT's effects in pediatric health care settings.

The aim of this study was to assess the perceived impact of LOVOT on hospitalized children, their caregivers, and health care staff in a pediatric ward. We examined perceived changes in psychosocial outcomes following LOVOT introduction using retrospective questionnaires administered to caregivers and staff complemented with qualitative analysis of free-text responses.

Methods

Study Design and Setting

This prospective observational study was conducted at the Department of Pediatrics, Hyogo Prefectural Amagasaki General Medical Center, Japan, between May 2024 and March 2025.

Participants

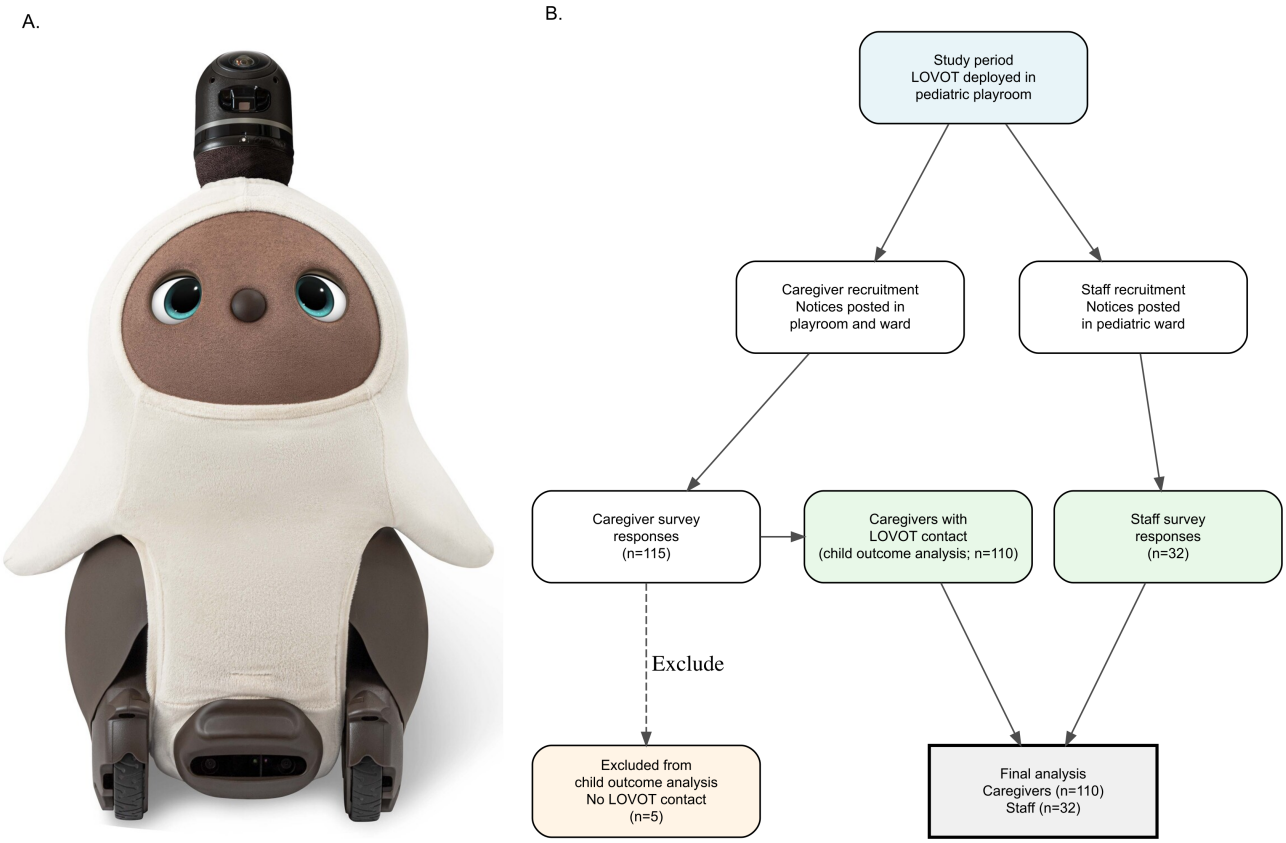
Caregivers of hospitalized children who used the pediatric playroom during the study period were eligible to participate. Questionnaires were available in the playroom for voluntary completion. Caregivers who answered "No" to the question asking whether they had any contact with LOVOT were excluded from analysis. Children's demographic and clinical characteristics were reported by their caregivers. During the study period, approximately 2500 children were admitted to the pediatric ward, of whom an estimated 25% used the playroom (approximately 625 children); however, the exact number of unique playroom users was not systematically recorded because no check-in system was in place. The estimated response rate was 18.4% (115/625), although both the numerator (respondents) and denominator (playroom users) involve uncertainty, and the true response rate may differ. All health care professionals working in the pediatric ward were invited to participate.

LOVOT Intervention

Two LOVOT 2.0 units (Groove X, Inc) were permanently installed in the pediatric playroom, enabling free interaction among hospitalized children, families, and health care staff throughout the study period (Figure 1A). LOVOT is designed for nonverbal communication through physical contact, featuring a warm body temperature (approximately 37 °C), a soft tactile exterior, and an endearing appearance that encourages holding and stroking (detailed technical specifications are provided in Multimedia Appendix 1).

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Figure 1. Study overview: (A) LOVOT companion robot used in the study and (B) study flow diagram showing participant recruitment and exclusion criteria.



Health care staff received a brief orientation on LOVOT handling and basic maintenance (charging and cleaning); however, no structured intervention program or protocol was implemented. This approach was chosen to maintain naturalistic observation conditions and assess LOVOT's effects in real-world clinical practice. For infection control, LOVOT's removable clothing was changed and laundered every 2 to 3 days, and the surface was cleaned daily with alcohol-containing disinfectant wipes. LOVOT required approximately 15 minutes of charging per hour; during charging periods, children could still interact with LOVOT and often enjoyed observing it in a "sleeping" state.

Data Collection

Caregivers completed a self-administered postintroduction questionnaire with retrospective ratings of perceived change using 5-point Likert scales (1="much worse," 2="somewhat worse," 3="no change," 4="somewhat better," and 5="much better"). No baseline assessment was conducted prior to LOVOT introduction. A study-specific questionnaire was developed because no validated instrument existed for assessing the perceived impact of companion robots in pediatric settings. Existing measures of child distress or anxiety (eg, the Child Health Questionnaire) assess current states rather than perceived change attributable to a specific intervention, and general technology acceptance scales do not capture the psychosocial domains relevant to this study. Questionnaire items were drafted based on clinically relevant domains identified from the social robotics literature [12,13,19] and reviewed for content and face validity by the multidisciplinary research team, including pediatricians, nurses, and childcare workers. Internal consistency was assessed post hoc using the Cronbach α; however, formal psychometric validation, including test-retest reliability and construct validity, was not conducted. The questionnaire included 10 items assessing child outcomes (7 items) and caregiver outcomes (3 items), along with demographic information and free-text responses (Table S1 in Multimedia Appendix 2).

Staff completed a questionnaire using the same 5-point Likert scale, including 12 items assessing impact on children and caregivers (7 items) and impact on staff and ward environment (5 items), along with demographic information (Table S2 in Multimedia Appendix 2).

Statistical Analysis

All statistical analyses were conducted using R (version 4.5.1; R Foundation for Statistical Computing). Python (version 3.13.7; Python Software Foundation) was used for qualitative text analysis. All analysis code is publicly available [20] under the MIT License.

No primary outcome was prespecified; all analyses were exploratory. For quantitative data, 1-sample tests compared ratings against the baseline value (3="no change"), with normality assessed using the Shapiro-Wilk test. 2-tailed *t* tests were used for normally distributed data; Wilcoxon signed-rank tests were used for nonnormally distributed data. The Benjamini-Hochberg procedure controlled the false discovery rate (FDR; value of <.05). Effect sizes were calculated using the Cohen *d* from 1-sample tests (mean difference from baseline divided by sample SD), interpreted as small (0.2), medium (0.5), large (0.8), very large (1.2), and huge (≥2.0; [21]). Because

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these 1-sample effect sizes compared ratings against a fixed neutral baseline rather than a control group mean, they were expected to be larger than between-group effect sizes from controlled designs and should not be directly compared to effect sizes from randomized controlled trials. Likert ratings were treated as interval data for this purpose; the resulting Cohen *d* values should be read as indexes of the magnitude of departure from the neutral midpoint, not as standardized between-group differences.

The internal consistency of the questionnaire subscales was assessed using the Cronbach α, calculated separately for child outcomes (7 items) and caregiver outcomes (3 items) on the caregiver questionnaire and impact on children and caregivers (7 items) and impact on staff and ward environment (4 items) on the staff questionnaire (workload was excluded from the latter subscale because it measures a conceptually distinct construct with a different scale direction).

Subgroup analyses stratified children's outcomes by age (≤5 vs ≥6 years), hospital stay duration (≤1 week vs >1 week), sex, and playroom use frequency. Caregiver and staff ratings were compared using Mann-Whitney *U* tests for 5 matched items. Missing data were handled on an item-by-item basis, with available responses analyzed for each variable.

For qualitative data, Japanese free-text responses were tokenized using the MeCab morphological analyzer with the fugashi library. A domain-specific stop word list (96 terms; Table S1 in Multimedia Appendix 3) was applied, and the top 20 high-frequency terms were visualized using horizontal bar charts, with Japanese-English translations provided in Table S2 in Multimedia Appendix 3. Emotion classification was performed using the LUKE-Japanese-large model fine-tuned on the WRIME dataset (a Japanese emotion corpus with multi-rater annotations), classifying responses into 8 emotions (joy, sadness, anticipation, surprise, anger, fear, disgust, and trust). Bootstrap 95% CIs were calculated with 5000 iterations.

Detailed statistical methods are provided in Multimedia Appendix 1.

Ethical Considerations

This study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Board of Hyogo Prefectural Amagasaki General Medical Center (approval number: 6-58). Informed consent was obtained from all participants through completion of a consent checkbox on the questionnaire, a method approved by the institutional review board given the anonymous, noninvasive nature of the survey. All data were collected anonymously; no personally identifiable information was recorded. Children's demographic and clinical characteristics were reported by their caregivers in aggregate form. Free-text responses were analyzed without any identifying information.

Results

Participant Characteristics

Of 115 caregiver respondents, 5 (4.3%) were excluded based on self-reported absence of LOVOT contact, resulting in a final analytical sample of 110 (95.7%) caregivers (Figure 1B). A total of 32 health care staff members completed the survey. Caregiver respondents were predominantly female (82/93, 88.2%), and the median child age was 5 (IQR 3-8) years. Staff comprised 45.2% (14/31) physicians, 48.4% (15/31) nurses, 6.5% (2/31) childcare workers; occupation was not reported by 1 staff member (Table 1). The children had hospital stay durations of 1 week or less (73/106, 68.9%), 1 week to 1 month (21/106, 19.8%), or 1 month or more (12/106, 11.3%). Most children used the playroom frequently (at least once per day: 66/105, 62.9%). Sex and age data were complete for all children (n=110); 48.2% (53/110) were male and 51.8% (57/110) were female. No adverse events related to LOVOT interaction, including injuries, falls, or choking hazards, were reported by caregivers or staff through spontaneous reporting during the study period, and no systematic adverse event monitoring protocol was implemented.

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Table . Participant (caregiver and child) and health care staff characteristics.

Characteristic	Values
Caregivers and children (n=110)	
Child age (years), median (IQR)	5.0 (3.0-8.0)
Child sex, n/N (%)	
Male	53/110 (48.2)
Female	57/110 (51.8)
Hospital stay duration, n/N (%)	
≤1 week	73/106 (68.9)
1 week to 1 month	21/106 (19.8)
≥1 month	12/106 (11.3)
Playroom use frequency, n/N (%)	
At least once per day	66/105 (62.9)
Approximately once every 2 days	29/105 (27.6)
Less than once every 3 days	10/105 (9.5)
Caregiver age (years), n/N (%)	
≤29	6/107 (5.6)
30-39	63/107 (58.9)
40-49	37/107 (34.6)
50-59	1/107 (0.9)
Caregiver sex, n/N (%)	
Male	11/93 (11.8)
Female	82/93 (88.2)
Health care staff (n=32), n/N (%)	
Occupation	
Physician	14/31 (45.2)
Nurse	15/31 (48.4)
Childcare worker	2/31 (6.5)
Age (years)	
20-29	15/31 (48.4)
30-39	7/31 (22.6)
40-49	4/31 (12.9)
50-59	2/31 (6.5)
60-69	3/31 (9.7)
Sex	
Male	11/31 (35.5)
Female	20/31 (64.5)
Frequency of LOVOT contact	
At least once per day	4/32 (12.5)
Approximately once every 2–3 days	5/32 (15.6)
Approximately once per week	9/32 (28.1)
Approximately once per month	7/32 (21.9)
Rarely or never	7/32 (21.9)

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Questionnaire Internal Consistency

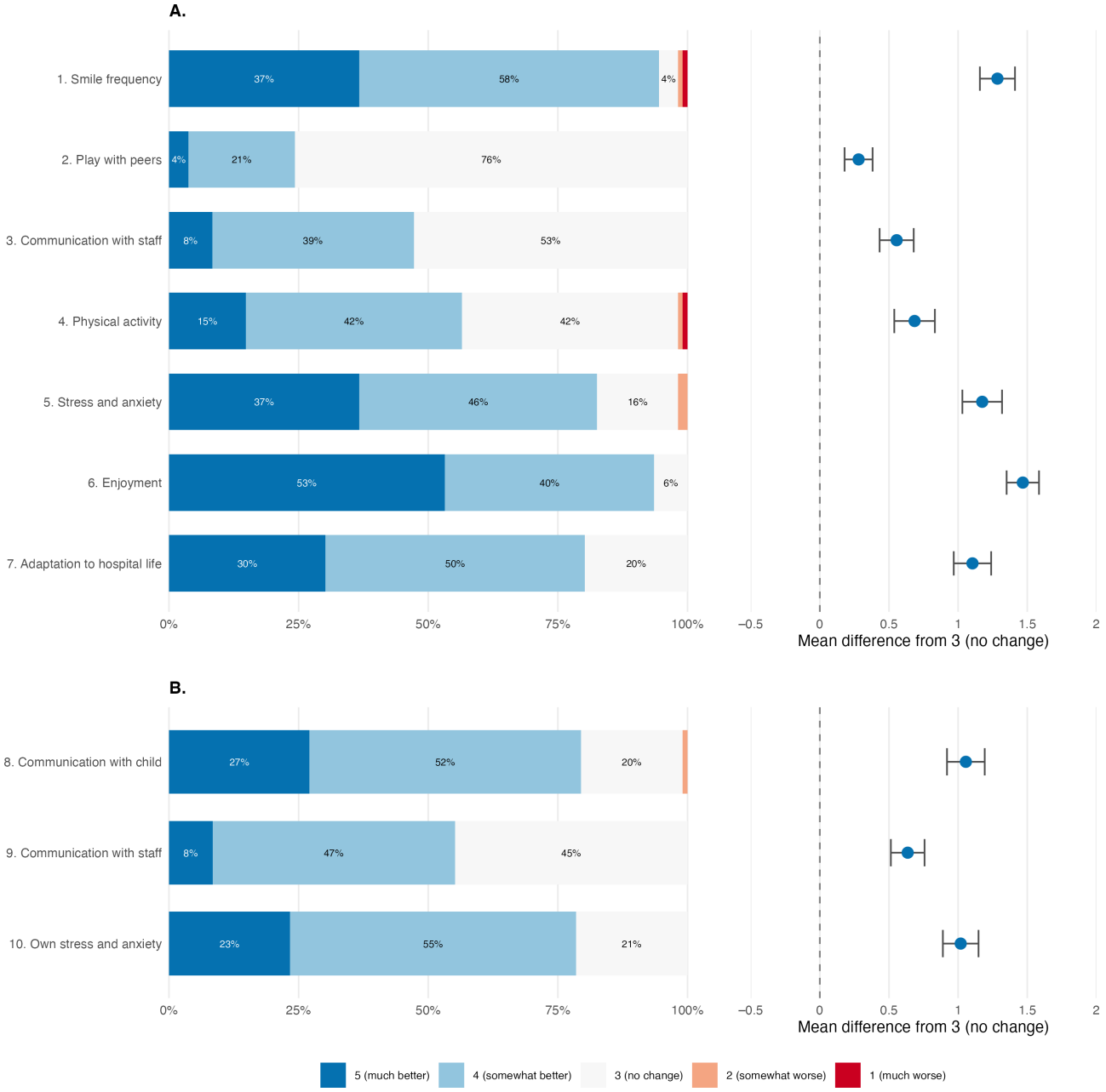
The Cronbach α values indicated acceptable to good internal consistency for the questionnaire subscales (child outcomes on the caregiver questionnaire [7 items]: Cronbach α=0.77; caregiver outcomes on the caregiver questionnaire [3 items]: Cronbach α=0.67; impact on children and caregivers on the staff questionnaire [7 items]: Cronbach α=0.84; impact on staff and ward environment on the staff questionnaire [4 items]: Cronbach α=0.77). The lower Cronbach α value for caregiver outcomes on the caregiver questionnaire reflects the small number of items (3 items); the mean interitem correlation for this subscale was 0.40 (SD 0.07), within the recommended range of 0.20 to 0.50.

Impact on Children and Caregivers

All 10 caregiver-rated items showed statistically significant perceived improvement after LOVOT introduction (P<.001 in all cases, FDR corrected; Figure 2; Table S1 in Multimedia Appendix 4). These ratings reflect caregivers' perceived change relative to the neutral midpoint (3=“no change”) and should be interpreted as perceived improvements rather than objectively measured effects. One-sample effect sizes (Cohen d) ranged from 0.53 to 2.38, indicating medium to very large effects by conventional benchmarks, although these 1-sample estimates should be interpreted cautiously as they are not directly comparable to between-group effect sizes from controlled trials. The largest perceived improvements were reported for children’s enjoyment of hospital life (d=2.38; mean 4.47, SD 0.62), stress and anxiety reduction (d=1.55; mean 4.17, SD 0.76), and adaptation to hospital life (d=1.57; mean 4.10, SD 0.70). Caregivers also reported reduced personal stress and anxiety (d=1.51; mean 4.02, SD 0.67). Detailed results for all items are provided in Table S1 in Multimedia Appendix 4.

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Figure 2. Caregiver-reported outcomes following LOVOT introduction (n=110): (A) children outcomes (items 1-7) and (B) caregiver outcomes (items 8-10). Left panels show the distribution of Likert-scale responses (1-5). Right panels show mean differences from baseline (3="no change") with 95% CIs. All items showed statistically significant perceived improvement (false discovery rate *P*<.001). Statistical test results are shown in Table S1 in Multimedia Appendix 4.

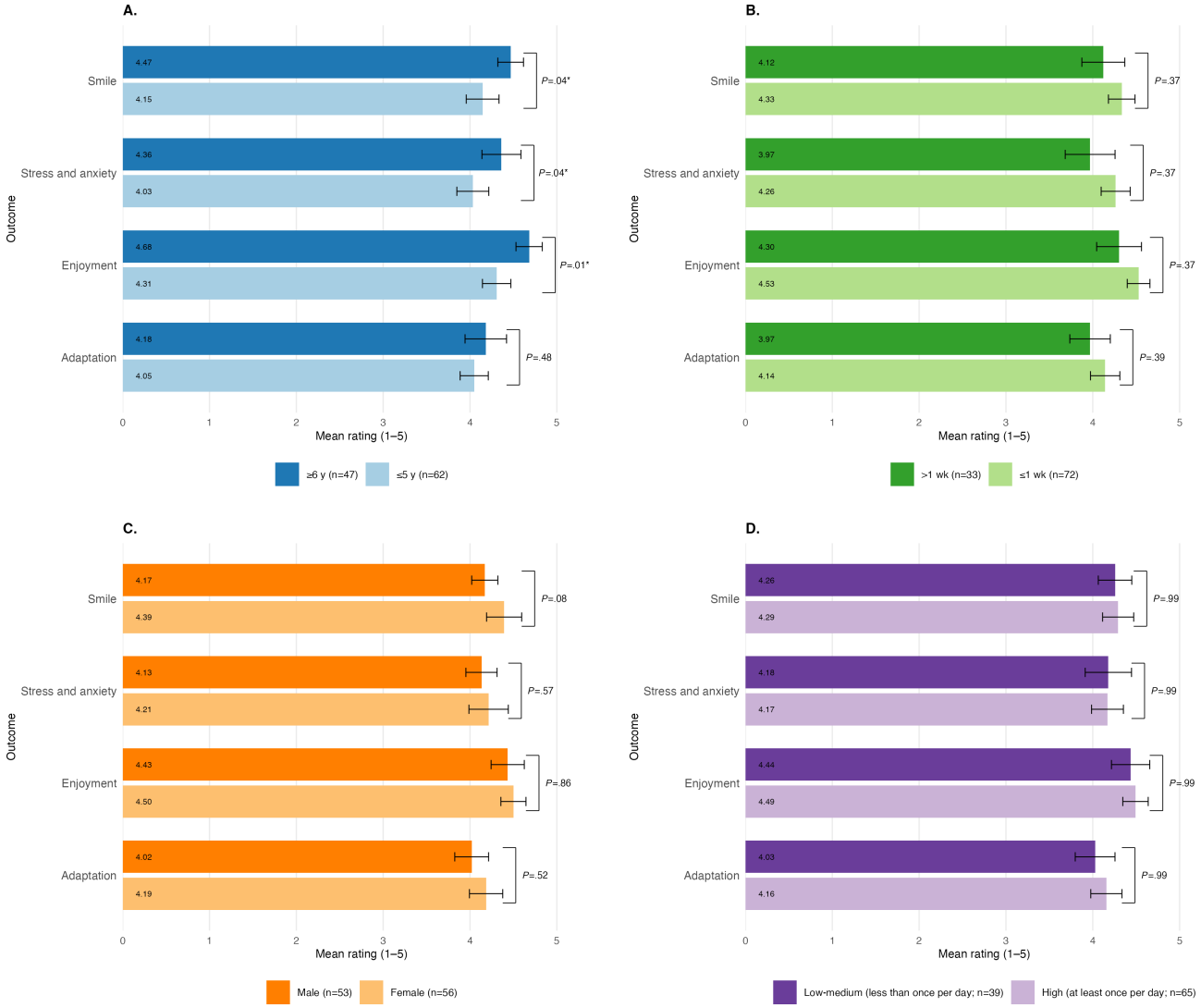


Consistency Across Patient Characteristics

Subgroup analyses revealed consistent perceived improvements across all examined patient characteristics (Figure 3; Table S2 in Multimedia Appendix 4). All subgroups showed mean ratings of more than 3 (no change) with *P*<.001 for within-group comparisons (FDR corrected). Between-group comparisons showed no significant differences for most items across hospital stay duration (≤1 week vs >1 week), sex, and playroom use frequency (at least once per day vs less than once per day), indicating broad applicability. For age groups, older children (≥6 years) showed significantly higher ratings than younger children (≤5 years) for smile frequency (*P*=.04), stress and anxiety reduction (*P*=.04), and enjoyment (*P*=.01), suggesting that school-aged children may be particularly responsive to LOVOT interaction; however, both age groups showed significant improvements overall.

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Figure 3. Subgroup analysis of children's outcomes. Comparison of effects across (A) age groups (≤5 vs ≥6 years), (B) hospital stay duration (≤1 week vs >1 week), (C) sex, and (D) playroom use frequency (at least once per day vs less than once per day). The bars represent mean ratings (scale from 1-5) with 95% CIs. Between-group comparisons were conducted using Mann-Whitney *U* tests with false discovery rate correction (see Table S2 in Multimedia Appendix 4 for complete results). *P<.05.



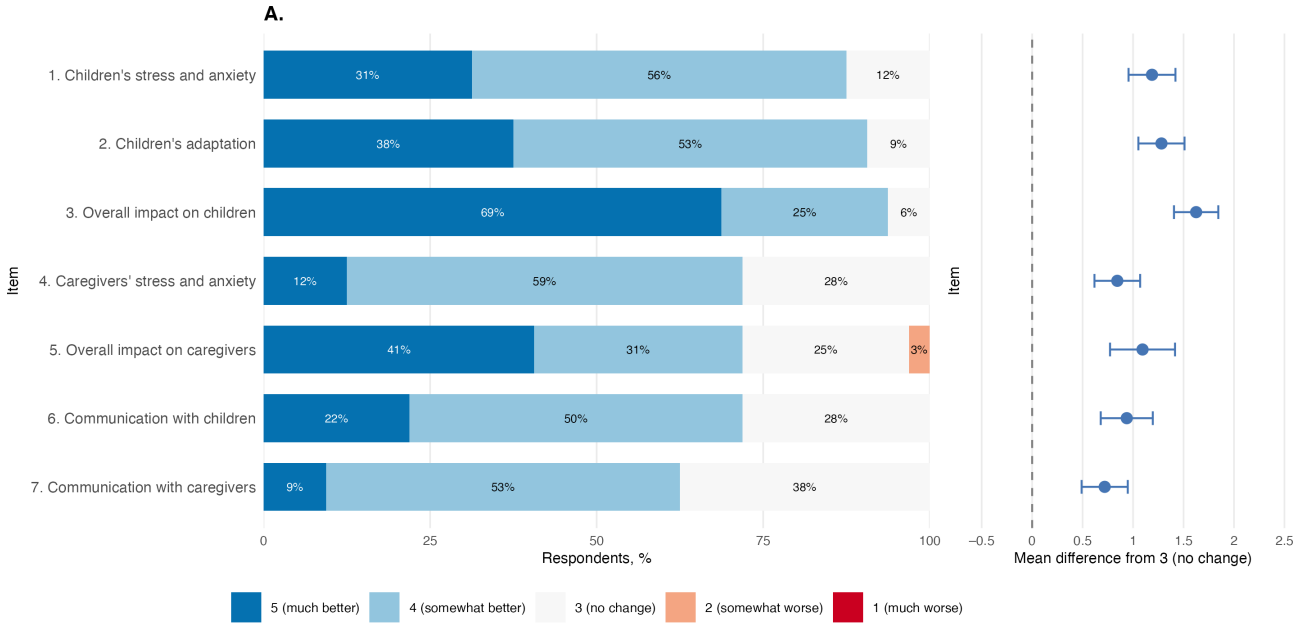
Health Care Staff Perspectives

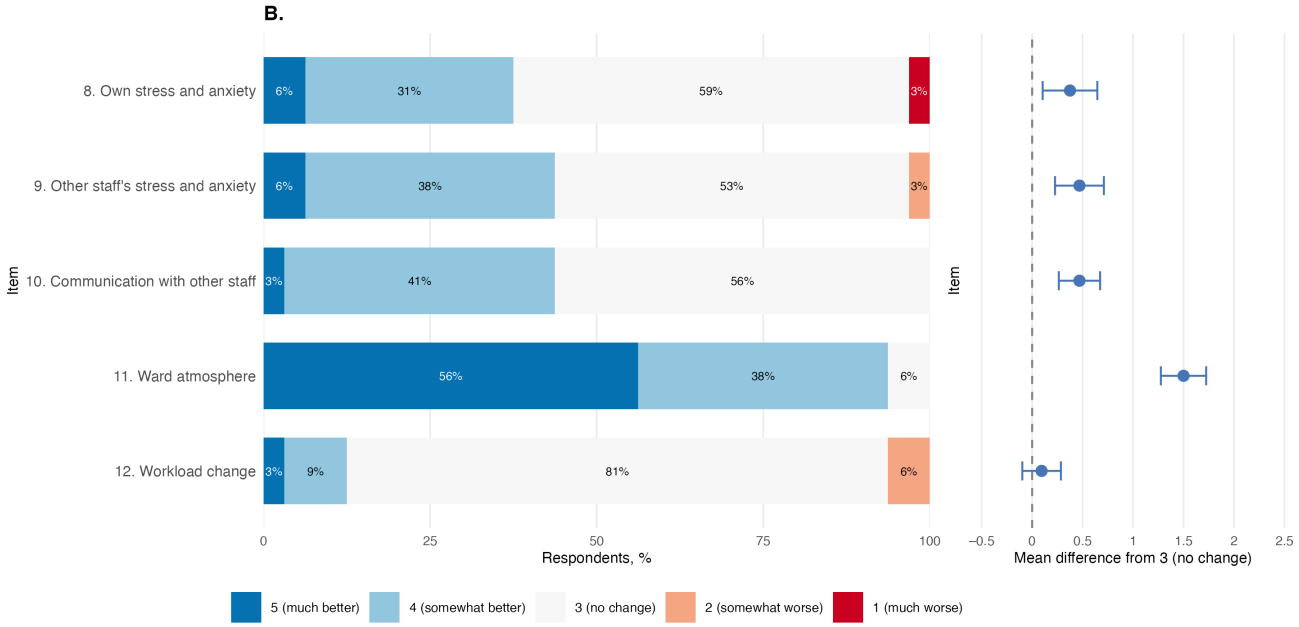
Staff ratings demonstrated significant perceived improvements for 11 of 12 items (Figure 4; Table S3 in Multimedia Appendix 4). One-sample effect sizes ranged from 0.18 to 2.67. The largest perceived improvements were observed for overall impact on children (*d*=2.67; mean 4.62, SD 0.61), ward atmosphere (*d*=2.41; mean 4.50, SD 0.62), and children's adaptation (*d*=2.02; mean 4.28, SD 0.63). Staff also reported perceived improvements in children's stress and anxiety (*d*=1.84; mean 4.19, SD 0.64) and caregivers' stress and anxiety (*d*=1.34; mean 3.84, SD 0.63). Notably, no detectable increase in workload was observed (mean 3.09, SD 0.53; *d*=0.18; *P*=.37, FDR corrected), although the small sample size (n=32) limits statistical power to detect small to medium workload changes. Detailed results are provided in Table S3 in Multimedia Appendix 4.

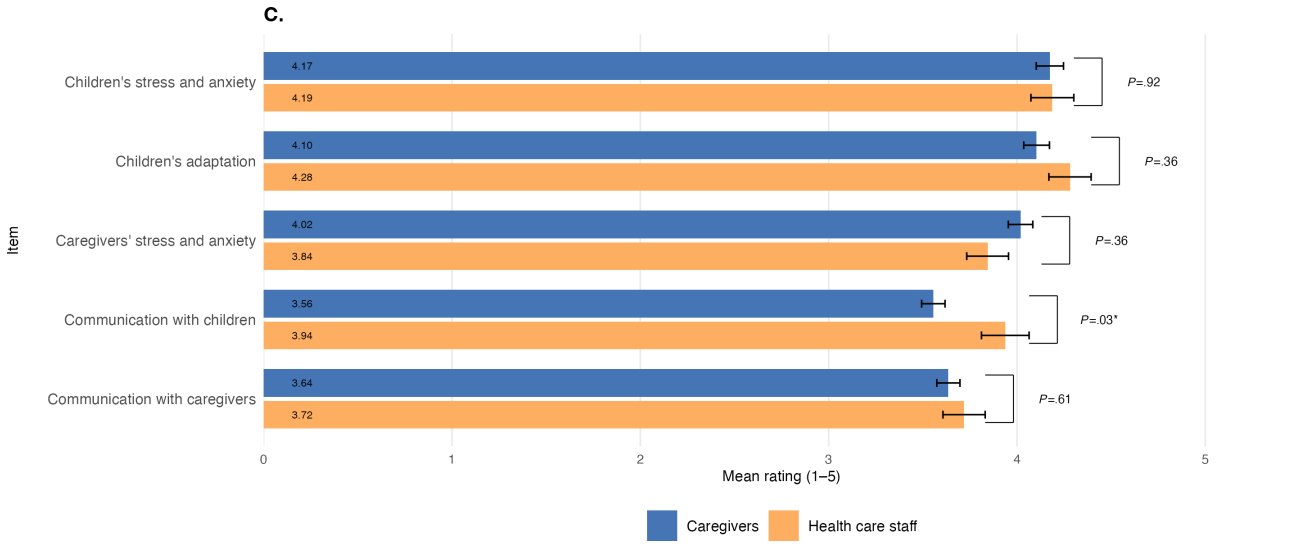
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Figure 4. Health care staff perspectives on LOVOT impact (n=32): (A) impact on children and caregivers (items 1-7), (B) impact on staff and ward environment (items 8-12), and (C) comparison between caregiver (n=110) and staff (n=32) ratings for 5 matched items. Left panels show the distribution of Likert-scale responses (1-5). Right panels show mean differences from baseline (3="no change") with 95% CIs. The bars represent means with SEs. Between-group comparisons were conducted using Mann-Whitney *U* tests with false discovery rate correction. Statistical test results are shown in Table S3 in Multimedia Appendix 4. **P*<.05.

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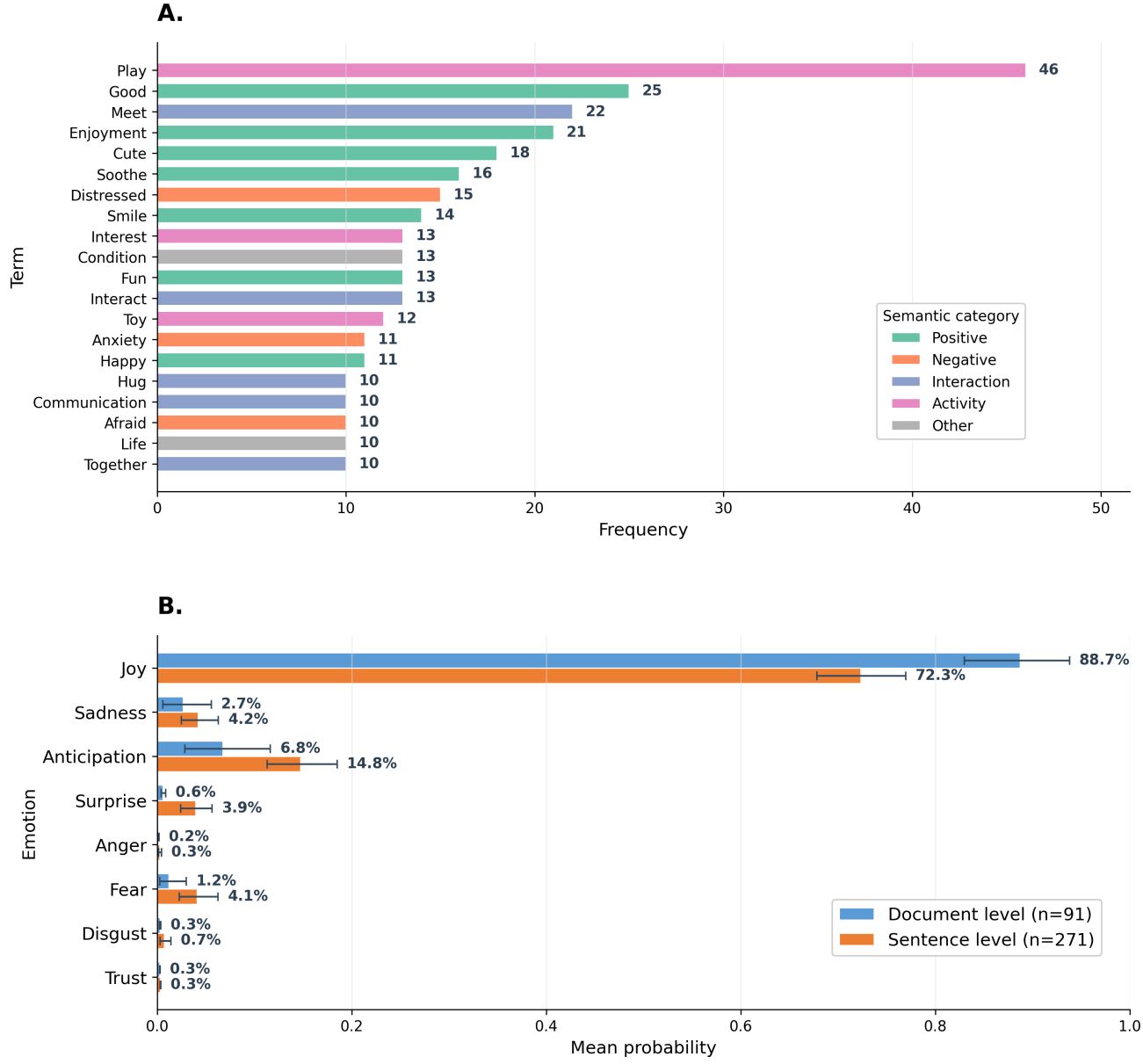
Agreement Between Caregiver and Staff Ratings

For 5 matched items, ratings from caregivers and staff were compared using Mann-Whitney *U* tests with FDR correction (Figure 4). Four of 5 comparisons showed no significant differences: children's stress and anxiety (*P*=.92), children's adaptation (*P*=.36), caregivers' stress and anxiety (*P*=.36), and communication with caregivers (*P*=.61). Only communication with children showed a significant difference (*P*=.03), with staff rating perceived improvement higher than caregivers (mean 3.94, SD 0.72 vs mean 3.56, SD 0.65).

Qualitative Findings

Analysis of 91 free-text responses revealed predominantly positive experiences (Figure 5). The most frequent terms included "play" (n=46), "good" (n=25), "meet" (n=22), "enjoyment" (n=21), and "cute" (n=18), reflecting themes of play, positive evaluation, and emotional engagement. Emotion classification using the LUKE-Japanese-large model classified "joy" as the predominant emotion at both the document level (mean probability 88.7%, 95% CI 86.8%-90.6%) and sentence level (mean probability 72.3%, 95% CI 69.1%-75.5%). At the document level, most responses (82/91, 90.1%) were classified as joy dominant. Other emotions detected at lower probabilities included anticipation (6.8% at the document level and 14.8% at the sentence level) and fear (1.2% at the document level and 4.1% at the sentence level). The predominance of joy and the prominence of play and positive evaluation themes in the qualitative responses are consistent with the quantitative findings of perceived improvement in children's enjoyment and adaptation, and the 2 analyses thus reinforce each other.

Figure 5. Qualitative analysis of free-text responses (n=91): (A) top 20 high-frequency terms in the Japanese free-text responses, shown with their English translations (translation dictionary provided in Table S2 in Multimedia Appendix 3) and (B) emotion distribution comparing document-level (n=91) and sentence-level (n=271) classification using the LUKE-Japanese-large model. The bars represent mean emotion probabilities with 95% CIs (bootstrap: 5000 iterations).



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Discussion

Principal Results

This study examined the perceived impact of LOVOT, a companion robot, on hospitalized children, their caregivers, and health care staff. Both caregivers and staff reported consistent perceived improvements across nearly all assessed outcomes, with mean ratings ranging from 3.28 to 4.62 on a 5-point scale. The largest perceived improvements were observed for children's enjoyment and overall well-being. However, because these effect sizes were calculated from 1-sample tests comparing retrospective ratings against a fixed neutral baseline (3="no change") rather than a control group, they are inherently larger than between-group effect sizes from controlled designs and should not be directly compared to those from randomized controlled trials. Importantly, no detectable increase in staff workload was observed, supporting implementation feasibility, although the small staff sample (n=32) limits power to detect small to medium workload changes. Accordingly, the nonsignificant workload result (P=.37) should be interpreted as the absence of a detectable increase rather than as evidence of no change and warrants confirmation in adequately powered studies. The convergence of findings across independent observer perspectives and predominantly positive qualitative responses strengthens confidence in these observations.

Comparison With Prior Work

The positive effects reported are consistent with the broader literature on social robots in health care settings. LOVOT, a companion robot designed for emotional engagement rather than task performance, shares characteristics with other social robots studied in pediatric care, such as Paro [14] and humanoid robots [15-17]. The 1-sample effect sizes in our study appear comparable to or larger than those previously reported [19]; however, direct comparison is limited by fundamental methodological differences as our 1-sample design yielded inherently larger effect sizes than the between-group designs used in most prior studies. Our findings also align with research on animal-assisted therapy, which has demonstrated reductions in anxiety and distress in hospitalized children [8,9]. However, animal-assisted therapy faces practical barriers in busy pediatric wards, including infection control concerns, the need for trained animal handlers, and inconsistent availability due to animal welfare requirements [10,11]. LOVOT offers practical advantages as a robotic alternative: it can be disinfected regularly, operates autonomously without requiring a handler, and provides 24-hour availability without rest periods. Its design, emphasizing passive, tactile interaction through warmth and softness rather than verbal communication, may be particularly suited to pediatric settings where children of varying ages interact freely.

Possible Mechanisms

Several mechanisms may account for these effects. Physical contact with soft, warm objects reduces stress through parasympathetic activation and oxytocin release [22,23]. The presence of tactile-related terms such as "hug" and "touch" in free-text responses supports the importance of physical contact. LOVOT may also function as a positive distraction, redirecting attention from medical concerns to enjoyable interaction [24,25]. Furthermore, LOVOT appears to serve as a social catalyst; staff reported improved communication with both children and caregivers, and "meet" was among the most frequent terms in qualitative responses. Some caregivers described attachment-like relationships developing, with temporal emotional transitions (initial fear→subsequent joy) suggesting LOVOT may facilitate adaptation to the hospital environment.

Implementation Feasibility

An important practical finding is that no detectable increase in staff workload was observed despite positive effects across other domains, addressing concerns about introducing new interventions in resource-constrained settings. This may be attributed to LOVOT's autonomous features, including automatic return to its charging station, which minimizes the need for staff intervention. The minimal training required and LOVOT's self-directed operation make it a low-burden intervention, distinguishing it from other therapeutic interventions that require dedicated staff time. Subgroup analyses revealed consistent effects across age, hospital stay duration, sex, and playroom use frequency, suggesting broad applicability. The substantial improvement in ward atmosphere indicates benefits extending beyond individual interactions. These findings support LOVOT as a feasible addition to pediatric care, complementing rather than replacing existing human-centered psychosocial support. For pediatric wards considering a similar deployment, our experience suggests that a shared playroom placement, a simple infection control routine (regular disinfection and laundering of removable clothing), brief staff orientation, and reliance on the device's autonomous operation are sufficient for day-to-day use. These observations are offered as preliminary practical guidance and require confirmation in controlled, multicenter evaluations.

Limitations

This study has several limitations. First, it relied on retrospective self-report measures of perceived change at a single postintroduction time point rather than prospective pretest-posttest assessments using validated clinical scales. No baseline data were collected prior to LOVOT introduction. Retrospective ratings are subject to recall bias, social desirability bias, and response shift bias (where participants' internal standards for evaluating change may shift over time), potentially inflating perceived improvements. Unlike a prospective pretest-posttest design, which captures contemporaneous baseline and follow-up measurements, our single–time point retrospective approach cannot separate perceived improvement attributable to LOVOT from natural recovery or adaptation occurring over the course of hospitalization. Thus, the reported improvements reflect caregivers' and staff's subjective perceptions rather than objective clinical changes. The observational design without a control group further limits causal inference as improvements may reflect natural adaptation or placebo effects, the stimulating playroom environment itself, or the novelty of interacting with a robot. Our design cannot disentangle these influences from any LOVOT-specific contribution. Additionally, no primary outcome was prespecified. Voluntary participation may have introduced

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selection bias at multiple levels: caregivers who had positive experiences with LOVOT may have been more motivated to complete the questionnaire, and because questionnaires were available in the playroom, respondents were inherently those who used the playroom—creating a compound engagement bias favoring families with greater LOVOT exposure. Consistent with this, 62.9% (66/105) of respondents reported using the playroom at least once daily, which may overrepresent high-exposure families. The estimated response rate was 18.4% (115/625); however, the denominator was itself estimated based on the assumption that 25% of admitted children used the playroom, and the actual number of unique playroom users was not systematically recorded. This low and uncertain response rate means that findings may not represent the experiences of all playroom users and likely overestimate the perceived benefits of LOVOT. The staff sample (n=32) was relatively small, and the single-center design in Japan limits generalizability to other cultural contexts. Notably, Japanese culture has historically demonstrated a high affinity for robots, which may have positively influenced not only acceptance and willingness to interact but also the magnitude of perceived emotional benefits; whether similar effects would be observed in cultures with different attitudes toward robots remains to be determined. In regions where attitudes toward social robots are more skeptical, both acceptance and the magnitude of perceived psychosocial benefit may be attenuated; cross-cultural, multicenter replication is therefore needed before these findings can be generalized internationally. The study-specific questionnaires showed acceptable to good internal consistency (Cronbach α=0.67-0.84); however, formal psychometric validation including test-retest reliability and construct validity was not conducted. Without established construct validity, the extent to which items accurately capture the intended constructs remains uncertain, and the questionnaire items were designed to assess distinct facets of LOVOT's impact rather than a single unidimensional construct. The emotion classification model (LUKE-Japanese-large) was fine-tuned on general Japanese text rather than medical or pediatric contexts, and its validity for analyzing health care–related free-text responses has not been established. Because the model was trained on social media–style text, domain shift relative to caregivers' and staff's clinical free-text responses may bias the estimated emotion probabilities; we therefore treat the emotion classification results as exploratory and corroborative rather than confirmatory. The convergence between model-based classification and the model-independent high-frequency term analysis provides partial triangulation. We could not link the perceived outcomes to objective measures of interaction intensity: the device's internal interaction logs (eg, touch and hold frequency) were not available for research export under our deployment configuration, and no separate behavioral observation log was maintained. Integrating objective sensor- and behavior-derived metrics (touch frequency, hold duration, proximity, and interaction duration) is an important direction for future controlled studies and would strengthen the link between interaction and perceived benefit. Finally, the observation period (approximately 11 months) may not fully capture novelty effects or long-term sustainability, although subgroup analyses showed consistent effects among children hospitalized for longer periods (>1 week), suggesting that benefits may persist beyond initial novelty. Future studies should use randomized controlled designs with objective outcome measures, include longitudinal follow-up, and involve multiple centers across diverse cultural contexts.

Conclusions

This study provides preliminary evidence that LOVOT may positively affect hospitalized children, caregivers, and staff across multiple psychosocial outcomes. The convergence of findings across multiple stakeholder perspectives and analytical methods strengthens confidence in these observations, and positive effects were achieved without a detectable increase in staff workload. While the observational design and low response rate limit causal conclusions and generalizability, these findings justify further investigation through controlled trials with prospective outcome measures. Companion robots represent a promising adjunct to psychosocial care in pediatric settings.

Acknowledgments

The authors thank all participating families, children, and health care staff for their cooperation in this study. Generative artificial intelligence (AI) tools were used in the preparation of this manuscript. Claude Code (Anthropic) was used to assist in writing and debugging the R and Python scripts for statistical analysis and figure generation. In addition, AI-based tools were used for English-language editing and proofreading of the manuscript text. The authors reviewed and verified all AI-assisted output, made all scientific and interpretive decisions themselves, and take full responsibility for the content of the manuscript. Generative AI was not used to generate study data, interpret results, or author substantive scientific content.

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Data Availability

The datasets generated and analyzed during this study are not publicly available due to institutional privacy requirements but are available from the corresponding author on reasonable request and with appropriate ethics approval. The complete analysis code is publicly available [24] under the MIT License.

Authors' Contributions

Conceptualization: AI, KT, KK, IU, TM, YI
Data curation: AI, NM, MO, IY, AY, AO, TT, HK
Formal analysis: AI, NM
Funding acquisition: YI
Investigation: NM, MO, IY, AY, AO, TT, HK
Methodology: AI
Project administration: AI
Software: AI
Supervision: KT, KK, IU, TM, YI
Visualization: AI
Writing—original draft: AI
Writing—review and editing: KT, KK, IU, TM, YI
All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary methods: detailed technical specifications of the LOVOT companion robot and the detailed statistical analysis methods.
[PDF File, 469 KB - pediatrics_v9i1e93897_app1.pdf]

Multimedia Appendix 2
Questionnaire items.
[PDF File, 316 KB - pediatrics_v9i1e93897_app2.pdf]

Multimedia Appendix 3
Text analysis materials.
[PDF File, 569 KB - pediatrics_v9i1e93897_app3.pdf]

Multimedia Appendix 4
Statistical results.
[PDF File, 326 KB - pediatrics_v9i1e93897_app4.pdf]

Checklist 1
STROBE checklist.
[PDF File, 159 KB - pediatrics_v9i1e93897_app5.pdf]

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Abbreviations

FDR: false discovery rate
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

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Original Paper

Understanding Adolescents' Experiences of Cyberbullying in Jordan: Evidence From a Narrative Perspective

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Abstract

Background: Based on its nature, cyberbullying is expected to be frequent and prevalent because of the continuity of technological advancement over time. This change results in more victims and is challenging to detect, negatively affecting their health. Given that adolescents in Jordan face a high rate of cyberbullying, it is essential to understand how this experience affects them.

Objective: This study aims to explore individual experiences and perspectives on cyberbullying victimization among adolescents to intervene and reduce future incidences of cyberbullying.

Methods: We based our analysis on a cross-sectional study investigating cyberbullying and its mental health consequences among 400 students aged 14-17 years from public schools in central and northern Jordan. These respondents were asked to answer 3 open-ended questions describing their experiences with cyberbullying if they experienced cybervictimization as either victims or bully-victims, resulting in 240 responses. Thematic analysis was then used to interpret patterns of shared meaning across participants' narratives related to cyberbullying experiences in cyberspace.

Results: A total of 3 key themes and several subthemes emerged from this study: (1) effects of cyberbullying, (2) challenges in overcoming its consequences, and (3) elements influencing the severity of cyberbullying experiences.

Conclusions: The findings offer valuable insights for creating safer online environments and reducing cyberbullying's psychological and social harms through appropriate interventions.

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KEYWORDS

adolescents; consequences; cyberbullying; online harassment; victimization

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Introduction

Cyberbullying is defined as the intentional and repeated use of information and communication technologies to harm, harass, or humiliate others [1]. While the concept of bullying itself has long been studied, the rise of information and communication technologies has shifted many aggressive behaviors into digital spaces. The foundational work of Olweus [2] on traditional bullying remains relevant; however, cyberbullying differs significantly because of its anonymity, potential for wide audience reach, and persistence [3,4].

Adolescents are particularly vulnerable to cyberbullying due to their developmental stage, marked by rapid emotional, social, and cognitive changes [5,6]. According to Bronfenbrenner's Ecological Systems Theory, adolescents interact with multiple individual, family, peer group, and environmental factors that can all influence their experiences with cyberbullying [7]. As they form their identities and social competencies, they become more susceptible to peer pressure, social comparison, and emotional distress, increasing the risk of being both victims and perpetrators of cyber aggression [8,9]. Within this context, other findings suggest that extended online engagement, particularly during nonschool hours, combined with the use of anonymous or fake profiles, significantly increases the risk of cyberbullying [10]. The anonymity afforded by fake identities appears to lower social accountability and facilitate harmful behaviors, positioning such profiles as key risk factors in the digital ecology of adolescent cyberbullying [10].

Globally, cyberbullying prevalence varies depending on age group, data collection methods, and cultural context. In the United States, studies report adolescent victimization rates ranging from 3% to 72% and perpetration rates ranging from 1% to 41% [11]. Another national American sample of 1034 preadolescents aged 9-12 years completed an online survey to report their experience with cyberbullying. Of them, 21% have been exposed to cyberbullying as a target, aggressor, or witness to cyberbullying [12]. In Malaysia, 31.6% of adolescents reported recent victimization, and 20.9% reported perpetration [13]. In Indonesia, approximately 80% of seventh-grade students reported experiencing occasional cyber victimization [14]. In Saudi Arabia, the rate was 42.8%, with boys more affected than girls [15]. In Jordan, few studies exist, but moderate to high prevalence has been reported, often linked to educational level and academic performance [16-18]. These findings suggest that cyberbullying is a widespread issue, but one that requires culturally contextualized understanding.

Cyberbullying has serious psychological consequences, particularly for adolescents. Victims often experience anxiety, depression, low self-esteem, and social withdrawal [19,20]. Cyberbullying differs from traditional bullying in its ability to invade the victim's private space continuously, and the anonymity of aggressors intensifies its effects [4]. The diathesis-stress model of psychopathology posits that psychological problems arise from a combination of an individual's experience of stressful events and their inherent susceptibility to developing the disorder [21]. This model helps explain how individual vulnerabilities (eg, impulsivity and low self-regulatory efficacy) interact with environmental stressors such as cyberbullying to produce mental health symptoms [22]. Limited coping skills, a lack of social support, and the ubiquity of digital access can exacerbate the impact [3].

Despite growing research on cyberbullying, many studies focus on prevalence and institutional responses, often overlooking the subjective experiences of adolescent victims. A deeper comprehension of the context of bullying and its effects on young people is required [23]. There remains a critical gap in understanding how victims personally experience and cope with cyberbullying, as well as the long-term psychological, emotional, and social repercussions of this type of behavior. This gap is particularly critical in regions such as the Middle East, where digital behaviors intersect with unique social and cultural norms [24]. In Jordan, youth face distinct challenges related to family expectations, gender norms, and limited digital literacy resources [25,26]. These factors may shape how cyberbullying is perceived, reported, and addressed. Understanding adolescents' lived experiences in this context is essential for developing effective, culturally grounded interventions. Since cyberbullying can be prevented through several interventions and programs [27], current interventions might not be deep enough to address victims' particular struggles if victims' voices are not included, which could result in an insufficient support network.

Therefore, this study aims to explore the lived experiences of Jordanian adolescents who have been victims of cyberbullying, focusing on their emotional reactions, coping mechanisms, and self-perceptions. This victim-centered approach is grounded in the principles of trauma-informed care, which emphasizes safety, empowerment, and recognition of the long-term psychological impact of trauma, especially in adolescent populations [28,29]. By centering adolescents' narratives, the study aligns with narrative psychology, which recognizes the role of personal storytelling in shaping identity, meaning-making [30], psychological growth, and event distress [31]. Furthermore, this perspective reflects the principles of participatory and context-sensitive research, which advocate for involving participants as active contributors to knowledge production and ensuring interventions are culturally and socially relevant [32]. In doing so, the study addresses a critical gap in the literature and contributes valuable insights for the design of culturally grounded, psychologically responsive cyberbullying interventions in the Jordanian context.

Since this study is likely grounded in exploratory and descriptive goals rather than hypothesis testing, several exploratory questions were provided to align with the narrative and qualitative nature of the study, as follows:

- How do adolescents who have experienced cyberbullying describe its effects?
- What factors do adolescents who have experienced cyberbullying perceive as worsening the impact of cyberbullying on their well-being?
- What ongoing challenges to recovery from cyberbullying do adolescents who have experienced cyberbullying report?

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Methods

Ethical Considerations

Institutional Review Board approval was obtained first from the University of Wisconsin-Milwaukee (#24.112), followed by approval from the Jordan Ministry of Education (#4218) and school principals. Participants were informed of their right to withdraw at any time without consequences and of the confidentiality of their data. Parental consent and student assent were secured before data collection. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

Design and Setting

This is a qualitative descriptive study embedded within a cross-sectional survey aimed at examining the prevalence of cyberbullying and investigating its mental health impacts among adolescents and whether gender may moderate the correlation between cyberbullying and mental health. The current qualitative analysis was not explicitly designed to investigate gender differences in narrative content. The main objective was to investigate common experiences and significant themes concerning the effects of cyberbullying on adolescents instead of performing a comparison among demographic subgroups. Using a qualitative descriptive approach provides a practical method for revealing the facts of a phenomenon without requiring an in-depth focus on meaning, as in other qualitative methods such as phenomenology, especially among adolescents [33]. A total of 8 governmental schools in central and northern Jordan were selected for their accessibility and the availability of teachers to facilitate data collection. These schools accommodate a large student population due to mandatory primary education laws [34], with Amman and Irbid, the most populous cities, facilitating recruitment.

Participants, Sample, and Instrument

Participants were male and female adolescents aged 14-17 years in grades 9-11 from public schools in central and northern Jordan. A multistage stratified cluster sampling method was used to select geographical areas, education directorates, schools, and classes. Students diagnosed with uncontrolled mental illness, intellectual disabilities, or narcotic drug use were excluded because of potential impacts on mental health and cyberbullying involvement. School representatives (eg, school principals or teachers) were asked whether students in the selected classes had any detected exclusion conditions that needed to be addressed to ensure the exclusion criteria were met. Also, the exclusionary conditions (chronic illness and untreated psychological disorder) were explained in the consent form so that participants or guardians could decide. Accordingly, no one was excluded.

A total of 400 participants completed a survey consisting of several sections. Participants' involvement in cyberbullying was assessed using the Revised Cyber Bullying Inventory–II (RCBI-II) Questionnaire [35], which includes 10 statements presented in 2 parallel columns, and participants must respond from the viewpoints of both the bully and the victim in the last 6 months. Each item is rated on a 4-point Likert scale reflecting the frequency of behaviors. Based on participants' scores, individuals were categorized into involvement groups. A "bully-victim" was operationally defined as a participant who scored >10 points in both the cyberbullying and cybervictimization sections. In contrast, "pure victims" were those who scored >10 points on cybervictimization only without endorsing any perpetration behaviors, whereas "pure perpetrators" reported perpetration only (scored >10 points on the cyberbullying section). This classification approach is consistent with prior studies using the RCBI-II, allowing differentiation among distinct roles in cyberbullying involvement.

The last section of the survey asked participants to complete it only if they had experienced victimization. As a result, 240 participants (identified as victims or bully-victims based on the RCBI-II) answered 3 additional questions narratively about their online victimization to understand the impact of cyberbullying on them. Those questions were as follows: "What was the effect of the cyberbullying involvement you have had?" "What do you think makes the effect of experiencing cyberbullying worse on you?" and "What are the factors that determine the severity of cyberbullying impacts?" Each of these questions was intended to answer the previously provided research questions. Open-ended survey responses were selected for their ability to enable participants to convey personal experiences in a flexible, anonymous, comfortable, and less intrusive way compared with semistructured interviews or focus groups, which was especially fitting given the sensitive nature of the subject and the adolescent study group. This approach also allowed the inclusion of diverse, large samples within the limits of time, resources, and accessibility, which might not have been practical with interviews or focus groups.

Procedure

Data were collected between January and February 2024. Students were briefed on the study's purpose, procedures, voluntary participation, confidentiality, and withdrawal rights during the first interview. Parental consent and student assent were secured before data collection. Consent forms were distributed during parent-teacher conferences and sent home for signature. School representatives (eg, school principals or teachers) were asked to send the recruitment flyer to parents who did not attend the conferences, reach out to them, explain the study's purpose and procedures, and send the consent forms. Data were collected individually using paper-and-pencil questionnaires in private rooms by researchers and assistants administering the questionnaires, taking 30-40 minutes per student. Personal incentives were provided upon completion, but they were simple, such as pens and notebooks, to avoid any bias in participation or responses. Consent forms and questionnaires were entered into Qualtrics via University of Wisconsin-Milwaukee access. At the same time, hard copies were kept anonymous and securely stored in a locked file cabinet in the researcher's office in Jordan.

When using mental health, behavioral, and quality-of-life assessments, the Committee on the Use of Humans as Experimental Subjects evaluates the merits and drawbacks of addressing these topics with study participants [36]. It assists researchers in determining whether to include mental

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health-related inquiries and devising risk mitigation plans. Unintentional identification may occur when assessing quality-of-life issues like sadness, anxiety, or stress, prompting the Committee on the Use of Humans as Experimental Subjects to recommend a "safety plan" for populations at elevated risk [36]. This plan involved assessing the immediacy of risk by qualified researchers on "Social and Behavioral Research Best Practices for Clinical Research," providing staff training on intervention procedures, and offering participants a resource referral flyer because the data would be anonymous; the flyer included mental health resources, crisis intervention services, or hotline information, depending on the type of risk. After completing data collection, none of the participants required intervention under this protocol.

Data Analysis

Overview of the Analytic Process

Descriptive statistics, including means, SDs, percentages, and frequencies, were used to describe participants' demographic characteristics. Then, a thematic analysis strategy was used as a structured and flexible framework to detect, analyze, and interpret patterns of shared meaning across participants' narratives of cyberbullying experiences in cyberspace [37]. Braun and Clarke's [38] 6-phase framework for thematic analysis was specifically used to analyze the data and is one of the most clearly defined approaches to performing reflexive thematic analysis to describe and summarize data and to offer a range of higher-level inductive or deductive analyses of small or large datasets [39]. The phases are familiarization, coding, initial theme generation, theme development and review, theme definition and naming, and writing up [38]. This framework was suited to this study's aim of exploring the lived experiences of Jordanian adolescents who have been victims of cyberbullying, concentrating on their emotional reactions, coping mechanisms, and self-perceptions. The application of each phase is described in the following subsections.

Phase 1: Familiarization With the Data

This stage involves examining and reexamining data to gain a deeper understanding of the specifics and the broader context of the data, typically beginning with an emphasis on the more evident semantic interpretations before progressing to an analytical engagement with the data [38]. Applying this, participants' responses were translated from Arabic to English using a forward-backward strategy by 2 bilingual translators proficient in both English and Arabic, with knowledge of health care and qualitative research terminology. The first translator translated the Arabic responses into English. The translator and research team discussed and compared the translated versions to create a unified, agreed-upon English version.

Then, backward translation into Arabic was conducted by a second translator who was blinded to the original Arabic version to ensure accuracy and evaluate language clarity. The back-translated versions were compared with the initial responses to detect inconsistencies, ambiguities, or loss of significance. Careful emphasis was placed on maintaining the semantic, cultural, and contextual significance of terms associated with cyberbullying experiences in the Jordanian sociocultural framework. The first author read and reread the transcripts to gain an in-depth understanding of the participants' accounts while noting preliminary impressions and recurrent expressions related to emotional reactions, coping strategies, and perceptions of online interactions.

Phase 2: Coding

This phase starts by organizing data systematically and meaningfully, reducing large amounts into smaller, more meaningful segments. Coding methods can vary, but one approach is to address the research question, which yields theoretical rather than inductive analysis. Thereby, following open coding, which means that we do not have preset codes but rather a coding process [40], we assigned codes to every segment of data that pertained to or highlighted something significant regarding our research question. To enhance engagement with participants' responses, the original coding was carried out manually by the first author, who identified meaningful text units, essential elements, related phrases, and patterns that reflected the research aim, condensed them, arranged them according to similarities and differences, and lastly assigned codes that possess characteristics such as "anxiety and fear," "stress and pressure," and "social agreement."

A selection of the transcripts was independently reviewed by the senior author, who also provided interpretive comments on the coding scheme and thematic organization to ensure reliability. Through cooperative interpretation and consensus building, investigator triangulation was used to reinforce trustworthiness, even though formal intercoder reliability metrics were not computed. Two authors reviewed transcripts and coded data independently to minimize individual interpretive bias. Inconsistencies in coding and theme understanding were addressed through ongoing discussions and agreement. To enhance analytical rigor and minimize possible coder bias, reflexive memoing and peer debriefing were also used to record researchers' beliefs, analytical choices, and thoughts regarding possible impacts on data interpretation. The researchers were mindful of how their expertise and prior knowledge of cyberbullying research might influence their interpretations; therefore, they engaged in ongoing critical reflection throughout coding and theme development. Emphasis was placed on reducing power dynamics by highlighting voluntary participation, ensuring confidentiality, and allowing participants to skip questions or withdraw at any time.

Phase 3: Search for Themes

A theme is a manner that reveals something meaningful or intriguing concerning the data and/or research inquiry [40]. To align with that, the codes were checked for conceptual uniformity and grouped into candidate themes developed by observing recurring patterns in the data. For instance, following connected codes "anxiety and fear," "stress and pressure," and "emotional distress" were assorted into the psychological effects of cyberbullying theme. While codes reflecting "facing the uncomfortable," "disconnection," and "invisible perpetrators" formed a theme called challenges in overcoming cyberbullying consequences. Thematic analysis was conducted iteratively, and codes were contrasted across responses until no new themes emerged, showing a degree of thematic adequacy suitable for

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this research design. Despite the responses being relatively brief, the substantial sample size (n=240) provided a wide range of viewpoints, enabling the identification of consistent trends and prevalent themes.

Phase 4: Reviewing Themes

The identified themes were then reviewed to enhance clarity and coherence. Some overlapping codes were merged, and all themes were checked against the data to verify their reflection of a deeper understanding of participants' viewpoints and experiences with cyberbullying. When suitable, subthemes were created to encapsulate detailed yet consistent patterns of significance within overarching themes. Subthemes were used purposefully to deepen analysis and were not regarded as hierarchical classifications or subcategories. This iterative process enhanced the validity and clarity of the thematic structure.

Phase 5: Defining and Naming Themes

The final thematic structure included 3 major themes: effects of experiencing and being involved in cyberbullying (psychological and social effects), challenges in overcoming consequences of cyberbullying experiences (anonymity of perpetrators, threat and exposure context, and public exposure of incidents), and elements influencing the severity of cyberbullying experiences (individual vulnerability, social response, and digital environment). All themes and subthemes were explicitly outlined to highlight a unique facet of adolescents' experiences of cyberbullying in digital environments, focusing on the interaction between emotional distress, social relationships, and situational influences. During this process, analytic choices were influenced by a focus on meaning-based interpretation rather than frequency or classification.

Phase 6: Producing the Report

In the final phase, the results were presented using themes and subthemes, which were synthesized into a coherent narrative supported by illustrative verbatim quotations that reflected the variation and depth of experiences, in parallel with Braun and Clarke's [38] reflexive thematic analysis. This framework provides a rich understanding of the psychological, social, and technological aspects of cyberbullying as experienced by adolescents. The findings were interpreted within the framework of adolescent developmental psychology and the sociocultural context of Jordan.

Results

Descriptive Characteristics of the Participants

A total of 240 participants admitted to engaging in cyberbullying as a victim or bully-victim; of these, 47% (113/240) were females aged 14-17 years, with a mean age of 15.2 (SD 1.01) years. Approximately half were located in Amman. The distribution of grades was approximately 34.2% (82/240) in 9th grade, 32.8% (79/240) in 10th grade, and 33% (79/240) in 11th grade. Approximately 34.8% (83/240) of participants were unaware of their monthly earnings; 30% (72/240) indicated earning between JD 500-1000 (Jordanian dinars; exchange rate: JD 1=US $0.70 as of February 4, 2024), 29% (70/240) earned less than JD 500, and 6.3% (15/240) earned more than JD 1000. Concerning academic achievement, 27% (65/240) indicated an average above 90 in the previous semester, 25.8% (62/240) averaged between 80 and 89, 23% (55/240) between 70 and 79, 13.7% (33/240) between 60 and 69, and 10.5% (25/240) below 60.

All participants had internet access, and 81.5% (196/240) reported having 1-5 social media accounts, with about 64.7% (155/240) spending 1-7 hours online daily. About 51.4% (123/240) of the people who engaged in cyberbullying were victims, and 48.6% (117/240) were bully-victims. Answers to the questions assessing the bully's identity indicated that 47.1% (113/240) of the 240 people who reported being a victim, a bully, or a bully-victim had met a bully in real life, and 44.2% (106/240) said the bully was the same gender as them. Friending the bully was the most common relationship (99/240, 41%), followed by someone in the school (46/240, 19.2%), strangers (42/240, 17.5%), former friends 29/240, 12.1%), and chat room users (24/240, 10%), respectively. Three key themes and 8 subthemes emerged from this study: (1) effects of experiencing and being involved in cyberbullying, (2) challenges in overcoming consequences of cyberbullying experiences, and (3) elements influencing the severity of cyberbullying experiences (Table 1).

Table 1. Themes and subthemes related to cyberbullying experiences.

Theme	Subthemes
Effects of experiencing and being involved in cyberbullying	• Psychological effects (eg, anxiety, emotional distress, and sleep disturbances) • Social effects (eg, isolation, withdrawal, and relationship difficulties)
Challenges in overcoming consequences of cyberbullying experiences	• Anonymity and sense of powerlessness (difficulty identifying perpetrators and lack of control) • Threatening and exploitative nature (fear, coercion, and misuse of personal content) • Public exposure and wider harm (rapid dissemination and long-term reputational impact)
Elements influencing the severity of cyberbullying experiences	• Individual vulnerability and coping capacity (age, resilience, prior experiences, and self-confidence) • Role of others in shaping the experience (peer, family, and institutional responses) • Digital environment as an enabler (cyberbullying tactics, the purpose of cyberbullying, the number of bullies, the lack of regulations and penalties, and platform features that facilitate the spread of harmful content)

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Themes

Effects of Experiencing and Being Involved in Cyberbullying

Psychological Effects

Participants stated profound emotional consequences of being involved in cyberbullying as victims or bully-victims. Feelings of badness, leading to crying because they did not know how to deal with such an experience, were common. Further, feelings of emotional distress, anxiety, fear, stress, and pressure, and cognitive and behavioral issues were recurrently expressed. The following quotes illustrate those feelings. For anxiety and fear, a participant said, "I felt embarrassment, inferiority, ugliness, dissatisfaction with one's body, and a feeling of not being included with other people in society." While this quote, "I got angry and sensitive regarding any word," is an example of stress and pressure. Finally, the following quote reflects cognitive and behavioral issues:

> *I felt unfortunate; I felt that I do not deserve friends, I do not trust anyone, even my friends, I have suicidal ideation because the people around me damage my heart.*

Several participants reported intrusive thoughts, sleep disturbances, and a sense of helplessness. One participant noted:

> *I felt afraid to open my phone because I did not know what I would find next... I was thinking about that the whole night, so I was not able to sleep.*

Some mentioned self-accusation and internalized shame, thinking they had somehow triggered or warranted the bullying. Such responses frequently resulted in diminished self-esteem and a negative self-image, as one participant explained: "I started to think, is there something wrong with me?!" Another participant stated, "I had bad feelings because I did not know how to deal with that person and get revenge on him... I felt like a useless and bad person in this life."

Social Effects

Participants reported experiencing equally significant social effects. Many participants reported altered trust in others, becoming more cautious, withdrawing from social circles, and experiencing isolation and loneliness, along with changes in social situations, as a result of their experiences.

> *I remember when I posted strictly in the snap in a group, then a girl bullied me and said I am a Lier, black, and ugly; I left the group and broke the phone.*

Another participant stated:

> *It is a bad experience to the degree that you do not want to confront others and felt embarrassment, making you isolated and do not want to see others.*

Participants described being isolated from others because of feeling forsaken and depressed, which subsequently affected their academic performance, social interaction, and caused social anxiety and loneliness, especially if the perpetrator is a close person. Others described avoiding social interactions in schools or online platforms to avoid victimization. A participant described:

> *The experience impacted my social relationships directly... it affects social situation by being isolated from others and affects academic performance.*

Another one said, "I stopped talking to my peers because I thought they were all laughing at me." These experiences often damaged friendships and family relationships, intensifying feelings of loneliness and social alienation.

Challenges in Overcoming Consequences of Cyberbullying Experiences

Overview

This theme highlights several traits that make the cyberbullying experience terrible and hinder participants' ability to recover from cyberbullying victimization, including knowing the identity of the perpetrator, the exploitative nature of cyberbullying, and public exposure.

The Anonymity and Sense of Powerlessness

The participants addressed this subtheme by mentioning 3 features that intensify the difficulty of coping with harm caused by a hidden perpetrator: a disconnected, invisible perpetrator, and facing the unconfrontable. The anonymity of the perpetrator is the most reported trait because the inability to see the perpetrator is a provocative thing, not to know who is behind the screen, so they say whatever they want without fear, freely, and make it difficult to confront them, subsequently, making it difficult to limit or control cyberbullying, especially through the distancing communication, which amplified feelings of powerlessness and fear. As one participant expressed, "not knowing who was behind the screen made me feel fear and unsafe everywhere."

The following quote refers to facing the unconfrontable feature:

> *The anonymous feature of the perpetrator is terrible, so you cannot reach the perpetrator to confront and defend yourself and talk about your feelings.*

The bullies cannot see the victim, then will say whatever they want without fear, freely, which represents the invisible perpetrator feature. The following quote is an example of the disconnected feature: "Lack of face-to-face contact, and the distance interaction makes one feel bad."

The Threatening and Exploitative Nature of Cyberbullying

The threatening and exploitative context are other crucial traits that can be acquired by accessing private information, threatening to share it with the public, deleting things that are not theirs, and passing judgment without evidence. For instance, a participant said, "Exploitation using photos or videos or voice messages to request huge amounts of money to remove them is the worst thing." Another participant said, "Exploitation in public and threatening to reach the relative was so bad." In contrast, a third one recalled, "Using the private context to request immoral or intolerant things or to threaten the victim was challenging." Such actions of unauthorized distribution of personal material exacerbated emotional distress and fostered a continual feeling of susceptibility. "They said they would share my pictures if I did not do what they wanted. I felt blackmailed and exploited," one participant explained.

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The Public Exposure and Wider Harm of Cyberbullying

Public and remaining possible nature of cyberbullying victimization emerged as a critical challenge to overcome such experiences, which appeared in 3 features, including quick spread, presence of many audiences, and direct psychosocial impacts. “The worst thing about it was happening in the public context and making others laugh at me...” is an example of the many-audience feature. Another participant reported that once harmful content was shared, it spread rapidly across online platforms, inhibiting the ability to move on and recover. “The spread of behavior in social media,” “Even if I delete or deactivate my account, people still remember what was posted,” some participants expressed.

Regarding the direct psychosocial impact of such public experience, when cyberbullying is directed explicitly to the psychosocial effects impacting an individual’s emotional status, social connections, and self-esteem, leading to feelings of inferiority and isolation, because a person tries to avoid others to prevent re-experiencing cyberbullying again. In this regard, participants expressed:

> *Cyberbullying impacted my self-esteem and caused fear of dealing with others to avoid re-experiencing it again, which impacts all aspects of life, like getting a job.*

Elements Influencing the Severity of Cyberbullying Experiences

Overview

When the participants were asked what they thought were the factors determining the severity of the cyberbullying effects, they mentioned several personal, social, and digital aspects that influence the intensity and duration of cyberbullying impacts.

Individual Vulnerability and Coping Capacity

This subtheme includes several individual characteristics, such as age, identity, self-confidence, psychological resilience, prior psychological problems, prior experience of cyber victimization, and lack of awareness of online security and regulations. Participants expressed that younger individuals or those with lower self-esteem are more pointedly affected by cybervictimization. While those with strong emotional regulation were more likely to cope, a participant recalled that “Older people have experience and know how to deal with cyberbullying; younger children are at higher risk.” Further examples that reflect the rest of the characteristics are: “Lack of confidence and weak personality intensify impact,” “being a victim of previous bullying experience.”

> *The awareness about the response to cyberbullying victimization, like informing about electronic crimes, blocking the bullies, and keeping accounts secure and not giving passwords to anyone, has a great role in strengthening victim response.*

Role of Others in Shaping the Cyberbullying Experience

This subtheme includes 4 aspects: social agreement, bystander and close people support, unhealthy social relationships and family conflicts, and the relationship with the perpetrator.

Regarding social agreement, participants discuss how cyberbullying begins with one individual and escalates as others join in, forming a larger group engaged in the behavior when the social context does not reject such behavior, leading the perpetrator to repeat the same behaviors due to the nature of social agreement. This quote is an example of “the social agreement, starting with one person, then others participate in the bullying, and it becomes a big group cyberbullying.” Social support arises as a protective factor against the impacts of cyberbullying. A participant said:

> *Lack of bystander support makes bullies think that they are correct... presence of support, especially emotional support from trustworthy people like family and friends, can minimize cyberbullying impacts.*

Those responses indicate that adolescents with supportive families, educators, or peers experienced less anxiety and faster healing.

Unhealthy social relationships and family conflicts worsen cyberbullying impact by adding extra emotional distress. For instance, a participant expressed that “What aggravates the bullying effects is the emotional pressure and the family conflict or problems.” The relationship with the perpetrator was mentioned as an essential factor that interferes with the bullying experience effect. Being close or related vs a stranger can elevate the adverse effects of cyberbullying: “Knowing the perpetrator... the relationship with him, if he is a close friend, relative, or a stranger, differs in the effects.” Additionally, societal expectations regarding shame and reputation frequently prevented teenagers, especially girls, from revealing incidents. “I did not inform my parents since I feared they would confiscate my phone or hold me responsible,” one participant stated.

Digital Environment as an Enabler of Cyberbullying

Many participants discussed other digital features that directly determine the severity of cyberbullying’s impacts, including the context of cyberbullying behavior, the tactics used, the purpose of cyberbullying, the number of bullies (one vs group), and the lack of regulations and penalties. Regarding the context of cyberbullying, the type of posted information can aggravate adverse effects because posting personal information to exploit others, sharing sensitive family secrets, or private photos or videos has more emotional impacts than general nonfamily-related information. For instance, a participant stated that “the type of shared information, private versus usual... posting the personal issues online so hurtful.” When it comes to tactics and targets of cyberbullying, the ways used to bully a victim (photos, videos, posts, or comments), the words used, the purpose of bullying (color, body image, or religion), the number of bullies (one vs group), and continuing out of the online context to in-person bullying are essential to determine adverse effects. A participant recalled:

> *...the ways used to bully victims influence severity of experience, it differs if bullies use images, videos, posts, or comments, and what kind of words are used.*

Another participant expressed that:

> *Targeting the body image or one of the innate characteristics that are difficult to change using*

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> *hurtful wards... the loneliness effect and realizing that these things that I was bullied about are things that exist in me, and I cannot change them increase the severity of adverse effects on me.*
>
> *The situation was so terrible because not one but group of my classmates had bullied on me through hurtful wards in the class WhatsApp group, then they started to do the same in the school in front of many.*

Some participants mentioned the lack of educational sessions on how to deal with cyberbullying, the lack of protective regulations and rules (eg, no regulation of posts and their spread), and the level of expertise of the perpetrator, all of which are factors that affect how bullying impacts the victim. These quotes illustrate this: "...how expert the perpetrator is influences the impact because of his ability to use different techniques."

> *Lack of punishments for bullies, lack of knowledge how to respond, and lack of support for victims... There are no educational sessions on how to deal with cyberbullying.*

In conclusion, the study revealed the multifaceted nature of adolescents' experiences with cyberbullying. The findings highlight that beyond the digital realm, cyberbullying effects extend to affect psychological status and social functioning, including emotional distress, anxiety, cognitive disturbances, social withdrawal, and damaged trust. Key challenges in coping with cyberbullying were linked to the anonymity of perpetrators, the exploitative use of private information, and the public nature of online attacks, all of which intensified feelings of helplessness and humiliation. The presence of social support is a protective factor that facilitates recovery from cyberbullying victimization. The severity of these effects was influenced by personal vulnerability, social agreement and support, the nature of the relationship with the perpetrator, and digital factors such as the tactics used, the number of bullies involved, and the absence of regulations or accountability mechanisms. Together, these findings highlight the urgent need for targeted prevention, context-sensitive interventions, and educational initiatives to promote emotional resilience and online safety among Jordanian youth.

Discussion

Overview

This study added evidence on the effects of cyber victimization and elaborated further on the challenges and determinants of this experience. The results can be interpreted via the Stress–Diathesis Model, which suggests that psychological outcomes result from the interplay between environmental stressors and personal vulnerabilities [21,22]. Cyberbullying served as a major stressor in this study due to its ongoing presence, anonymity, public visibility, and exploitative nature. Participants' experiences vary based on factors such as individual coping abilities, resilience, and prior emotional vulnerabilities. Participants with limited coping resources seemed more vulnerable to anxiety, emotional suffering, and social isolation. Concurrently, social support from family, peers, and teachers served as a protective factor, mitigating the adverse psychological effects. These results indicate that the effect of cyberbullying is influenced not only by exposure but also by the complex interplay of digital stressors and personal vulnerabilities.

The findings provided an answer to the first research question about the effect of cyberbullying experience. According to the participants, cyber victimization mainly affects psychological health and social relationships, which are sometimes overlapping. This is in line with Sung [41], who states that cyberbullying impacts psychosocial adjustment, including mental health, self-esteem, and social relationships. The negative emotions that cyberbullying elicited ranged widely from wanting to avenge and retaliate to feeling sad, hurt, embarrassed, angry, humiliated, isolated, marginalized, and powerless. The findings are also consistent with a study that used data from a qualitative thematic analysis of several data sources considering the effects of cyberbullying; numerous people mentioned crying for extended periods and feeling upset, emotional, choked, crushed, hurt, and generally miserable [42].

Cyberbullying victimization as a stressful situation may lead to changes in the brain's internal structures, as shown by the discovery that cyberbullying victims have more severely disrupted cortisol reactivity [20] and altered emotional brain function [43]. Social isolation is one of the most severe effects of cyberbullying. It differs significantly from traditional bullying in that there are no limitations on when or where technology can be used for communication. Social isolation, increased suspicion, and signs of posttraumatic stress disorder may happen when cyberbullying tactics expose the victim's humiliation to an extensive audience viewing [44]. The lack of acceptance among their peers causes victims to feel lonely and socially isolated, have low self-esteem, and be depressed [45,46]. It can also cause stress-related disorders, problems with concentration and learning in school, emotional disorders, and even suicidal thoughts [46]. Thus, developing effective prevention and intervention strategies to support those affected is crucial.

The analysis supported the second question that participants' narratives revealed persistent barriers to overcoming cyberbullying victimization. Participants shared a wide range of thoughts on the most challenging part of their cyberbullying experience. They described those difficulties in a manner that reflects the unique cyberbullying attributes of anonymity, publicity, and threatening context. Cyberbullying possesses distinctive traits due to its online nature and lack of face-to-face contact, such as its persistent nature, broad audience reach, and anonymity, distinguishing it from traditional bullying [47]. Anonymity, particularly in public online spaces, may hinder prevention efforts as perpetrators can remain unidentified. Anonymity exacerbates feelings of helplessness and perceived power imbalances in cyberbullying situations, pushing victims to keep their experiences silent without reporting. Victims may feel powerless and vulnerable when perpetrators possess embarrassing or harmful material that cannot be controlled and published online at any time in front of many people [48]. However, earlier studies, predating 2010, did not prioritize these characteristics, as evidenced by the systematic review by Berne et al [49].

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Participants stated that the threatening and exploitative context of cyberbullying is one of the critical reasons why they consider this experience challenging, primarily when the bully uses private information to request immoral or intolerable things or to threaten the victims in public and threaten to reach their relatives. Also, accusing victims and passing judgment on them for things that are not true without evidence leads to feelings of inadequacy and altered psychosocial functioning, including suicidal thoughts and avoidance of social interaction to avert re-experiencing bullying. Thus, it is necessary to develop interventions to overcome such situations. For example, using celebrity endorsements is effective in highlighting the effects of cyberbullying and favoring an inclusive strategy that educates on prevention skills, promotes reporting, allows anonymous online reporting, and revokes internet privileges for perpetrators, where mandatory reporting, suspensions, or police involvement predicted a significant decrease in support from uninvolved students, witnesses, victims, and perpetrators [50].

The study findings illustrated that personal and interpersonal factors significantly shape how severe the impact of cyberbullying is on adolescents, which answers the third question. Adolescents in Jordan stated that the severity determinants of experience impacts are an integration of many personal, social, and digital factors related to cyberbullying behavior. According to participants, with age, people gain more skills and knowledge to deal with bullying; personality and beliefs, psychological strength, awareness of online security, and previous bullying experience are the most personal determinants of cyberbullying effects. Subsequently, younger children need more interventions that focus on enhancing their awareness of and skills to deal with cyberbullying and online websites, specifically school-based intervention programs [51] that target emotional intelligence and strengthen psychological well-being.

The participants stated that some social factors determine the severity of cyberbullying effects as well, such as social acceptance, lack of support, family conflicts, and relationship with the bully. Given the reality that adolescents experience marked patterns of cyberbullying victimization and perpetration based on individual and social support factors [52]. Social support is essential for victims of cyberbullying because it can protect them from the damaging effects of bullying. Individuals are more able to handle the strain and emotional anguish brought on by cyberbullying when they have supportive relationships with friends, family, or peers [53]. In addition to offering practical help, emotional validation, and a sense of community, social support can make victims feel less alone and more resilient in the face of bullying [54]. Having supportive relationships can also motivate victims to report incidents, seek assistance, and take precautions to stay safe online when they believe they have friends who support them in solving problems, regaining their confidence, and resuming social interactions in their surroundings [55]. In general, social support is essential for reducing the negative impacts of cyberbullying and enhancing the well-being of its victims. However, there is low perceived family and peer social support among youth [56], making this an essential area for intervention. As youth spend a long time online, initiatives are needed to promote online help-seeking and empower parents and peers to support their well-being [57].

Lastly, participants talked about some digital factors that are directly related to the nature of cyberbullying behavior, which were essential in determining the severity of victimization. The type of posted information can aggravate adverse effects because posting personal information to exploit others, sharing sensitive family secrets, or sharing private photos or videos has a greater emotional impact than general, nonfamily-related information. On the other hand, the ways used to bully victims (photos, videos, posts, or comments), the words used, the target of bullying (color, body image, or religion), the number of bullies (one vs group), and continuing out of online context to in-person bullying are essential determinants of adverse effects.

Implications

The findings of this study underscore the urgent need for culturally responsive victim-centered clinical and technology supported interventions, policy reforms, and accessible mental health services to mitigate the psychological and social harms of cyberbullying on adolescents. Raising awareness of harmful content and the dangers of sharing personal information online should be prioritized through school-based education and parental guidance. Schools need targeted interventions, such as implementing digital safety and mental health programs that include emotional regulation training and peer-support methods, in light of the identified effects of distress, isolation, and relationship difficulties, taking into consideration the sociocultural context of adolescents and parents, such as communication norms and culturally specific views on online conduct. Family-based interventions are essential, as parents play important protective roles. These interventions should focus on open communication, digital literacy, and supportive oversight methods that can enhance teenagers' ability to cope and their resilience when dealing with cyberbullying. Mobile apps or online platforms offering psychoeducational resources could enhance parental understanding and facilitate early recognition of distress related to cyberbullying, effectively.

Health care providers, especially nurses and public health professionals, have a critical clinical role in routine screening for bullying during medical visits, such as including questions on intake forms [51], which can facilitate disclosure and early intervention. Following the COVID-19 pandemic, increases in online activity have altered the landscape of cyberbullying, highlighting the need for updated, trauma-informed care policies [58]. Moreover, integrating innovative tools, such as narrative-based audio-visual interventions, into prevention programs may enhance adolescents' engagement and emotional processing. For instance, initiatives like programs that have shown that multimedia storytelling can foster empathy and resilience [59,60]. In line with scalable digital mental health strategies [61], interventions could benefit from using mobile health technologies, digital counseling services delivered through schools, and chatbot-assisted psychoeducation to deliver prompt, accessible assistance. Future studies should be built on longitudinal, intervention-based designs to explore the efficacy and cultural relevance of these technology-driven approaches across various social and cultural contexts.

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Limitations

Although this study provides valuable insights into the contexts and perspectives surrounding cyberbullying victimization among adolescents in Jordan, several limitations should be acknowledged. First, data collection relied solely on 3 open-ended narrative questions within a survey, which may have limited the depth and nuance of participants' responses in reflecting subtle coping strategies, long-term effects, or intricate family and school interactions. Future research could benefit from using in-depth interviews or focus groups to allow adolescents' experiences to be expressed more richly and in greater detail. Second, the sample was drawn exclusively from central and northern Jordan, limiting the generalizability of the findings to adolescents in other regions. Environmental, cultural, and technological factors in southern or rural areas may shape cyberbullying experiences differently.

Additionally, the use of self-report methods may introduce bias due to participants' desire to present themselves in a favorable light or their reluctance to disclose sensitive information. The timing of data collection during the school year may also have influenced responses, as experiences of cyberbullying can fluctuate depending on school-related stress and peer interactions. To strengthen generalizability and validity in future research, studies should aim to include more diverse regional samples, consider longitudinal designs to capture temporal patterns, and incorporate mixed methods approaches that combine narrative inquiry with quantitative measures. Future studies should also explore how gender may shape experiences, interpretations, and coping strategies related to cyberbullying.

Conclusion

This study provides a novel and context-specific contribution to the understanding of cyberbullying's psychological and social impact on adolescents in Jordan, a region where such research remains limited. Our findings illuminate how the anonymity of perpetrators, the exploitative nature of online threats, and the public exposure of cyberbullying significantly amplify adolescents' emotional distress, social withdrawal, and behavioral disruption. Notably, the results also highlight how the absence of moral courage and bystander intervention, shaped by social dynamics, personal vulnerabilities, and unhealthy relationships, intensifies victims' feelings of isolation and helplessness. This underscores the need to incorporate frameworks that foster moral courage and active defense behaviors into intervention strategies, which are currently underexplored. By addressing these gaps, this study contributes to a victim-centered understanding of cyberbullying and offers direction for targeted, culturally relevant prevention efforts. Future research should build on these insights by using in-depth interviews or longitudinal designs to explore long-term effects and associated outcomes such as coping mechanisms, academic disruption, self-harm, and other high-risk behaviors. These extensions would deepen our understanding of how early experiences with cyberbullying shape adolescent development and inform more holistic and trauma-informed support systems.

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Authors' Contributions

All authors have met the authorship requirements. All authors contributed to the study conception and design. Material preparation, data collection, and analysis were performed by AME, HAA, MMA, YIC, AM, and VT. The first draft of the manuscript was written by AME and JG, and all authors commented on previous versions. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

RCBI-II: Revised Cyber Bullying Inventory–II

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Original Paper

Neurobiosensory and Visual Patterns of Attentional and Emotional Functioning in Children Using Machine Learning: Cross-Sectional Study

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Abstract

Background: Attentional functioning in childhood emerges from the interaction between cognitive, behavioral, and emotional processes. Children with these vulnerabilities frequently exhibit executive function deficits, including working memory, inhibitory control, cognitive flexibility, and processing speed, which compromise the ability to regulate attention, plan, and organize tasks, and modulate emotional responses, highlighting the need for screening approaches that integrate multiple dimensions of child functioning.

Objective: This study aimed to develop and evaluate an automated, real-time, and simultaneous multimodal screening approach capable of identifying individualized cognitive-emotional-attentional profiles and behavior patterns in children through the integration of oculomotor, emotional, and neuropsychological measures, supporting earlier detection and personalized interventions.

Methods: A cross-sectional design was used to assess a sample of 260 children aged 7-15 years through a multimodal approach integrating neuropsychological tests (2- and 3-symbol cancellation tasks from the Coimbra Neuropsychological Assessment Battery; Trail Making Test Parts A and B), eye-tracking metrics, and automated facial emotion recognition during rapid naming and emotion recognition tasks. Oculomotor, emotional, and cognitive data were captured simultaneously and in real time, enabling dynamic characterization of cognitive-emotional interactions at millisecond resolution during task performance. A machine learning pipeline based on a random forest classifier, with a gradient boosting surrogate model used for Shapley additive explanations interpretability analyses, analyzed these data to differentiate children with lower attentional performance from children with normative attentional performance.

Results: The random forest classifier achieved the best performance in the exploratory 80/20 hold-out evaluation (area under the receiver operating characteristic curve=0.9527; F_2-score=0.9055; accuracy=94.2%; sensitivity=88.5%; specificity=100%). To validate the absence of test-set selection bias, a nested 5×5 stratified cross-validation was conducted with model selection based exclusively on inner-fold F_2-scores. The negligible difference between nested cross-validated area under the curve (AUC; mean 0.9506, SD 0.0378) and the hold-out AUC (ΔAUC=0.0021) confirmed that the original result was not inflated. Children with lower attentional performance showed increased emotional reactivity, greater gaze instability, fragmented visual exploration patterns, higher variability in fixation behavior, and more frequent impulsive saccadic movements during emotionally salient tasks. Anger and fear stimuli showed stronger discriminative value across attentional performance levels, suggesting that emotional processing modulates attentional allocation.

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Conclusions: The simultaneous, real-time capture of eye-tracking, emotion recognition, and neuropsychological data, combined with post hoc analysis within an interpretable machine learning framework, may support the identification of behavioral patterns associated with attentional functioning in children. This multimodal approach provides ecologically grounded and behavior-centered indicators that may support future screening and intervention strategies in educational and clinical contexts.

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KEYWORDS

attentional functioning; eye-tracking; machine learning; real-time multimodal capture; risk profiles; screening-support; support neurovisual assessment

Introduction

Attention-deficit/hyperactivity disorder (ADHD) is a neurodevelopmental condition with a global prevalence estimated at approximately 8% in children and adolescents [1], characterized by persistent patterns of inattention, hyperactivity, and impulsivity that interfere with functioning or development [2]. A diagnosis of ADHD requires a full clinical evaluation that cannot be based solely on screening measures. In addition to the core symptoms, impairments are also observed in executive functions (EFs; including working memory, inhibitory control, and cognitive flexibility), as well as emotion dysregulation and attentional processes (sustained/selective attention), which collectively contribute to academic, social, and emotional difficulties [3-5].

The EFs are a set of interrelated higher-order cognitive processes that emerge and develop during early childhood, supporting attention regulation, suppression of distractions, and the planning and coordination of goal-directed tasks [3,5,6]. Key components include working memory (holding and manipulating information), inhibitory control (suppressing impulsive responses), cognitive flexibility (the ability to shift perspectives), and processing speed (the efficiency of cognitive processing). These foundational skills are crucial for many developmental outcomes, including social, emotional, and academic achievement [7,8]. Early childhood represents a sensitive period for the maturation of executive systems, particularly within the prefrontal cortex, which underpins these functions. Deficits in EF during this period are associated with decreased resilience, lower self-regulatory efficacy, and increased behavioral problems in school-age children, and are longitudinally linked to increased risk of neurodevelopmental difficulties [9-11].

A growing body of research highlights the role of EFs in emotion regulation. A comprehensive study found that working memory, inhibitory control, cognitive flexibility, and processing speed play an important role in the regulation of emotional responses and behavioral adaptation [12]. New neurodevelopmental evidence suggests reduced spontaneous activity in frontal regions associated with executive and inhibitory control, while adolescents exhibit more widespread alterations, including cerebellar and sensorimotor areas, suggesting age-dependent differences [13]. Longitudinal evidence further shows that EF and processing speed are closely linked to attentional difficulties, each contributing uniquely to inattentive behaviors [14]. These executive deficits are closely linked to emotional dysregulation, including increased reactivity and difficulties in emotion recognition, and are associated with elevated risk for anxiety and mood difficulties [4,15].

Despite growing recognition of attentional functioning as a multimodal phenomenon, diagnosing ADHD remains challenging, often relying on clinical interviews, behavioral observations, and rating scales that may be influenced by contextual and interpretative biases. As a result, growing attention has been given to data-driven, noninvasive technologies to complement traditional assessments [16]. One such technology is eye-tracking, which has emerged as a promising tool for the objective assessment of attentional mechanisms across cognitive, clinical, and developmental contexts [17,18]. Visual attention is dynamically expressed through eye movements, which reflect how visual information is organized and processed during task performance. Eye movements are therefore not merely motor responses, but functional indicators of attentional allocation, inhibitory control, visual exploration strategies, and visual-cognitive regulation [19,20]. These processes can be objectively examined through eye-movement patterns, including fixation stability, gaze dispersion, saccadic regulation, and visual scanning organization, which provide measurable indicators of attentional control and cognitive efficiency [21]. Children with lower attentional performance have been shown to exhibit atypical gaze patterns, including reduced attention to others' eyes during emotion recognition tasks [22], as well as broader difficulties in processing emotional scenes [23].

According to Barkley's [24] theoretical model, ADHD may arise from a primary deficit in behavioral inhibition, disrupting the development of EFs such as working memory, self-directed speech, emotion regulation, and planning. Recent eye-tracking studies have provided further insight into visual attention and oculomotor control in children, advancing understanding of underlying neurocognitive processes [25,26]. However, traditional assessment approaches often fail to capture the dynamic, moment-to-moment interplay between gaze behavior and emotional reactivity that characterizes real-world attentional functioning [27-29]. Addressing these gaps, this study aims to develop a rapid and ecologically valid method for identifying individualized cognitive-emotional-attentional profiles in children and adolescents, grounded in the premise that attentional functioning is inherently linked to emotional and social cognition.

By integrating eye-tracking data with measures of EF and emotional regulation, this study adopts a multimodal neurovisual perspective on attentional functioning, aiming to characterize behavioral profiles associated with differences in

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visual-attentional regulation, emotional processing, and cognitive control. To this end, the study uses a machine learning (ML) classification approach in which multiple algorithms are used.

The random forest classifier was used as the primary model within a multimodal analytical framework integrating neuropsychological measures, emotion-processing tasks, and eye-tracking indicators to characterize attentional-functioning profiles in children and adolescents. A key methodological feature of this study is the integration of oculomotor, facial-emotional, and cognitive data collected within a single platform, enabling the analysis of multimodal behavioral streams with high temporal precision. The use of ML algorithms, combined with explainability techniques such as Shapley additive explanations (SHAP), may support strong predictive performance while providing interpretable outputs in clinical and educational settings [30]. However, it should be emphasized that the approach used in this study characterizes behavioral patterns of attentional functioning rather than establishing clinical classifications and is therefore limited to a screening process based on psychometric and behavioral indicators, not representing a clinical diagnosis, which requires a comprehensive multidisciplinary assessment by qualified professionals. In this study, behavioral profiles refer to recurring multimodal patterns derived from neuropsychological, oculomotor, and emotional measures associated with different levels of attentional functioning. These profiles are identified through a data-driven approach and do not represent clinical categories or diagnostic classifications; rather, they reflect variability in attentional, emotional, and visual-processing dynamics during task performance.

Building on the previous theoretical and empirical foundations, the following hypotheses were formulated:

- H1: Children with lower attentional performance will exhibit less efficient and more unstable oculomotor patterns compared to children with higher attentional performance, reflected in greater gaze dispersion, increased variability in fixation durations, less organized visual exploration, and a higher frequency of impulsive saccadic movements;
- H2: Emotional stimuli are expected to differentially affect attentional allocation, with children showing lower attentional performance exhibiting distinct gaze patterns and emotional responses compared to children with higher attentional performance.
- H3: Children with lower attentional performance will exhibit weaker integration between gaze behavior and facial emotional expression patterns, reflected in greater variability across both domains.

This study aims to advance understanding of the mechanisms underlying attentional and emotional processing and to inform the development of tailored interventions based on cognitive and emotional profiles. By leveraging behavioral and emotional data, this approach enables faster and more consistent evaluations [31]. By integrating eye-tracking, emotion analysis, and cognitive measures collected in real time, the proposed framework provides a more automated screening model for identifying subtle behavioral patterns through multimodal analysis.

Methods

Participants and Procedure

A total of 260 children aged 7-15 (mean 10.36, SD 2.50; median 10, IQR 8-12) years from a public elementary school in the northern region of Portugal participated in the study. Of the total participants, 142 (54.6%) were male. The age distribution was mainly concentrated among children aged 7 years (n=46, 17.7%), 12 years (n=45, 17.3%), and 8 years (n=41, 15.8%), while the remaining participants were distributed across the other age groups within the 7-15-year range. Regarding attentional performance, the sample was evenly distributed, with 130 children classified as having adequate attentional performance (“good”) and 130 classified as having poorer attentional performance (“poor”), each group representing 50% of the sample. A balanced distribution was obtained through a case-control sampling procedure, preserving the ecological validity of both groups while ensuring methodological rigor in the context of ML classification. Sex distribution was also comparable between groups: the good attentional performance group comprised 60 female and 70 male individuals, whereas the lower attentional performance group comprised 58 female and 72 male individuals.

Inclusion criteria comprised children aged 7-15 years attending a regular school setting. Exclusion criteria were based on the student’s school records: (1) not having Portuguese as a first language, (2) inability to recognize the alphabet, (3) presence of any motor impairments that could interfere with task performance, and (4) intellectual disability or developmental delay. Only participants with complete data across all experimental conditions were included in the final sample, ensuring consistency and robustness for subsequent multimodal and ML analyses.

Eye movements were recorded using the Tobii Eye Tracker 4C, a remote, infrared-based binocular eye-tracking system operating at 90 Hz. According to manufacturer specifications, the system provides spatial accuracy of approximately 0.4°-0.5° and a precision of less than 0.2° root mean square under optimal calibration conditions.

All assessments were conducted under standardized environmental conditions, including controlled ambient lighting and a fixed viewing distance of approximately 60 cm between the participant and the display monitor. Participants were seated comfortably, and a standardized 9-point calibration procedure was performed individually prior to each assessment session. Recalibration was undertaken whenever tracking quality was deemed suboptimal. Only recordings demonstrating stable binocular tracking and complete data acquisition across all experimental conditions were retained for subsequent analysis.

Experimental tasks were administered under fixed presentation parameters within the Neurobiosensorial platform, which integrates real-time eye-tracking with automated facial emotion recognition during rapid naming and emotional face recognition paradigms. Facial emotional responses were recorded via

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webcam and analyzed using the HSE-AffectNet framework embedded in the platform. The system was designed to detect basic facial emotions (happiness, sadness, anger, fear, and surprise), which are widely regarded as universal expressions within Ekman's theoretical framework and are comparatively less dependent on linguistic processing.

The assessment protocol was administered individually by a trained psychologist during a single session lasting approximately 45-60 minutes, in the absence of caregivers. Although no formal breaks were scheduled, task demands were systematically alternated to mitigate fatigue and sustain participant engagement. The protocol was previously piloted to ensure developmental appropriateness for the target age group, thereby supporting standardized data acquisition while minimizing potential sources of external interference.

The protocol followed a fixed sequence: (1) 2- and 3-symbol cancellation tasks from the Coimbra Neuropsychological Assessment Battery (CNAB), (2) Trail Making Test (TMT), Parts A and B, and (3) eye-tracking–based tasks, including Rapid Naming of Shapes and Colors and emotion recognition. In line with the study's hypotheses, oculomotor indices derived from eye-tracking (eg, fixation variability, gaze dispersion, and saccadic patterns) were used to capture attentional stability and visual efficiency, while emotion-related measures were used to examine the modulation of attention by emotionally salient stimuli.

Cutoff scores from assessment instruments were used to support screening-based interpretations of attentional difficulties, applied solely for research purposes and not for clinical diagnosis. This distinction is critical given the study's focus on characterizing variability in attentional functioning rather than establishing diagnostic categories.

Ethical Considerations

The study was conducted in accordance with the Declaration of Helsinki and was approved by the Clinical Review Board, the Ministry of Education (approval number 0786500001), and the school principal. Parental or legal guardian written consent was obtained for all participants, authorizing the use of the children's data for research purposes. Participation was voluntary with no compensation, and confidentiality and the right to withdraw at any stage were guaranteed. All data were anonymized and deidentified prior to analysis, and appropriate data protection measures were implemented to safeguard participants' information.

Assessment Instruments

Sociodemographic Questionnaire

This questionnaire was specifically designed for the purpose of this study to characterize the sample (eg, age, gender, educational level, and parental occupational status).

Neuropsychological Assessment

The Cancellation Scale From the CNAB

This subscale evaluated attention and EFs in children [32]. The task required the child to visually scan a sheet filled with various symbols and mark specific target stimuli within a specified time limit. Performance was measured based on the number of correctly identified targets and the number of commission and omission errors. Higher accuracy and fewer errors indicate better attentional control and executive functioning.

In the original validation studies, the CNAB Cancellation subtests showed adequate psychometric properties for the pediatric population, including satisfactory internal consistency (Cronbach α values ranging from 0.78 to 0.86 across age groups) and good interrater reliability (intraclass correlation coefficients >0.90). Construct validity was supported by significant correlations with other established measures of attention and processing speed, and discriminant validity was evidenced by the subtest's ability to differentiate between typically developing children and those with attention-related disorders [32]. In this study, only the 2- and 3-symbol cancellation tasks from the CNAB were used, each consisting of a single trial; therefore, internal consistency indices such as Cronbach α could not be calculated. Evidence of reliability for the current application relied on prior validation studies of the CNAB, which have reported acceptable stability and sensitivity coefficients for these tasks in similar populations [32]. A screening cutoff score of 7 or below was also used as an indicator of potential attentional difficulties [32].

The TMT (CNAB Subscale)

This subscale [32] assessed attention and EFs in children and consisted of 2 parts: Trail A and Trail B. In Trail A, the child is asked to draw lines connecting numbers in ascending order (eg, 1-2-3...), while in Trail B (applied to children aged 7 years or older, as it requires knowledge of the alphabet), the task becomes more complex by requiring the child to alternate between numbers and letters in ascending order (eg, 1-A-2-B...). Time to complete the instrument is measured in seconds. Errors are not directly scored, but they can influence overall performance, as the examiner intervenes when a mistake occurs by pointing out the last correct response, thereby increasing completion time. Each part of the Trail Task consists of a single trial; thus, internal consistency indices could not be computed. Moreover, in the absence of a test-retest design, it was not possible to directly assess temporal stability. Reliability evidence for the present application is therefore based on previously published psychometric studies of the TMT, which have shown satisfactory stability and validity in similar populations [32]. In this study, performance was interpreted using established screening cutoff scores, with values <7 indicating poorer attention performance [32].

The Rapid Automatized Naming of Shapes and Colors (CNAB Subscale)

This instrument [32] was integrated with eye-tracking and facial emotion recognition tools. The child was presented with a visual sheet containing a sequence of shapes (triangles, circles, and squares) in different colors (yellow, green, and blue) and was asked to name each shape and its corresponding color line by line, as quickly and accurately as possible. During task performance, an eye-tracker recorded oculomotor activity to analyze visual exploration patterns, including fixation count and duration, regressions, and loss of sequence. Raw gaze data were processed using a velocity-based fixation classification

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algorithm (Identification by Velocity Threshold) with a minimum fixation duration of 100 ms. Additional metrics included saccadic amplitude, interfixation interval variability, and the coefficient of variation of fixation duration. These measures index attentional stability, visual exploration efficiency, and visual-cognitive organization. Composite indicators of visual efficiency and attentional instability were derived from gaze dispersion, fixation variability, and saccadic transition patterns. Simultaneously, a facial emotion recognition system records spontaneously displayed emotions, providing insight into the affective experience associated with cognitive performance. This combined approach may support a multimodal examination of attentional and emotional processes during rapid visual-verbal tasks. No screening cutoff score was used; instead, comparative analyses were based on the distribution of total response times across participants. Children were divided into groups representing higher and lower task performance, determined by e-based segmentation of total naming time (with the lowest quartile representing faster, more efficient performance and the highest quartile indicating slower processing). Between-group comparisons were then conducted to examine differences in accuracy, eye-tracking parameters (eg, fixation count, fixation duration, and regressions), and patterns of emotional expression.

Emotional Processing Multimodal Assessment

Emotion Recognition

This task was performed by the Neurobiosensorial program [33]. This platform was specifically designed to enable the simultaneous, real-time recording of eye movements and facial emotional responses within a single integrated environment. This program tracks eye movements and pinpoints eye position while executing a specific task (emotion naming), while detecting emotional responses [33]. Eye-tracking measures eye movement at millisecond intervals, providing insight into the cognitive processes involved in task interpretation. The participant's facial expressions are analyzed using HSE-AffectNet and webcam image analysis combined with AI technology to identify emotions experienced throughout the task [34]. The program's interface relies on 27 simple facial recognition points (eg, pupils, eyebrows, and the nose area) as reference markers. During each task, whether it involves a higher cognitive demand or emotional identification, a list of the emotions felt by the child throughout the experience is generated as an outcome [34].

Emotion Naming

This task was based on the emotion recognition paradigm developed by Paul Ekman, adapted to assess children's ability to identify basic facial emotions [35]. The task focuses on 5 fundamental emotions: happiness, sadness, anger, surprise, and fear. In each trial, the child is presented with 4 images of facial expressions, each depicting a distinct emotion. The child is then asked to identify which images correspond to the target emotion verbally indicated by the examiner (eg, "Which face shows sadness?"). The primary variables are the ocular movement patterns and the emotions experienced by the participants, recorded simultaneously and in real time using an eye-tracking system and a camera-based facial emotion recognition system. This synchronized, dual-stream capture allows direct examination of moment-to-moment interactions between where a child looks and what emotional state they express. While the child is asked to identify the target emotion among the 4 images, the system captures their visual scanning paths, fixation points, and saccades, providing insight into the attentional strategies used during emotion recognition. Raw gaze data were processed using a velocity-based fixation classification algorithm (Identification by Velocity Threshold), with a minimum fixation duration threshold of 100 ms [34]. This procedure segmented gaze data into fixations and saccades based on movement velocity profiles.

Areas of interest (AOIs) were defined based on the spatial structure of each task. In the rapid automatized naming task, AOIs corresponded to the stimulus grid and sequential naming regions [36]. In the emotion recognition task, AOIs were defined around facial stimuli, including key regions such as the eyes, mouth, and overall face, given their relevance for social and emotional processing. A tolerance margin was applied to account for minor tracking variability [36].

Composite indicators of attentional instability and visual efficiency were derived from gaze dispersion, fixation variability, and saccadic transition patterns, capturing higher-order interactions between visual attention, emotional reactivity, and oculomotor regulation. Eye-tracking data were analyzed using custom computational pipelines. Extracted metrics included fixation count (total fixations within task-relevant AOIs), mean fixation duration (attentional engagement), saccadic amplitude (visual exploration dynamics), and gaze dispersion (spatial distribution of attention) [35,36].

Additionally, the facial emotion recognition system recorded the spontaneous emotional reactions elicited in the child while observing the stimuli, assessing the child's ability to recognize emotions and their affective responses, as well as the visual processing behaviors associated with each emotion. Some participants may spend more time on the eye region, while others may focus on the mouth or the overall facial contour. Additionally, the number and sequence of oculomotor metrics can differ depending on attentional control, processing speed, and familiarity with emotional expressions. This natural variability affects the consistency of the data when aggregated across participants; however, it remains meaningful as it reflects genuine differences in attentional and cognitive processing styles [34,36].

Data Analysis

Overview

Two significant sources were used: (1) clinical test results (Cancellation, Trail A, and Trail B) providing screening-based attentional-performance labels (1=lower attentional performance, 0=typical attentional performance) and (2) behavioral metrics collected from eye-tracking and emotion recognition during 6 tasks: "Rapid Naming of Shapes and Colors-NRFC)," "anger," "joy," "sadness," "fear," and "surprise." A child was included only if all metrics were available across all tasks.

A total of 30 variables selected from an initial set of 61 engineered features were used in the final model. Each variable

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reflects cognitive-emotional interaction patterns. The features were selected spanning 5 behavioral domains: (1) oculomotor and attentional metrics derived from eye-tracking (eg, gaze path length, dispersion, fixation duration variability, interfixation interval variability, and visual efficiency), (2) emotion-specific expression and gaze features (eg, expression duration, dwell time, and gaze allocation per emotional category), (3) aggregated emotional indices (eg, emotional intensity, transition rate, valence balance, emotion bias duration, and number of active emotions), (4) composite cognitive-emotional indices (Attentional Instability Index, Gaze-Emotion Congruence Index, Emotional Reactivity Index, Visual Efficiency Index), and (5) a demographic covariate (age). These indices represent multimodal neurobehavioral markers integrating visual-attentional, emotional, and oculomotor dimensions.

Preprocessing

The raw integrated dataset contained variables for each child, representing both aggregated and emotion-specific behavioral metrics. No missing values were present in the final preprocessed dataset. The final dataset comprised 260 participants, with a balanced distribution across groups (130 with attentional difficulties; 130 with typical performance). The data pipeline followed a structured three-step procedure prior to model training:

- Step 1: data cleaning and preprocessing. Categorical variables were encoded using one-hot encoding. Missing values in fixation-related metrics were encoded with zeros to ensure dataset completeness and maintain consistency across participants. During this step, absent behavioral events, such as fixations in a stimulus zone not visited by a given participant, were assigned a value of zero, reflecting the absence of that behavior rather than a measurement gap. This domain-appropriate substitution resulted in a complete feature matrix with no missing values at the modeling stage. This preprocessing stage produced a clean, analysis-ready dataset.
- Step 2: feature engineering. Behavioral metrics derived from eye-tracking and emotion recognition were aggregated at the participant level using summary statistics (mean and SD) across trials. In addition, composite indices were computed to capture higher-order cognitive-emotional processes, including the Attentional Instability Index, Oculomotor Control Index, Emotional Reactivity Index, and Visual Efficiency Index). This process resulted in an initial feature set of 61 variables.
- Step 3: feature selection. Feature selection was conducted using mutual information scoring combined with redundancy filtering (correlation threshold $|r|<0.80$). This procedure yielded a final set of 30 features spanning oculomotor attention metrics, emotion-specific gaze and expression variables, aggregated emotional indices, composite cognitive-emotional indices, and age. All feature selection procedures were performed exclusively on the training set to prevent information leakage.

The final dataset was partitioned into training (n=208, 80%) and testing (n=52, 20%) subsets using a stratified split (random state=42) to preserve class proportions. The held-out test set was strictly excluded from preprocessing, fitting, feature selection, and hyperparameter optimization procedures.

ML Model Definition

The classification model was based on 7 classification architectures that were trained and compared, including 5 individual learners—gradient boosting, extreme gradient boosting (XGBoost), light gradient boosting machine (LightGBM), random forest, and support vector machine (SVM)—as well as 2 ensemble strategies: a soft-voting ensemble combining the top 3 models based on cross-validated area under the receiver operating characteristic curve (AUC-ROC; random forest, XGBoost, and gradient boosting), and a stacking ensemble using a logistic regression meta-learner trained on out-of-fold predictions from all base models.

Hyperparameters were independently optimized using Optuna (Bayesian optimization, tree-structured Parzen estimator, 15 trials per model), evaluated via 5-fold stratified cross-validation AUC-ROC on the training set. Optimized hyperparameters and corresponding AUC-ROC scores are reported in Table 1. A 5×3 repeated stratified K-fold was additionally applied to the training data to assess hyperparameter stability; the unbiased performance estimate is provided by the nested 5×5 cross-validation described below.

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Table 1. Models trained, hyperparameters, and Optuna cross-validated area under the curve (AUC-CV).

Model	Type	Key hyperparameters (Optuna best)	AUC-CV	F_2-score (test)
Gradient boosting	Tree ensemble	n_estimators=102, max_depth=6, lr=0.111, subsample=0.865, min_samples_leaf=16	0.9635	0.9055
XGBoost[a]	Boosting	n_estimators=695, max_depth=8, lr=0.158, subsample=0.708, colsample=0.996	0.9566	0.8661
LightGBM[b]	Boosting	n_estimators=768, max_depth=8, lr=0.023, subsample=0.509, colsample=0.739	0.9614	0.8984
Random forest[c]	Bagging	n_estimators=539, max_depth=15, min_samples_leaf=2	0.9528	0.9055
SVM[d]	Kernel	kernel=rbf, C=2.971, gamma=0.039	0.8633	0.8214
Voting ensemble	Soft voting	Top-3 models by AUC[e] (RF[f] + XGB[g] + GBM[h])	0.9589	0.9055
Stacking ensemble	Stacking	Base: top-5 models; Meta: logistic regression (C=1.0)	0.9596	0.9055

[a]XGBoost: extreme gradient boosting.

[b]LightGBM: light gradient boosting machine.

[c]Random forest selected as primary screening framework/predictive model.

[d]SVM: support vector machine.

[e]AUC: area under the curve.

[f]RF: random forest.

[g]XGB: extreme gradient boosting.

[h]GBM: gradient boosting machine.

Model generalization was estimated using a 5×3 repeated stratified K-fold cross-validation strategy applied exclusively to the training set (n=208). This procedure was used to estimate hyperparameter stability during model development. Repeating the 5-fold procedure 3 times (15 folds total) reduces the variance of the performance estimate and provides a more robust basis for comparing models during training.

Although random forest did not achieve the highest cross-validated area under the curve (AUC-CV; AUC-CV=0.9528; full rankings in Table 1), it was selected as the primary model based on its F_2-score (0.9055) and zero false positives (FPs) in the exploratory 80/20 hold-out evaluation (Table 2). The absence of test-set inflation was confirmed by nested 5×5 cross-validation (area under the curve [AUC]: mean 0.9506, SD 0.0378; ΔAUC: mean 0.0021, SD 0.0378).

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Table 2. Classification performance—exploratory 80/20 hold-out.

Model	AUC-ROC[a] (test)	AUC-CV[b] (train, 5×3), mean (SD)	Accuracy	Precision	Recall (sensitivity)	Specificity	F_1-score	F_2-score	FP[c]	FN[d]
Random forest[e]	0.95	0.95 (0.03)	0.94	1.0000	0.8846	1.00	0.94	0.91	0	3
Gradient boosting	0.94	0.96 (0.02)	0.94	1.0000	0.8846	1.00	0.94	0.91	0	3
Voting ensemble	0.95	0.96 (0.03)	0.94	1.0000	0.8846	1.00	0.94	0.91	0	3
Stacking ensemble	0.95	0.96 (0.03)	0.94	1.0000	0.8846	1.00	0.94	0.91	0	3
LightGBM[f]	0.94	0.96 (0.03)	0.92	0.9583	0.8846	0.96	0.92	0.90	1	3
XGBoost[g]	0.95	0.96 (0.03)	0.90	0.9565	0.8462	0.96	0.90	0.87	1	4
SVM[h]	0.81	0.86 (0.05)	0.69	0.6389	0.8846	0.50	0.74	0.82	13	3

[a]AUC-ROC: area under the receiver operating characteristic curve.

[b]AUC-CV: cross-validated area under the curve.

[c]FP: false positive.

[d]FN: false negative.

[e]The primary clinical model uses an optimized classification threshold of 0.48.

[f]LightGBM: light gradient boosting machine.

[g]XGBoost: extreme gradient boosting.

[h]SVM: support vector machine.

The random forest classifier was selected as the primary screening framework based on its F_2-score (0.9055) and zero FPs on the held-out test set. The F_2-score weights recall twice as much as precision, prioritizing clinical sensitivity; the cost of a missed lower-attentional-performance case (false negative [FN]) substantially exceeds that of an unnecessary referral (FP). Although gradient boosting achieved the highest cross-validated AUC, the random forest demonstrated comparable discrimination while providing a more favorable balance between sensitivity and specificity for screening. Its robustness was further confirmed through nested 5×5 cross-validation, achieving a mean AUC-ROC of 0.9506 (SD 0.0378), F_2-score of 0.8953 (SD 0.0664), recall (sensitivity) of 0.8923 (SD 0.0877), specificity of 0.9154 (SD 0.0740), and accuracy of 0.9038 (SD 0.0408). The minimal difference between the nested cross-validation AUC and the held-out test AUC (ΔAUC=0.0021, smaller than the cross-validation SD) indicates that model performance was stable and showed no evidence of performance inflation, supporting its selection as the final screening framework. LightGBM (AUC-CV=0.9614) produced one FP and a lower F_2-score (0.8984) on the test set, making it suboptimal for clinical screening where minimizing false referrals is a priority. Among all models with FP=0 and F_2-score=0.9055 (gradient boosting, voting ensemble, stacking ensemble, and random forest), the random forest achieved the highest test-set AUC-ROC. A gradient boosting model with identical features and data split was trained as a surrogate solely for SHAP interpretability analysis, as TreeExplainer requires direct access to the underlying tree structure.

Training and Validation Strategy

The held-out test set was not used during preprocessing, feature selection, or hyperparameter optimization. In the exploratory phase, model selection was informed by F_2-score and the false-positive rate observed on the hold-out set. The absence of test-set inflation was subsequently confirmed by nested 5×5 cross-validation (ΔAUC: mean 0.0021, SD 0.0378).

Each model was fitted on the full training set (n=208) using its Optuna-optimized hyperparameters. Final evaluation was performed once on the held-out test set (n=52, 26 per class) using the decision threshold optimized on the training cross-validation folds. Performance was assessed using AUC-ROC (threshold-independent), accuracy, precision, recall (sensitivity), specificity, F_1-score, and F_2-score. Recall was designated as the clinically primary metric, with F_2-score used for model selection.

In addition, a threshold sensitivity analysis was conducted across 9 decision thresholds (0.25 to 0.65 in steps of 0.05) for the primary model, to characterize the precision-recall trade-off and support clinical deployment decisions for different use cases (mass screening vs diagnostic confirmation).

Results

Classification Performance

Among the 7 candidate models, random forest, gradient boosting, voting ensemble, and stacking ensemble all achieved F_2-score=0.9055 with 0 FPs; random forest was selected for its highest AUC-ROC within this group. On the held-out test set (n=52), the random forest classifier (threshold=0.48,

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Optuna-optimized) achieved an AUC-ROC of 0.9527, accuracy of 94.23%, precision of 100%, recall of 88.46%, and F_2-score of 0.9055 (Table 2). Every child with typical attentional performance was correctly excluded (FP=0); 3 children with lower attentional performance were missed (FN=3, FN rate=11.54%). Nested 5×5 cross-validation confirmed the absence of test-set inflation (AUC: mean 0.9506, SD 0.0378; ΔAUC=0.0021), supporting the validity of the reported estimates.

Sensitivity Analysis

To assess whether the facial expression confidence score reflected a genuine behavioral signal or acquisition-quality effects, a sensitivity analysis was conducted comparing the full model against a reduced version excluding this feature, with all preprocessing, hyperparameter optimization, and evaluation procedures kept identical. Classification performance remained essentially unchanged (ΔAUC=0.000; Δrecall=0.000; n=52), and SHAP-based feature rankings showed high stability (Spearman ρ=0.959; P<.001; 8/10 top features identical), indicating that the model's predictive behavior does not depend on this feature and is unlikely to be driven by acquisition-quality differences. Full results are presented in Table S1 in Multimedia Appendix 1 and Table 3.

Table 3. Sensitivity analysis: facial expression confidence score.

Metric	Full model (30 features)	Reduced model (29 features)	Δ[a]
AUC-ROC[b]	0.9527	0.9527	+0.0000
Recall (sensitivity)	0.9231	0.9231	+0.0000
F_2-score	0.8955	0.9023	–0.007
SHAP[c] rank correlation (ρ)	—[d]	0.959[e]	—

[a]Δ = full model – reduced model.

[b]AUC-ROC: area under the receiver operating characteristic curve.

[c]SHAP: Shapley additive explanations.

[d]Not available.

[e]P<.001.

Model Comparison

All 7 models were evaluated on the same held-out test set (Table 2). LightGBM and XGBoost produced FP=1 on the test set and were therefore excluded from the primary model selection. Within the FP=0 group, random forest achieved the highest AUC-ROC and was retained as the primary model. The SVM substantially underperformed (AUC-CV=0.8633; test AUC=0.8092; FP=13) and was excluded from further consideration. A gradient boosting surrogate was used for SHAP-based interpretability analysis.

Clinical Threshold Analysis

A threshold sensitivity analysis was performed for the gradient boosting surrogate across 9 decision thresholds (0.25-0.65). Performance remained stable between 0.25 and 0.55 (recall=88%; specificity=96%; FP=1; FN=3), reflecting strong probabilistic separation. Above threshold 0.60, recall drops to 84.6% (FN=4); this range is therefore not recommended. The primary random forest model operates at the Optuna-optimized threshold of 0.48, achieving FP=0 and specificity of 100% (full results in Table 2).

Feature Importance and SHAP Analysis

Feature importance was assessed using SHAP [30] values computed via Tree Explainer on a gradient boosting surrogate model trained on the same 30 features, the same stratified 80/20 split, and the same preprocessing pipeline as the primary random forest classifier (surrogate AUC-ROC=0.9438). This surrogate-based approach was adopted because Tree Explainer yields exact Shapley values for gradient boosting's additive ensemble of shallow trees, whereas application to a random forest requires approximations that degrade under correlated predictors [37,38]. This strategy is consistent with established practice in clinical ML interpretability research [38,39].

Surrogate fidelity was confirmed by a Spearman rank correlation of ρ=0.78 (P<.001) between GBM-SHAP and random forest Gini-impurity rankings, with the 4 most influential features shared across both: attentional bias toward emotional stimuli, visual attention toward joyful facial expressions, visual exploration efficiency, and the proportion of time expressing sadness-related facial expressions. This consistency ensures that the clinical narrative derived from SHAP faithfully reflects the primary model's discriminative logic. It should be noted that the surrogate exhibited FP=1 across all tested thresholds, reflecting stochastic variability inherent to independent model fitting; this does not affect the validity of the SHAP analysis, as both models achieved comparable AUC-ROC (ρ=0.78). SHAP contributions were aggregated by feature group and by facial emotion stimulus category.

Aggregating SHAP contributions by feature category reveals the relative importance of each behavioral domain to the classification decision, as represented in Table 4.

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Table 4. Shapley additive explanations (SHAP) weight distribution by feature group.

Feature group	Total absolute SHAP value (%)
Per-emotion features (expression + gaze)	3.6677 (37.1)
Eye-tracking (oculomotor/attention)	3.2362 (32.7)
Aggregated emotion	2.4375 (24.6)
Composite indices (VEI[a]/AII[b]/OCI[c]/ERI[d]/SEI[e])	0.3895 (3.9)
Demographic (age)	0.1641 (1.7)

[a]VEI: Visual Efficiency Index.

[b]AII: Attentional Instability Index.

[c]OCI: Oculomotor Control Index.

[d]ERI: Emotional Reactivity Index.

[e]SEI: Social Exploration Index.

The 3 most informative domains collectively account for 94.4% of total SHAP weight. Per-emotion features (37.1%) capture how children's facial expressions and gaze allocations differ per emotional stimulus, particularly fear (|SHAP|=0.753), sadness (|SHAP|=0.717), and anger expressions (|SHAP|=0.571). Eye-tracking metrics (32.7%) capture oculomotor instability and scanning inefficiency: higher gaze path length, greater fixation duration variability, and elevated interfixation interval variability are all associated with the lower attentional-performance profile. Aggregated emotion indices (24.6%) are dominated by the mean of recognition bias (|SHAP|=1.726), the ratio of fixations toward negative vs positive emotional faces, which is the single most predictive feature in the model.

The results indicate that lower attentional performance prediction derives from converging evidence across emotional face processing, oculomotor control, and cross-emotion behavioral consistency, consistent with theoretical accounts linking attentional difficulties in childhood to lower attentional performance in both executive attention and socioemotional processing (Table 4).

Among the 30 selected features, the subset of per-emotion features, derived specifically from 1 of the 5 emotional face stimuli (happiness, fear, sadness, anger, and surprise), accounts for a cumulative SHAP weight of 3.667, representing 37.1% of the total model importance. The contributions are markedly unequal across emotional categories:

- Happiness (SHAP=1.338, 36.5%): the dominant emotional stimulus. The majority of this effect was driven by the average visual attention directed toward joyful facial expressions (SHAP=1.249), the proportion of fixations directed toward the joyful face. Children with lower attentional performance show an atypical allocation of visual attention to positive emotional faces, a pattern consistent with altered social orienting.
- Fear (SHAP=0.861, 23.5%): the second most informative stimulus, combining sustained fear expression duration (SHAP=0.753) and its variability (SHAP=0.108). Prolonged and variable fear expressions in the lower attentional performance group suggest heightened anxious reactivity and difficulty recovering from negative emotional arousal.
- Sadness (SHAP=0.717, 19.5%): captured entirely by the proportion of time spent expressing sadness-related facial expressions. Elevated sadness expression was associated with the lower attentional-performance profile, potentially reflecting lower task motivation and negative affective responses during sustained attention demands.
- Anger (SHAP=0.703, 19.2%): contributed through expression duration (SHAP=0.571) and gaze allocation toward the angry face (SHAP=0.132). Together, these indicate both prolonged angry expression episodes and an attentional bias toward threat stimuli, a pattern associated with emotional dysregulation in children with lower attentional performance.
- Surprise (SHAP=0.027, 0.7%): the least informative emotional stimulus. The short duration of expressed surprise provides minimal discriminative power, suggesting that surprise stimuli do not elicit substantially differentiated behavioral responses between the 2 groups.

The 3 negative emotional stimuli combined (fear, sadness, and anger) account for 62.2% of the emotional stimulus contribution, underscoring the disproportionate role of negative affect processing in the attentional-functioning classification. Happiness, while positive, ranks first partly because gaze allocation toward a joyful face is a sensitive marker of social attention, a process known to be altered in children with attentional and executive difficulties.

Multimodal Behavioral Profiles Associated With Attentional Functioning

Overview

To move beyond aggregate performance metrics and toward a clinically meaningful characterization of the model's discriminative logic, 2 composite behavioral profiles were constructed. These profiles describe the patterns of oculomotor, attentional, and facial-emotional behavior that systematically differentiate children at high risk of lower attentional performance from those presenting typical attentional development, as identified through SHAP analysis of the gradient boosting surrogate model.

Each dimension reported below is grounded in the feature's mean absolute SHAP value, its contribution to the multivariate classification decision, and independent univariate group

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comparisons (independent-samples *t* tests, n=130 per group, 2-tailed), as well as Cohen *d* effect sizes.

Profile A: Neurobehavioral Profile Associated With Lower Attentional Performance

Children with lower attentional performance exhibited a coherent multidimensional behavioral profile characterized by:

- Attentional bias toward negative stimuli and increased gaze allocation to socially salient faces.
- Instability and inefficiency in oculomotor control, reflecting disrupted attentional regulation.
- Diffuse and inflexible emotional expression patterns, combining broader affective range with reduced intensity and slower transitions.

This lower attentional-performance profile emerges from the convergence of these 3 behavioral signatures: a systematic attentional bias toward emotionally salient and threatening stimuli, markedly inconsistent and inefficient oculomotor control, and a pattern of diffuse, emotionally inflexible facial expression. Importantly, no single feature is sufficient to define this profile; rather, it is the combined expression of these dimensions that characterizes the lower attentional-functioning profile.

Profile B: Neurobehavioral Profile Associated With Higher Attentional Performance

Children with higher attentional performance exhibited a distinct and active behavioral profile, rather than simply the absence of high-risk markers. This profile reflects efficient, balanced, and flexible cognitive-emotional processing, characterized by adaptive attention allocation, stable and economical oculomotor control, and clear, dynamic emotional expression. Importantly, the low-risk profile emerges from the convergence of three complementary behavioral signatures: balanced attentional deployment across emotional stimuli, consistent and efficient gaze dynamics, and emotionally expressive yet flexible affect regulation. These characteristics represent positive indicators of attentional health rather than merely the inversion of lower-performing attentional features.

Children in the low-risk group, therefore, displayed a coherent and adaptive behavioral profile characterized by:

- Balanced attentional allocation, avoiding overfocus on emotionally salient or threatening stimuli.
- Stable and efficient oculomotor behavior, reflecting organized and sustained attentional control.
- Clear, expressive, and emotionally flexible responses, indicating effective affect regulation.

Discussion

Principal Findings

This study aimed to identify multimodal behavioral patterns associated with different levels of attentional functioning, integrating neuropsychological, oculomotor, and emotional measures within an ML framework. Consistent with previous eye-tracking studies, which have demonstrated that objective measures of visual attention can capture subtle attentional impairments in children with lower attentional performance beyond traditional behavioral observation [40,41], the current findings suggest that combining these objective markers may enhance the sensitivity of assessment frameworks. Overall, the results supported the proposed hypotheses, though with some nuances in the strength and specificity of the observed effects.

The results indicate that children with lower attentional performance exhibit less efficient, more unstable oculomotor patterns, characterized by increased gaze instability, greater variability in fixation duration, and more fragmented visual exploration, along with a higher frequency of impulsive saccadic movements. These results are consistent with previous literature indicating that lower attentional performance is associated with impaired oculomotor control and reduced visual efficiency [20,22]. From a neurodevelopmental perspective, such patterns may reflect underlying inefficiencies in EFs, particularly inhibitory control and processing speed, which are critical for regulating visual attention and goal-directed behavior [3,6]. This interpretation aligns with theoretical models suggesting that deficits in behavioral inhibition disrupt attentional regulation [24]. These findings are consistent with H1, supporting the expectation that lower attentional performance is associated with less efficient and more unstable oculomotor behavior.

A distinctive methodological contribution of this study is the simultaneous, real-time capture of oculomotor, emotional, and cognitive-behavioral streams within a single platform. Unlike traditional assessments, in which gaze data, emotional responses, and neuropsychological performance are collected separately and analyzed post hoc, the present approach enables direct observation of dynamic cognitive-emotional interactions as they unfold during task performance. This revealed patterns, such as the cooccurrence of gaze instability and heightened expression of fear or anger within the same task. This approach allows us to identify not only whether a child performs poorly, but also precisely when and in what emotional context attentional dysregulation emerges, providing a richer basis for generating hypotheses about future personalized intervention strategies.

Additionally, emotional stimulus was found to play a significant role in modulating attention allocation. Conditions involving anger and fear showed strong discriminative value between groups, suggesting that attentional processes are particularly sensitive to emotionally salient information. Children with lower attentional performance demonstrated altered gaze patterns and heightened emotional reactivity to these stimuli, suggesting that emotional processing may interfere with attentional control.

The findings are consistent with previous research indicating that lower attentional performance is associated with atypical processing of emotional cues, including altered gaze allocation to socially relevant facial features and difficulties in social-emotional perception [27,42,43]. Furthermore, eye-tracking metrics revealed increased fixation pattern variability and altered saccadic latencies, consistent with difficulties in maintaining goal-directed visual attention and in efficient attentional control. Previous studies have shown that such oculomotor alterations are characteristic of children with ADHD and other neurodevelopmental conditions [22,44].

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From a broader perspective, the attentional inefficiencies may contribute to cognitive overload and emotional dysregulation, underscoring the close interaction between attentional and affective processes during development. Children with normative attentional performance, by contrast, exhibited more stable fixation patterns, consistent saccadic control, and lower variability across oculomotor indices. These findings are in line with previous eye-tracking studies indicating that normative developmental profiles are characterized by efficient visual attention allocation and a preference for socially relevant stimuli [40,45]. In this context, the results support H2, indicating that emotional stimuli differentially modulate attentional allocation as a function of attentional performance level. The correspondence between our results and the existing literature supports the use of multimodal behavioral markers as promising behavioral indicators of attentional functioning, providing a reference framework against which deviations related to attentional impairments and emotion-related processes can be identified.

Furthermore, the interaction between gaze behavior and emotional expression emerged as a relevant factor in distinguishing attentional profiles. Composite cognitive-emotional indices, such as the Gaze-Emotion Congruence Index and Emotional Reactivity Index, were identified as highly informative features, highlighting the importance of integrated processing across domains. Children with lower attentional performance showed greater variability in both gaze and emotional expression, suggesting less consistent and less coordinated responses. These findings align with theoretical perspectives that emphasize the interdependence of cognitive control and emotional regulation systems during development [42,46]. Rather than reflecting a complete dissociation between domains, the results point to a pattern of dysregulated integration, in which attentional and emotional processes interact in a less stable and less adaptive manner. Similarly, fear-related stimuli elicited attentional disruptions, including prolonged fixations and difficulty disengaging from threatening cues. These patterns are consistent with eye-tracking findings indicating that children exhibiting attentional difficulties display atypical gaze allocation toward fearful faces, accompanied by reduced accuracy in recognizing threat-related emotions [47]. Neurodevelopmental research suggests that atypical amygdala-prefrontal functional dynamics contribute to these effects, reducing top-down modulation and promoting hypervigilance to threat cues [48,49]. Therefore, the findings support H3, suggesting weaker integration between gaze behavior and emotional expression in children with lower attentional performance.

The integration of multimodal behavioral data into a multimodal ML framework suggests potential applications for early screening and for informing future personalized intervention approaches. SHAP analyses allowed identification of the features that most strongly influenced model predictions, offering concrete targets for interventions to improve gaze stability, visuomotor control, and emotion recognition [41,42]. Importantly, it highlights the dynamic interplay between attention, cognition, and emotion, emphasizing the need for integrated intervention strategies that target multiple domains simultaneously.

The study's findings support H1, H2, and H3, highlighting a pattern of oculomotor inefficiency, altered emotional modulation of attention, and reduced integration between cognitive and affective processes in children with lower attentional performance. Nevertheless, it is important to note that these findings reflect behavioral patterns associated with attentional functioning and do not constitute clinical diagnoses.

Finally, this study contributes to the growing body of literature advocating ecologically valid and data-driven approaches to the assessment of neurodevelopmental conditions. By integrating oculomotor behavior, emotional processing, and executive functioning, the present results support a more comprehensive understanding of attentional difficulties during development and highlight the value of multimodal assessment models for early identification and intervention.

Limitations

Despite the promising findings, several limitations warrant consideration. The study was conducted with a relatively small sample size (N=260), which may limit the generalizability of the results and increase the risk of model overfitting, despite nested cross-validation confirming the absence of test-set inflation (ΔAUC=0.0021). The class labels were derived from screening-based cutoff scores (≤7 in the Cancellation task, TMT A, and TMT B) rather than a formal clinical diagnostic gold standard. One feature related to facial expression detection confidence emerged as an influential predictor and showed significant differences between groups. A sensitivity analysis conducted with and without this feature demonstrated that classification performance remained unchanged (ΔAUC=0.000 and Δrecall=0.000) and SHAP-based feature rankings were highly stable (Spearman ρ=0.959; P<.001; 8/10 top features identical), indicating that the model's predictive behavior does not depend on this feature. Nevertheless, a contribution from recording-quality factors (eg, occlusion, lighting, or camera angle) cannot be completely excluded. Consequently, the proposed model should be interpreted as a decision-support or screening tool rather than a definitive diagnostic system. Although the model demonstrated strong internal validation performance through stratified cross-validation and holdout testing, external validation across independent cohorts, larger populations, and multicenter clinical settings remains necessary to further establish its robustness, reproducibility, and real-world clinical applicability. The protocol included tasks that were conducted in semicontrolled environments. Fully naturalistic settings may yield additional insights. Furthermore, medication use was not controlled for and may have influenced attentional and emotional performance, yet the observed patterns remained robust across participants. Cultural and linguistic factors may also influence emotion recognition and attentional patterns, suggesting the need for cross-cultural validation.

Future research should explore longitudinal designs to track developmental trajectories and evaluate the long-term effects of interventions on attentional and emotional regulation, particularly regarding their applications and potential for personalized intervention plans, thereby reinforcing the clinical

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relevance of combining behavioral, emotional, and neurocognitive indices.

Conclusion

The findings indicate that children with lower attentional performance exhibit a complex interplay of attentional instability, oculomotor variability, and heightened emotional reactivity, particularly in response to anger and fear stimuli. These patterns support the proposed hypotheses and suggest that attentional functioning is dynamically shaped by interactions between cognitive and emotional processes. The results highlight the multidimensional nature of attentional functioning, extending beyond isolated cognitive mechanisms to include integrated emotional dynamics. Notably, variability across oculomotor and emotional domains suggests that attentional performance is better understood as emerging from interactions between these systems rather than as discrete abilities.

From a clinical and educational perspective, the multimodal approach, grounded in real-time data capture and post hoc interpretable ML analysis, yields objective, scalable indicators of attentional and emotional functioning, providing a basis for generating hypotheses about future personalized intervention strategies.

This study provides preliminary evidence supporting the use of a multimodal screening approach for differentiating children with varying levels of attentional performance. By integrating eye-tracking, facial emotion recognition, and neuropsychological measures within a single platform, the random forest model achieved high predictive accuracy and robust generalization, as confirmed by nested cross-validation, highlighting its potential as a complementary and ecologically valid assessment tool. The ability to capture oculomotor and emotional data simultaneously within a single session supports the feasibility of a practical, time-efficient assessment approach, though further validation in pediatric and educational settings is needed. Additionally, the use of interpretable ML techniques (eg, SHAP) enhances model transparency and applicability across research and applied contexts. Overall, integrating multimodal behavioral data within an explainable AI framework represents a promising direction for advancing assessment practices regarding attentional functioning across development.

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Data Availability

The data that support the findings of this study are available from the corresponding author, MGP, upon reasonable request.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
All 30 selected features ranked by mean absolute Shapley additive explanations value.
[DOCX File , 33 KB - pediatrics_v9i1e90041_app1.docx]

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Abbreviations

ADHD: attention-deficit/hyperactivity disorder

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AOI: area of interest
AUC: area under the curve
AUC-CV: cross-validated area under the curve
AUC-ROC: area under the receiver operating characteristic curve
CNAB: Coimbra Neuropsychological Assessment Battery
EF: executive function
FN: false negative
FP: false positive
LightGBM: light gradient boosting machine
ML: machine learning
SHAP: Shapley additive explanations
SVM: support vector machine
TMT: Trail Making Test
XGBoost: extreme gradient boosting

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The Feasibility of Supporting Caregivers of Young Children With Disruptive Behaviors Through Nurse-Delivered Phone Coaching: Quality Improvement Study

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Abstract

Background: Although childhood behavior problems are common, and strong evidence-based interventions exist to address these challenges, many families struggle to access care and remain in treatment long enough to see results. The Support and Advocacy through Providing Parents Helpful Interventions, Resources, and Education (SAPPHIRE) program was developed to address barriers to accessing care for disruptive behaviors in young children.

Objective: This quality improvement program assessed the feasibility of SAPPHIRE, a primary care–based intervention delivered via telephone by trained nurses to caregivers of young children (n=36, ages 1 - 6 y) who exhibit disruptive behaviors.

Methods: The feasibility and acceptability of the SAPPHIRE program were assessed during a 3-month quality improvement study.

Results: Of 36 participants, 25 (69%) completed the SAPPHIRE program. Over the course of 3 months, the number of nurse calls with completers ranged from 1 to 15, with a mean of 5.3 (SD 3.4) calls. Overall, nurses spent an average of 120.9 (SD 99.2, range 15 - 380) minutes on the phone with each caregiver across the 3-month pilot period. Caregivers and nurses rated the program as acceptable across all metrics. For nurses, strengths of SAPPHIRE included the continuity of care with one family, while barriers included time constraints. Comparison of preintervention and postintervention caregiver ratings on measures of disruptive behaviors showed a moderate to negligible effect on reported behavior problems depending on the age of the child (children <4 y: d=0.55 and children 4 - 6 y: d=0.18). Caregiver-rated parenting self-competence increased over the course of the SAPPHIRE intervention, approaching a large effect (d=0.75).

Conclusions: Findings suggest that SAPPHIRE is a feasible and acceptable treatment for caregivers of young children with disruptive behaviors and shows promise for increasing parenting self-competence, which is a hypothesized moderator of future behavior problems. These preliminary data support the need for more rigorous empirical evaluation of the SAPPHIRE program.

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KEYWORDS

nursing; telephone; parenting; pediatrics; toddler; health services accessibility; disruptive behavior; parents; quality improvement; coaching

Introduction

Many young children struggle with disruptive behaviors (eg, physical and/or verbal aggression, defiance, etc) that impact their daily functioning at home and in school or daycare settings [1,2]. Prevalence rates of full-threshold disruptive behavior disorders in young children vary, but a recent meta-analysis estimates that as many as 4.9% of children between the ages of 1 and 7 years may meet the criteria for oppositional defiant disorder [2]. Although a spectrum of disruptive behaviors is considered normative in the developmental trajectory, children exhibiting these patterns of behavior—and their caregivers—can still benefit from interventions aimed at both decreasing disruptive behaviors and increasing family and caregiver functioning [3,4].

Even more, early childhood interventions targeting disruptive behaviors have been shown to decrease symptoms of early behavioral issues, bolster caregiver resiliency, and decrease the likelihood of later behavioral health diagnoses for their children [5,6]. Increasing accessibility and utilization of behavioral health

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treatment is particularly important, as studies support the efficacy of early childhood intervention in preventing later behavioral problems, with data suggesting that early emerging problem behavior in young children is malleable through family and caregiver-based interventions [7-9]. Data show that caregivers want opportunities to learn why their children are exhibiting disruptive behaviors and to develop skills to effectively respond to these patterns [10].

There are numerous effective interventions that target disruptive behavior in younger children; however, engagement in treatment may be limited due to a shortage of behavioral health providers trained in these modalities, as well as other accessibility challenges such as finding childcare, transportation, and cost [5,11-13]. Gold-standard interventions, such as Parent-Child Interaction Therapy [7], or Parent Management Training [14] are time- and resource-intensive, and mental health services are not always readily available in easy-to-access healthcare settings [11-13]. These interventions are thus characterized by access disparities, particularly across race and ethnicity [11,13]. Well-established interventions, such as Applied Behavioral Analysis, which are often offered in the home for families of children with behavioral concerns secondary to diagnoses including autism spectrum disorder, address some of these access issues by offering intervention in the family's home environment [15]. These interventions, however, are costly and similarly difficult to access, which is why they are typically used for high rates of symptom severity [15]. Studies have shown significant rates of caregivers of children with disruptive behavior problems being lost to care when referred to behavioral health providers, both in community and primary care settings [13,16]. Accordingly, there is a substantial need for innovative care models that address barriers to access and engagement in treatment aimed at early intervention for young children with disruptive behavior problems.

One potential solution to improve access disparities is to integrate pediatric behavioral health services into the primary care setting [17]. Most youth have access to and visit primary care settings at least annually, so integrating behavioral health services into these clinics has the potential to reach a broad range of patients early in their symptom trajectory [18]. This approach has particular promise for addressing concerns about disruptive behavior, as studies suggest that a first step for many caregivers of children with disruptive behavior is to consult with their primary care provider [19]. As such, positioning low-impact interventions for disruptive behaviors at the point of primary care may increase families' ability to follow through on receiving care [17,18,20-23].

Primary care–based behavioral health interventions have thus far been shown to be effective in decreasing and/or preventing depression, anxiety, and behavior issues in children and adolescents [20]. However, these approaches are not without their limitations regarding accessibility [22,23]. For one, most established primary care–based interventions for behavior problems exclude children younger than 5 years [24], precluding the use of those models as an early intervention. In addition, most models rely heavily on face-to-face, in-person care and the availability of embedded behavioral health providers to deliver the intervention. There is a relative dearth of literature examining alternative methods of behavioral health integration in primary care, such as using providers who may have more availability and are already staples of the primary care setting, such as nurses, or using alternative modes of treatment delivery, such as phone or video encounters, which reduce the need for in-person visits.

To our knowledge, only one group has developed a program designed to address this gap: the Strongest Families Smart Website (SFSW). This program, which was developed in Canada and further evaluated in Finland, includes 11 weekly web-based modules and accompanying telephone calls delivered by trained coaches, including nurses and individuals with public health backgrounds [25]. SFSW was found to have good acceptability and feasibility for parents of 4-year-olds with disruptive behavioral problems in Finland [26], and it demonstrated a significant impact on externalizing and internalizing behaviors that persisted after a 2-year follow-up period [26,27]. The promising results of this program lend support to the potential of phone- and web-based delivery of behavioral management strategies and suggest that nurses can be trained to effectively deliver coaching to help supplement skills training in this area. It should be noted, though, that the SFSW program remained a relatively sizable time commitment (an average of 451 min on web-based content and 418 min on calls) [26] and required sufficient staffing to deliver the coaching calls, which averaged 38 minutes per call. This may not be feasible for all health systems and potentially might be too much of a commitment for use as an indicated prevention or early intervention program for families of younger children and/or children with subclinical disruptive behavior concerns.

To address some of these gaps, the Support and Advocacy through Providing Parents Helpful Interventions, Resources & Education (SAPPHIRE) was developed—a primary care–based intervention that is delivered via brief telephone sessions with trained nurses. The program is designed to be used as part of a stepped care model for caregivers of young children (1 - 6 y) who have disruptive behaviors that may place them at risk for disruptive behavior disorders in the future. SAPPHIRE uses well-established, evidence-based principles from behavioral parent training [14] and was designed to increase accessibility and engagement through innovations such as the phone-based, nurse-delivered format.

The primary aim of this quality improvement study was to evaluate the feasibility and acceptability outcomes of the SAPPHIRE treatment, including participant retention, as well as nurse and caregiver satisfaction. A secondary aim of this study was to examine the impact that the SAPPHIRE intervention had on parenting self-efficacy over the 3-month intervention period, as parenting self-efficacy has precedent as serving as a proximal risk factor or moderator for the severity of behavioral problems in young children [28]. It was hypothesized that there would be minimal immediate changes to child behavior during the 3-month treatment period due to SAPPHIRE being a brief, pilot intervention; however, improvement in parenting self-efficacy was expected.

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Methods

Ethical Considerations

We assessed the feasibility and acceptability of SAPPHIRE. The Mayo Clinic Institutional Review Board reviewed this study and determined it should be designated as quality improvement and did not require further approval from the institutional review board or other ethics board. As this study was designated as quality improvement, no informed consent or assent was obtained; however, institutional guidelines for human subjects protection for quality improvement projects were followed at all times. No compensation was provided to participants.

Sample, Setting, and Recruitment

Participants were recruited through referrals from pediatric and family medicine providers, including physicians, nurse practitioners, and physician assistants, within the participating primary care practice. All referring providers practiced in the same primary care practice associated with a tertiary medical center located in a small city in the Midwest United States. Eligible participants were parents or guardians of children aged 1 to 6 years who had concerns about their child's behavior. Families already receiving treatment for disruptive behavior problems via a specialty service (eg, psychology, occupational therapy, sleep medicine, etc) were excluded. Aside from these exclusion criteria, providers offered the SAPPHIRE program to all eligible families presenting for a primary care visit between August 1, 2018, and July 31, 2021, with expressed concerns about their child's behavior.

Initial evaluations were completed in-person or, after the onset of the COVID-19 pandemic, when the clinic gained the capacity for video visits, via video by a licensed clinical social worker embedded in the primary care practice. During this evaluation, the social worker completed a diagnostic assessment and provided psychoeducation on behavioral parent training principles [14]. The social worker was responsible for assessing the severity of disruptive behaviors, determining if there was an immediate need for a higher level of care, and evaluating the family's ability and interest in participating in SAPPHIRE. The SAPPHIRE nurse then followed up with an initial phone call within approximately one week. Enrollment was contingent upon nurse availability. Given the high rates of staffing shortages due to both situational circumstances (eg, medical and parental leaves) and the impact of the COVID-19 pandemic, families were enrolled on a rolling basis, based on staff availability. Nursing staff typically followed 1 family at a time, with a maximum caseload of 2 concurrent families.

Intervention

SAPPHIRE is a phone-based program in which pediatric primary care nurses provide support and coaching for families implementing behavioral parent training-based strategies. SAPPHIRE was developed in 2018, before the primary care clinic in question had the capacity to deliver video-based care. As such, the telephone was selected as the delivery method to be more convenient for families, as opposed to an in-person visit, which was the only other modality available at that time. The intervention itself was developed using evidence-based parenting principles [14], by board-certified child and adolescent psychologists and licensed clinical social workers with expertise in behavioral interventions for children. Feedback from experts in the fields of child psychology and primary care nursing was obtained and incorporated into the development of the program. During the 3-month intervention period, phone calls took place weekly or biweekly, based on caregiver schedules and nursing clinical judgment. Calls were supplemented by portal messages sent by nurses to summarize the content of each call, as well as to check in with the family during any gaps in contact. Caregivers could also reach out to their nurse-provider via portal or phone between scheduled sessions as needed.

At their intake appointment, families established 2 to 3 behavioral goals for their SAPPHIRE participation. These goals were based on evidence-based parenting principles, including increasing praise and special time, setting clear and consistent expectations, using selective attention, and implementing reinforcement schedules [29]. At the start of each nurse call, these treatment goals were reviewed, progress was measured, and barriers to success were problem-solved. If these initial goals were met, new goals were established with the SAPPHIRE nurse, with as-needed behind-the-scenes consultation with the social worker. Families did not meet with the social worker again during the SAPPHIRE program. When applicable, nurses sent patient education materials or community resources to caregivers following the calls. Nurses also provided support for caregivers by using strategies such as normalizing developmentally appropriate child behaviors and caregivers' emotional responses to these behaviors, as well as providing education about typical childhood development.

Training and Supervision

Six registered nurses with experience working in a pediatric primary care setting (experience ranged from 10 to 30 y) delivered the SAPPHIRE intervention. One nurse had experience working on a child and adolescent psychiatric inpatient unit for 3 years. The other nurses did not have a background in behavioral health. Training was conducted by a board-certified child and adolescent psychologist and a licensed clinical social worker with a specialty in child behavior problems. Training included: (1) readings on behavioral parent training and behavior change principles; (2) participation in 2-hour-long interactive sessions on behavioral parent training strategies and strategies for supporting caregivers, including active listening, normalizing behaviors, promoting self-care, and motivational interviewing; and (3) shadowing social workers for a minimum of 2 hours to observe behavioral parent training therapy sessions.

In addition, nurses participated in monthly hour-long group case consultations with a clinical psychologist and/or a licensed clinical social worker. Topics included case consultation, assessment of treatment adherence and fidelity, and review of SAPPHIRE skills. During this time, nurses reviewed cases and worked collaboratively with the psychologist and social worker to evaluate patients' progress and re-evaluate the appropriateness of treatment goals and the SAPPHIRE program as a whole for the patients' current symptoms. Additionally, the psychologist and social worker were available for as-needed individual case consultations between meetings.

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Measures

At baseline and at the end of treatment, caregivers completed one of two questionnaires assessing their concerns about their child. For older children (ages 4 - 6 y), caregivers completed the Pediatric Symptom Checklist-17 (PSC-17) [30], a 17-item caregiver-report measure used to assess emotional and behavioral problems in children aged 4 years and older. The PSC-17 has been well-validated and contains 3 subscales—attention, internalizing, and externalizing—as well as a total score [31]. Caregivers of children younger than 4 years completed the Preschool Pediatric Symptom Checklist (PPSC) [32], an 18-item emotional and behavioral screening tool used for the early detection of emotional and behavioral problems in infants and preschoolers. This tool is widely used in primary care settings and contains 4 subscales: externalizing, internalizing, attention problems, and parenting challenges [32]. Additionally, at baseline and at the end of treatment, caregivers completed the Parenting Sense of Competence Scale [33], a 17-item measure that assesses self-efficacy in parenting.

Data Collection

Caregivers completed all measures on paper. Families who were scheduled to be on-site for another medical appointment completed the surveys at that time. No families made a separate trip to the clinic to complete the measures. For families who were not planning to be on-site, paper measures were either mailed to them along with a self-addressed stamped envelope or sent as an attachment in their patient portal. Finally, an option to complete the surveys over the phone with a nurse was also offered. If caregivers selected this option, in order to minimize response bias, the nurse who assisted them with their forms was not the same nurse who delivered their SAPPHIRE intervention. Nurses worked with caregivers to determine which method of survey delivery was most convenient for the family.

Data Analysis

Descriptive statistics were calculated to examine retention, patient or family characteristics, and treatment characteristics. In addition, Cohen *d* calculation for *t* tests was used to obtain the effect sizes of significant differences identified and was interpreted according to the following guidelines: 0.02=small effect, 0.05=moderate effect, 0.8=large effect [34].

Results

Participant Characteristics

In total, parents or guardians of 36 children (mean age=4.32, range: 1.42-6.92 y) were enrolled and participated in at least 1 nurse call as part of SAPPHIRE. The sample included 35 (97%) biological mothers and 1 (3%) biological father out of 36 caregivers. Children included 22 (61%) male-identifying children and 14 (39%) female-identifying children out of 35 children. The vast majority were White (34/36, 94%). Most had private insurance (25/36, 69%), followed by Medicaid (9/36, 25%) and Tricare (2/36, 6%). Children were given a range of *International Classification of Diseases, Tenth Revision* diagnoses, including problem behavioral child (18/36, 50%), any adjustment disorder (modifiers included with disturbed conduct, with mixed emotion and conduct, and undefined) (6/26, 17%), attention deficit/hyperactivity disorder or deficit of attention or concentration (3/36, 8%), developmental delay—speech (2/36, 6%), anxiety (1/36, 3%), and disruptive behavior disorder (1/36, 3%). Five out of 36 (14%) patients did not receive a diagnosis. See Table 1 for participant characteristics.

At baseline, 6 caregivers completed the PPSC with a mean score of 13.67 (SD 3.8). Scoring conventions suggest that scores higher than 9 on the PPSC indicate a child is “at risk” and warrant further intervention. Seventeen caregivers completed the PSC-17 for their children, with a mean global score at baseline of 12.94 (SD 5.8), which was slightly below the clinical cutoff of 15. Finally, 24 caregivers rated their parenting self-competence on the Parenting Sense of Competence Scale, with a mean baseline score of 68 (SD 9.6).

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Table . Demographic and clinical characteristics of patients aged 1 - 6 years old with behavioral concerns enrolled in the Support and Advocacy through Providing Parents Helpful Interventions, Resources, and Education (SAPPHIRE) program (N=36).

Characteristics of patients	Values
Age at baseline (y), mean (SD)	4.32 (1.55)
Race, n (%)	
White	34 (94)
Asian	2 (6)
Gender, n (%)	
Male	22 (61)
Female	14 (39)
Insurance, n (%)	
Private	25 (69)
Medicaid	9 (25)
Miscellaneous government	2 (6)
Primary diagnosis, n (%)	
Problem behavioral child	18 (50)
Adjustment disorder (with disturbed contact, with mixed emotion and conduct, undefined)	6 (17)
None	5 (14)
ADHD or deficit of attention or concentration	3 (8)
Developmental delay—speech	2 (6)
Anxiety	1 (3)
Disruptive behavior disorder	1 (3)

Feasibility

Twenty-five out of 36 (69%) families completed the SAPPHIRE pilot program. Treatment completers were defined as families who successfully finished 3 months of the SAPPHIRE intervention or achieved all treatment goals before the 3-month period. Drop-outs were families who did not return for scheduled nurse calls and were lost to follow-up before achieving all treatment goals. Four out of 36 (11%) families were referred to a higher level of care (eg, Parent-Child Interaction Therapy or another more intensive behavioral therapy) before completing the program, and 7 out of 36 (19%) families dropped out without completing treatment after an average of 2.7 nurse calls, with a mode of 1 nurse call. One outlier family received 10 nurse calls before dropping out. Once they were removed from the analyses, the average number of nurse calls for dropouts was 1.5.

Over the course of 3 months, the number of nurse calls with completers ranged from 1 to 15, with a mean of 5.3 (SD 3.4) calls. In total, caregivers from this group had an average of 1.4 (SD 1.7) no-shows for scheduled calls. The mean number of portal messages sent was 2.2 (SD 2.9; range: 0 - 14). Overall, nurses spent an average of 120.9 (SD 99.2, range: 15 - 380) minutes on the phone with each caregiver across the 3-month pilot period. Table 2 describes SAPPHIRE usage data.

Table . Usage data from families enrolled in the Support and Advocacy through Providing Parents Helpful Interventions, Resources, and Education (SAPPHIRE) program (N=36).

	Mean (SD)	Range
Number of sessions	4.4 (3.4)	1 - 15
Number of portal messages	2.2 (2.9)	0 - 14
Number of no-shows	1.4 (1.7)	0 - 8
Total time in intervention (min)	120.9 (99.2)	15 - 380

Acceptability

Caregivers rated the amount of time they spent participating in SAPPHIRE as “just right” and felt the phone-based format was “very convenient” (M=4.78/5). Overall, they thought the program was “very helpful” (M=4.61/5) and rated it as “very good” (M=4.78/5). Caregivers reported that, if they were to go back and do things over, they would be “very likely” (M=3.22/4) to participate in the program again and that they would “absolutely” recommend the program to another family of a

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young child with behavior concerns (M=3.5/4). See Table 3 for caregiver acceptability data.

Table . Caregiver feedback on the acceptability of the Support and Advocacy through Providing Parents Helpful Interventions, Resources, and Education (SAPPHIRE) program.

Questions	Mean (range)
How serious do you currently consider your child's behavior problem (0=not at all; 10=very serious, inpatient treatment necessary)?	3.5 (0 - 8)
How strongly did you influence your child's behavior during your time in the SAPPHIRE program (1=not at all; 5=very strong)?	3.5 (1-5)
How confident do you feel that you will be able to manage your child's behavior in the future (1=not at all confident; 5=very confident)?	3.72 (2-5)
How time-consuming did you find participating in SAPPHIRE (0=far too time-consuming; 3=wish there was more time)?	2 (1-3)
How convenient was the phone-based care coordination (0=inadequate; 5=very)?	4.78 (4-5)
How helpful was SAPPHIRE (0=very unhelpful; 5=very helpful)?	4.61 (3-5)
How would you rate the program as a whole (0=inadequate; 5=very good)?	4.78 (4-5)
If you were to go back in time, would you participate in this program again (0=no way; 4=absolutely)?	3.2 (0 - 4)
Would you recommend the program to another family whose young child has issues with behavior (0=no way; 4=absolutely)?	3.5 (2-4)

Caregivers also provided qualitative feedback on program acceptability. Caregivers felt that both the concrete suggestions for implementing and maintaining behavior plans, as well as the personalized support and reassurance, were the most helpful aspects of the program. Caregivers also commented on how the regular follow-up and accountability were very useful and how much they appreciated the continuity of care in meeting with the same nurse for every call.

The majority of nurses reported they were "satisfied" with being a part of the program (M=4/5), and half felt it increased their job satisfaction. The other half reported that their participation in the program had no impact on their job satisfaction. Nurses largely felt they had adequate training to deliver the interventions (M=2.5/3), and all felt they had adequate support through as-needed consultation with specialists and case consultation meetings. When asked what they liked most about the program, nurses reported finding it rewarding to be able to follow families over time and having continuity of care. They reported feeling like they were helping families and making a difference. One nurse stated that she particularly enjoyed "being able to help parents with their concerns. When I was able to get a hold of parents, providing some specific things to try and providing reassurance was rewarding."

Nurses also described challenges with the program, including finding time to make the calls and focus on their cases amidst their other job responsibilities. For example, one nurse noted that she felt there was "not enough time to focus on multiple (SAPPHIRE) patients due to other job responsibilities." They provided feedback that some of the processes around enrollment and data collection were time-consuming, and they discussed the difficulties of playing "phone tag" when families were unavailable during scheduled calls. See Table 4 for nurse acceptability data.

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Table . Nurse feedback on the acceptability of the Support and Advocacy through Providing Parents Helpful Interventions, Resources, and Education (SAPPHIRE) program.

Questions	Mean (range)
Please rate your satisfaction in being a part of the SAPPHIRE Program. (1=very unsatisfied; 5=very satisfied).	4 (3-5)
How did participating in the SAPPHIRE Pilot impact your job satisfaction? (1=decrease job satisfaction; 3=increase job satisfaction)?	2.5 (2-3)
Did you feel you had adequate training in SAPPHIRE strategies prior to seeing patients? (1=no; 3=yes)?	2.5 (1-3)
Did you feel you had adequate support from specialists (eg, social worker and/or psychologist) for as-needed case consultation during the intervention? (1=no; 3=yes)?	3 (3-3)
Were the amount of case consultation meetings (1=too few, 2=just right; 3=too many)?	2 (2-2)
What did you like most about participating in the SAPPHIRE pilot?	• I get to use my previous psychology experience and work toward my license. • I enjoy getting to know these families and helping them and their children succeed. • Relating to parents, as I have children the same age. • Continuity of care. • Being able to help parents with their concerns. When I was able to reach parents, providing some specific things to try and providing reassurance was rewarding. Reinforcing the tools that social work had discussed with parents in the office. • Felt like I was helping parents and patients and making a difference.
What did you like least about participating in the SAPPHIRE pilot?	• Not enough time to focus on multiple patients due to other job responsibilities. • I would like the referral process to be better streamlined. • Times when there was no warm handoff; inconsistency with enrolling patients (the email system did not work) • Not my area of clinical knowledge, and I did not like the work • When unable to reach parents, even when a date and time were set for a phone visit. • Finding time to do it and playing “phone tag” with parents. • Finding time to complete phone calls and calling families to complete the long surveys.

Preliminary Outcomes

At the end of treatment, caregivers stated that they felt they had a “quite strong” to “strong” influence on their child’s behavior during the course of the program (M=3.5/5) and felt “confident” that they would be able to manage their child’s behavior in the future (M=3.72/5). They rated their child’s current behavior problem as “slightly serious (no intervention necessary)” (M=3.5/10).

Comparison of preintervention and postintervention caregiver ratings on both the PPSC and PSC-17 showed decreases in reported behavior problems. The effect size for the decrease in behavior problems among younger patients who were rated with the PPSC (n=8) exceeded Cohen’s convention for a moderate effect (d=0.55). For the sample of older children (n=7), whose behavior was rated using the PSC-17, there was a negligible effect (d=0.18). Similarly, caregiver-rated parenting self-competence increased over the course of the SAPPHIRE intervention. The effect size for the increase in parenting self-efficacy approached a large effect (d=0.75). See Table 5 for preliminary outcomes.

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Table . Preliminary outcome data for patients completing the Support and Advocacy through Providing Parents Helpful Interventions, Resources, and Education (SAPPHIRE) program.

Measures	Baseline		End of treatment		Effect size
	Mean (SD)	n	Mean (SD)	n	
Preschool Pediatric Symptom Checklist (PPSC)	13.67 (3.8)	6	10.38 (7.5)	8	0.55
Pediatric Symptom Checklist-17 (PSC-17) total score	12.94 (5.8)	17	11.86 (6.1)	7	0.18
Parenting Sense of Competence Scale (PSOC)	68 (9.6)	24	75.5 (10.4)	16	0.75

Discussion

Principal Findings

Findings suggest that the SAPPHIRE program is a feasible intervention for caregivers of young children with disruptive behaviors. Overall, 69% (25/36) of caregivers completed the program, which compares favorably to the estimated 49% reported retention rate in larger studies of conventional disruptive behavior interventions [11] and is slightly less favorable than the 75% to 77.6% retention rate of the Canadian and Finnish implementations of the web- and phone-based SFSW program [25,26]. It is unclear whether differences in retention were due to characteristics of the program, cultural differences, or possibly differences in assessment periods (eg, part of the SAPPHIRE quality improvement study overlapped with the COVID-19 pandemic). Future evaluation of this is needed to clarify and address barriers to retention in the SAPPHIRE program, as well as to establish the effectiveness of the intervention in a larger sample.

SAPPHIRE required relatively few resources compared to other disruptive behavior programs, as nurses spent an average total of slightly more than 2 hours on calls with a family. This compared favorably with the approximately 7 hours of phone coaching included in the SFSW program [25,26], though it may have implications for retention that should be explored. Results also suggest that both nurses and participating caregivers found SAPPHIRE acceptable. Caregiver feedback reflects that aspects of the program that were particularly well-received included the regular follow-up, continuity of care, and focus on concrete interventions. Nursing staff also reported good satisfaction with the program, though time for implementation was cited as one of the barriers that might impact future dissemination in primary care settings.

The effect of SAPPHIRE on disruptive behavior was moderate for younger children and negligible, approaching small, for older children. These differences in effect sizes should be interpreted with caution, given the fact that younger and older children were evaluated using distinct measures with different scoring conventions and clinical cutoffs. However, these findings align with the literature, which suggests that younger children are typically more responsive to behavioral interventions [35]. Given that the program was implemented over the course of 3 months, which is likely too brief a time period to have a substantial impact on behavioral patterns, we would not necessarily expect to see large effects on behavior. This may explain why younger children whose parents completed the PPSC screener continued to score slightly above the “at-risk” cutoff of 9 at the end of treatment and why the intervention had a negligible-sized effect on the PSC-17 total score. The 3-month study period was chosen based on quality improvement pilot study parameters rather than clinical considerations. Caregivers expressed some dissatisfaction with the brevity of the program, though feedback also suggests that weekly phone calls may not always be necessary and that it may be possible to decrease the frequency of contact as the program progresses. Future iterations of SAPPHIRE would likely benefit from offering families the option to enroll on a flexible call schedule for longer periods of time, as needed.

It is also possible that effects on behavior were not observed in older children whose symptoms were measured by the PSC-17 because baseline scores for this group were only somewhat elevated and did not exceed clinical cutoffs. As SAPPHIRE was developed as an early intervention or indicated prevention option for children who have not yet developed significant behavior problems that warrant a higher level of intervention, it is important to note that even small decreases in reported behavioral concerns are potentially clinically significant. These results suggest that there is merit in further evaluating SAPPHIRE’s effectiveness and that a longer follow-up assessment period is needed to determine whether the intervention prevents the onset of more serious disruptive behaviors in the future. Though we might not expect major changes in child behaviors after the 3-month SAPPHIRE pilot, we would expect to see larger effects on proximal risk factors, such as caregiver self-competence. As such, the fact that the intervention approached a large effect on this variable (d=0.75) is promising, as are caregiver self-reports of increased confidence in their ability to positively influence their child’s behavior moving forward.

Overall, findings support the feasibility and acceptability of the SAPPHIRE program, and preliminary outcome measurements suggest it may positively impact parenting self-competence. It is possible that, as caregivers attested, the accountability and regular check-ins made possible by the phone-based format of SAPPHIRE helped caregivers apply behavioral parenting strategies consistently and allowed for real-time adjustments to

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behavior plans and treatment goals, which increased the likelihood of caregiver follow-through. Patient retention and compliance are major challenges of established, highly effective, evidence-based behavioral interventions. The SAPPHIRE format of nurse-led, phone-based coaching calls may potentially avoid some of the common barriers to accessing and remaining in traditional behavior therapies, including mitigating the difficulties inherent in coordinating in-person sessions while simultaneously trying to parent a young child with challenging behaviors.

There were important lessons learned that should be taken into account when considering the feasibility of this program moving forward. Notably, the field of nursing continues to be characterized by high demand, high turnover, and inadequate staffing models. We found this to be true with SAPPHIRE, as we were often delayed in enrolling patients due to nursing staffing shortages. At several points in the program, new cohorts of nurses had to be trained to provide the care. Though training was efficient and SAPPHIRE itself took a relatively brief amount of time, it still is an additional demand on the already overburdened primary care nurse's schedule. Nurses noted that the time burden of the intervention was still a limiting factor. As such, future iterations of the intervention would benefit from a stakeholder-engaged redesign, in which primary care nursing, nurse administrators, and caregivers are involved in brainstorming ways to further streamline and minimize burdens inherent in finding time for phone calls, playing phone tag, etc.

Limitations

This quality improvement study has several limitations, most notably that no conclusions about program effectiveness can be drawn from this study design, given the small sample. Interpretation of these results must also account for the homogeneous sample, particularly with regard to race and ethnicity, and the fact that the feasibility and acceptability of this study are limited by the brief, 3-month intervention period. In addition, the study time period was characterized by nurse staffing shortages which, while typical for a primary care setting, particularly during the time period that included the onset of the COVID-19 pandemic, prolonged the study enrollment period. This may have led to some time-modified confounding factors that impacted our findings. Patient characteristics and caregiver availability to participate in SAPPHIRE in the last year of this study may have been impacted by the dramatic demands placed on families by the COVID-19 pandemic. Because of this, all findings should be interpreted as preliminary, and the need for additional systematic evaluation of this program cannot be overstated. Even with limitations, however, this study effectively highlights the potential benefit of nurse-led interventions in the primary care setting.

Conclusion

In sum, due to robust support for behavioral parenting programs in improving childhood behavior problems, and despite considerable issues with access and retention for these interventions, the SAPPHIRE treatment model has potential for filling a much-needed treatment-access gap as an early intervention or indicated prevention program for first developing or subclinical behavior problems in young children. Our findings suggest that SAPPHIRE is feasible and acceptable for caregivers of young children and shows promise for increasing parenting self-competence and improving child behavior problems. Although these data are preliminary, they provide support for more rigorous empirical evaluation to examine whether SAPPHIRE is an effective treatment option for this population.

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Data Availability

The datasets generated or analyzed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

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Abbreviations

PPSC: Preschool Pediatric Symptom Checklist
PSC-17: Pediatric Symptom Checklist-17
SAPPHIRE: Support and Advocacy through Providing Parents Helpful Interventions, Resources, and Education
SFSW: Strongest Families Smart Website

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Feasibility, Diagnostic Accuracy, and Satisfaction of an Acute Pediatric Video Interconsultation Model in Rural Primary Care in Catalonia: Prospective Observational Study

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Abstract

Background: In Catalonia, Spain, pediatric primary care is undergoing restructuring, including greater integration of information and communication technologies. The adoption of digital health solutions has increased notably since the COVID-19 pandemic. In areas with limited availability of health care professionals, digital tools are a key strategy for facilitating access to services and ensuring continuity of care.

Objective: This study aimed to evaluate the feasibility, diagnostic agreement, and satisfaction of users and professionals of an acute pediatric video consultation model, referred to as video interconsultation, that includes a synchronous remote physical examination and takes place between health care professionals.

Methods: This was a 20-month prospective within-patient diagnostic accuracy study including 200 children (aged 0 - 14 y) with acute conditions in rural primary care in Catalonia. A secure, closed, real-time, web-based, clinician-assisted video consultation platform enabled remote pediatric assessment—visual examination, audio auscultation via a digital stethoscope, and caregiver-reported symptoms—with a pediatrician remotely guiding a nurse physically present with the child. The intervention was compared, in all cases, with a standard in-person pediatric assessment as the reference standard. Outcomes were feasibility, diagnostic accuracy, and user and professional satisfaction. The platform was developed based on telemedicine usability and clinical safety principles.

Results: Of the 200 children enrolled, remote video consultations were successfully completed in 64.5% (129/200) of cases. Diagnostic agreement with in-person assessment was 78.2% (129/165). Overall mean diagnostic accuracy across all diagnoses was 0.99 (95% CI 0.98 - 1.00), with a mean specificity of 0.99 (95% CI 0.98 - 1.00) and a mean sensitivity of 0.90 (95% CI 0.84 - 0.95), varying by condition, with lower performance for pathologies requiring detailed physical examination. Overall, 95% (190/200) of users and 74% (148/200) of professionals reported a positive experience.

Conclusions: The proposed pediatric video consultation model was feasible, accurate, and well accepted for managing a substantial proportion of acute pediatric conditions in primary care. Its implementation could improve access to medical care in

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rural areas and help reduce health care disparities. Further research is needed to support scalability and implementation in routine clinical practice.

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KEYWORDS

interconsultation; pediatrics; primary health care; remote consultation; rural health services; telemedicine; video consultation

Introduction

Background

In Catalonia, children and adolescents represent nearly 20% of the total population. These life stages are critical for development and have specific health needs and challenges. Health interventions during childhood and adolescence have both short- and long-term effects on adult health. Therefore, prevention, health promotion, and equitable access to high-quality pediatric care are essential priorities for the health system [1]. Ensuring appropriate care requires access to a pediatric referral team composed of pediatricians and specialized nurses [2].

When primary care teams include professionals with formal pediatric training, clinical practice becomes more efficient and better aligned with children's needs. Appropriate prescribing improves (particularly of antibiotics), vaccination coverage increases, and unnecessary diagnostic tests and specialist referrals decrease [3]. Similarly, pediatric-trained nurses play a key role in primary care by promoting child health within the community and schools, supporting the management of pediatric demand, and contributing to improved overall quality of care [4].

However, many regions, particularly rural and underserved areas, face a shortage of pediatric specialists, which challenges the continuity and quality of pediatric health care by limiting timely access to diagnosis and treatment. According to the Catalan Pediatrics Society, all primary care pediatric positions in Catalonia are currently filled; however, more than one-third are occupied by general practitioners who, although not pediatric specialists, provide pediatric care in primary care settings [5]. This proportion has increased in recent years, and the geographic distribution of pediatric providers remains uneven, making recruitment especially difficult in rural areas [6]. Similar patterns have been reported in other European countries and in the United States [7,8].

In this context, digital health tools have emerged as promising strategies to support primary care teams, improve access to pediatric expertise, and reduce disparities between urban and rural populations.

In Catalonia, the primary care system already incorporates information and communication technologies to enhance communication between patients and health care professionals, including *eConsulta*—an asynchronous teleconsultation platform—complementing telephone consultations [9]. The use of video consultations, however, remains limited despite a temporary increase during the COVID-19 pandemic. Although still rarely used in routine primary care, this experience has prompted renewed interest in exploring their potential applications in daily clinical practice [10].

Simple digital devices can now be integrated into video consultations to enable remote physical examinations using a digital camera, video otoscope, and digital stethoscope [11]. Initially designed for home use by caregivers, these devices allow pediatricians to receive real-time clinical information through a virtual connection. Similar telemedicine solutions are already implemented in several European countries and the United States, mainly in private health care settings [12,13].

When combined with these digital tools, video consultations can facilitate real-time collaboration between health care professionals. In this model, a nurse physically present with the patient performs the remote examination under the pediatrician's guidance, allowing both history taking and a basic remote physical examination to be conducted synchronously. As this interaction occurs between health care professionals, it is referred to as a video interconsultation.

This approach is particularly suitable for acute pediatric cases—commonly referred to as same-day or urgent visits—that require pediatric assessment within 48 hours. Implementing this model could enhance access to pediatric care in remote areas, promote territorial equity, and reduce unnecessary emergency department referrals.

However, the limited evidence on the use of digital tools such as video interconsultation in pediatric primary care highlights the need to develop and evaluate new technology-integrated models of care, especially in rural areas [14].

Objectives

This study aimed to evaluate the feasibility of a synchronous acute pediatric video interconsultation model that integrates a remote physical examination and is conducted between health care professionals, one of whom is physically present with the patient, in the rural primary care setting of Catalonia.

The study also sought to assess diagnostic adequacy compared with in-person visits and satisfaction among users and health care professionals, considering quality of care, patient safety, and key influencing factors such as reason for consultation, patient age, and visit duration.

This pediatric video interconsultation model is hypothesized to be a feasible, diagnostically adequate, and well-accepted approach in rural primary care settings.

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Methods

Study Protocol

The study protocol has been published in a separate publication [15].

Study Design

This was a prospective observational diagnostic accuracy study conducted in a real-world primary care setting, without modification of routine clinical practice. Each participant underwent both the index test (video interconsultation) and the reference standard (in-person visit) during the same clinical encounter, enabling a within-participant comparison of diagnostic performance.

Blinding of participants, clinicians, or outcome assessors was not feasible due to the design: the same pediatrician performed both evaluations sequentially in the same visit, and therefore, all parties were aware of the modality used. As the intervention was limited to a single synchronous video consultation per episode, the study design did not involve repeated use or longitudinal tracking of digital engagement.

Standard in-person pediatric assessment was selected as the reference comparator because it represents current clinical practice and the diagnostic gold standard in primary care.

The study follows the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines, incorporates relevant STARD (Standards for Reporting Diagnostic Accuracy Studies) principles, and adheres to CONSORT-EHEALTH recommendations, an extension of the CONSORT (Consolidated Standards of Reporting Trials) statement for reporting digital health interventions [16-18].

Setting and Period

The study was conducted within the primary care network of the Central Catalonia Health Region (Institut Català de la Salut) at the Cardona Primary Care Center by the pediatric care team. This rural area provides services to approximately 5000 residents, including approximately 800 children aged 0 to 14 years, with a population density of 68 inhabitants per square kilometer.

Data collection took place from June 7, 2023, to January 22, 2025. Diagnostic confirmation occurred immediately after the video consultation through the in-person reassessment; therefore, no additional follow-up was required.

No technological or operational changes occurred during the study that could have affected the feasibility or diagnostic performance of video interconsultations.

Participants

Eligibility criteria included children aged 0 to 14 years presenting with acute conditions requiring care within 48 hours. Acute illness was defined as a condition requiring medical attention within 48 hours. Parental informed consent was mandatory.

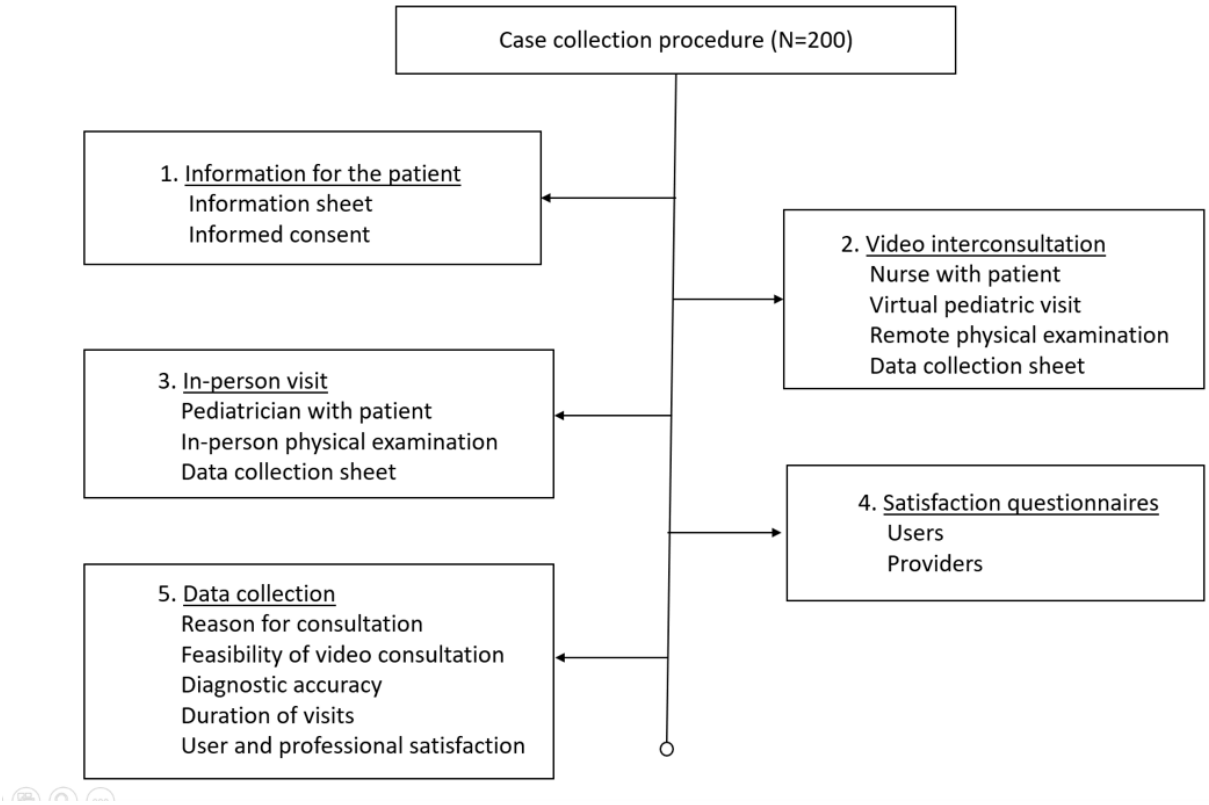
The exclusion criteria were routine checkups, chronic condition follow-ups, emergencies requiring immediate in-person care, cases that could be managed autonomously by nursing staff, and an absence of informed consent.

Sample Size and Sampling

A convenience sample of all eligible cases was included. To ensure adequate power for the main objective, the minimum required sample size was estimated at 170 cases to assess the feasibility and diagnostic concordance of video interconsultations compared with in-person visits. The calculation was conducted using the GRANMO-DATARUS online tool, with a 95% CI, an 8% margin of error, and an anticipated 10% dropout rate [19]. A total of 200 cases were recruited. Participant flow is shown in Figure 1.

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Figure 1. Sequential case collection process from recruitment and video interconsultation to in-person assessment, satisfaction evaluation, and data recording.



Digital Health Intervention and Procedures

Information and Consent

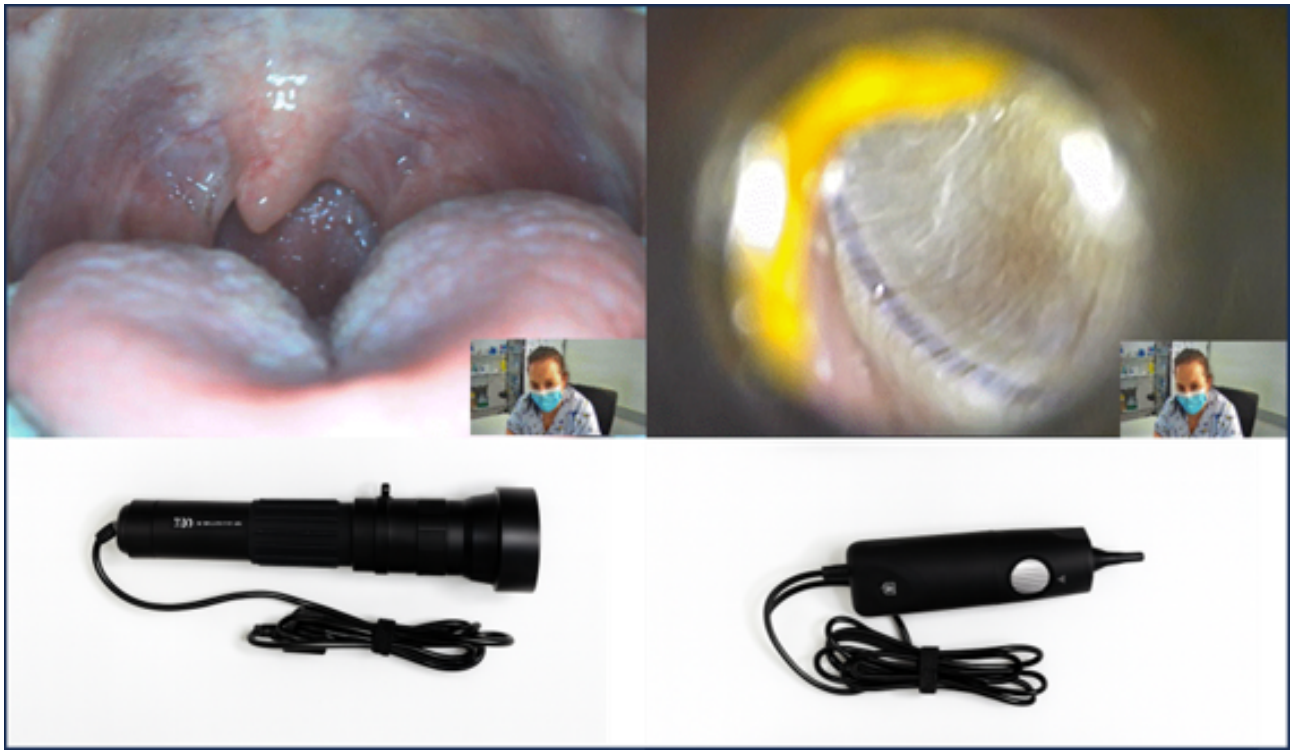
Families were informed in person by the pediatric nurse during the visit, before enrollment.

Video Interconsultation (Index Test)

A secure, encrypted Microsoft Teams video call connected the pediatrician remotely with the onsite nurse and patient. With the pediatrician's guidance, the nurse performed a physical examination using a digital camera, a video otoscope, and a digital stethoscope. A remote diagnostic impression was recorded. Example images are shown in Figure 2.

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Figure 2. Images of the pharynx and tympanic membrane captured during the remote physical examination and the certified digital camera and digital video otoscope used in the study.



In-Person Reassessment (Reference Standard)

Immediately afterward, the same pediatrician performed a face-to-face evaluation and confirmed the final diagnosis.

Satisfaction Assessment

At the end of the visit, two brief questionnaires were administered: one for users (patients and families) and one for health care professionals (categorized as receiving pediatricians, assistant nurses, or observers).

Data Collection

Data were collected using Microsoft 365 Forms via encrypted institutional accounts and stored on secure health services servers. All participants were exposed; no comparison group was included. As this trial was conducted in a rural primary care environment, all video consultations were mediated by trained health care staff.

A total of three data collection tools were used: (1) a clinical form, (2) a professional satisfaction questionnaire (validated Catalan version of the Health Optimum Telemedicine Acceptance Questionnaire) [20], and (3) a user satisfaction questionnaire (adapted from the Northern Saskatchewan Telehealth Network) [21].

No privacy breaches or adverse events occurred. Technical issues were managed by redirecting participants to an in-person assessment when needed.

Variables

The following variables were collected to describe the characteristics of the sample and to assess the feasibility, diagnostic adequacy, and satisfaction associated with pediatric video consultations:

- Sociodemographic variables
  - Age: grouped into five 3-year intervals
  - Sex: female, male, or nonbinary
- Clinical variables
  - Reason for consultation: recorded individually and categorized by affected system or area (respiratory; otorhinolaryngology or ear, nose, and throat; gastrointestinal; infectious diseases; dermatology; musculoskeletal; ocular; and other)
  - Diagnosis: recorded individually and categorized using the same classification
- Feasibility variables
  - Feasibility: feasible or infeasible based on the ability to establish a safe and appropriate diagnosis. Patient safety indicators are included in feasibility, defined as the ability to reach a correct diagnosis without causing harm.
  - Duration of both consultations (in minutes)
  - Limiting factors of nonfeasibility: classified into 6 groups (need for in-person physical examination, telematic auscultation difficulty, camera visualization difficulty, video otoscope visualization difficulty, urgent demand, and lack of patient cooperation)
- Diagnostic adequacy variables
  - Diagnostic concordance: correct or incorrect, using the in-person visit as the gold standard
  - Sensitivity, specificity, and accuracy of the video interconsultation

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- Satisfaction variables
- - Professional satisfaction score
  - User satisfaction score

Outcomes Measures

The primary outcomes were the feasibility and diagnostic accuracy of the pediatric video interconsultation model compared with in-person visits, as well as satisfaction levels among health care professionals and users.

The secondary outcomes included factors limiting feasibility (reason for consultation, patient age, and visit duration) and potential barriers identified during the implementation process.

Statistical Analysis

Categorical variables were summarized using absolute frequencies and percentages, whereas continuous variables were described using means and SDs. Associations between categorical variables were analyzed using the Pearson chi-square test or Fisher exact test when expected cell counts were less than 5. For continuous variables, comparisons were made using the *t* test or, when normality assumptions were not met, the Mann-Whitney *U* test.

Diagnostic performance of video consultations was evaluated using sensitivity, specificity, and overall diagnostic accuracy, considering the in-person assessment as the reference standard. CIs for accuracy estimates were calculated using the Wilson method. Diagnostic concordance was assessed using the Cohen κ coefficient, and Gwet's first-order agreement coefficient (AC1) was additionally computed to account for potential prevalence and bias effects. The binomial test was used to analyze the type and direction of diagnostic disagreements. When cell counts were small, estimates were interpreted with caution due to limited statistical power.

All estimates were reported with 95% CIs, and statistical significance was set at $P<.05$. Statistical analyses were performed using R software (version 4.0.3; R Foundation for Statistical Computing).

Ethical Considerations

This study was approved by the Ethical Committee for Research in Medicines of the Jordi Gol i Gurina Primary Care Research Institute (Barcelona, Spain; registration number 22/236-P; March 8, 2023).

As participants were minors, written informed consent from their parents or legal guardians was mandatory. Families received both oral and written information about the study at the time of the visit, before providing consent. The information included the study purpose, procedures (first, a video consultation performed with the pediatric nurse onsite while the pediatrician participated remotely, followed by a conventional in-person visit with the same pediatrician), eligibility criteria, potential risks, confidentiality, and lawful data protection. Participation was voluntary, and withdrawal was possible at any time without consequences for clinical care. Contact details of the principal investigator were provided to address any present or future questions. No images or videos were recorded during the video consultations, except in isolated cases where photographs of clinical findings were taken with explicit informed consent and used exclusively for research or training purposes, ensuring that patients could not be identified. Participants did not receive any financial or other form of compensation for participation in the study.

The telemedicine assessment was supplementary to standard in-person clinical care, ensuring that no diagnostic or therapeutic decisions relied solely on the digital evaluation. Video calls were conducted using secure and encrypted systems to ensure the confidentiality of clinical information.

All researchers signed a confidentiality agreement concerning the treatment and use of study data. No direct personal identifiers were collected, and all data were pseudonymized and processed confidentially. Access to the data was restricted exclusively to the research team. The project database is hosted on secure servers of the Primary Care Management and Community of the Catalan Health Institute (Institut Català de la Salut), which acts as the data processor. Data retention is planned for 10 years, and no international data transfers are anticipated.

The research team will only use the coded database for scientific purposes (eg, journal articles, scientific reports, and book chapters). The study was conducted in full compliance with the ethical principles of the Declaration of Helsinki (1964) and its latest amendment (Fortaleza, 2013), as well as with the European General Data Protection Regulation (GDPR EU 2016/679) and Spanish Organic Law 3/2018 on the Protection of Personal Data and Guarantee of Digital Rights.

Results

Participant Characteristics

A total of 200 pediatric video interconsultations for acute conditions were conducted in rural primary care. All diagnosis-related data were complete for all included cases; no missing diagnostic data were present. The sample distribution by age and sex, along with the main reasons for consultation, is summarized in Table 1. These reasons are provided both individually and grouped by system to facilitate analysis: respiratory, otorhinolaryngology or ENT, gastrointestinal, infectious diseases, dermatology, trauma, ocular, and other. The most prevalent reasons for consultation were respiratory, otorhinolaryngologic, and dermatologic conditions, with cough, earache, and skin lesions being the most frequent symptoms, followed in frequency by fever and odynophagia. Specific reasons for consultation for each organ system are provided in Multimedia Appendix 1.

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Table . Characteristics of the sample (N=200).

Characteristics	Values
Patient sex, n (%)	
Female	98 (49)
Male	102 (51)
Patient age (y), n (%)	
0 - 2	38 (19)
3 - 5	44 (22)
6 - 8	48 (24)
9 - 11	37 (18.5)
12 - 14	33 (16.5)
Grouped consultation reasons, n (%)	
ENT[a]	57 (28.5)
Respiratory	55 (27.5)
Dermatology	23 (11.5)
Infectious	21 (10.5)
Trauma	13 (6.5)
Gastrointestinal	11 (5.5)
Ocular	7 (3.5)
Other	13 (6.5)
Duration (min[b]), mean (SD)	
Video interconsultation	7.13 (3.85)
In-person visit	3.96 (1.57)
Feasibility video interconsultation, n (%)	
Feasible	129 (64.5)
Infeasible	71 (35.5)

[a]ENT: ear, nose, and throat.

[b]*P* value <.001 based on an independent samples Student *t* test.

Regarding consultation duration, video interconsultations had a significantly longer mean duration (*P*<.001) of 7.13 (SD 3.85) minutes compared with in-person visits, which had a mean duration of 3.96 (SD 1.57) minutes.

Feasibility

Video interconsultation was feasible in 129 (64.5%) of the 200 cases. In these visits, the video interconsultation could be completed appropriately, providing the necessary data to issue a reliable diagnosis while maintaining quality of care and patient safety.

In 71 (35.5%) cases, video interconsultation was not feasible. The causes were analyzed, and the most frequent cause of infeasibility was the inability to perform a complete physical examination electronically, requiring redirection to an in-person visit (27/71, 38%). Other limitations included difficulties in interpreting online auscultation (18/71, 25.4%), problems viewing images obtained with the digital camera (12/71, 16.9%), and problems with the video otoscope (10/71, 14.1%). In 5 (7%) cases, the consultation was urgent and could not be completed via video, and in 2 (2.8%) cases, the patient's lack of cooperation prevented completion. In 3 (4.2%) cases, there were combined technical difficulties, with simultaneous problems in interpreting images from both the digital camera and the video otoscope or in the quality of auscultation through the electronic stethoscope (Table 2).

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Table . Reasons for infeasibility of video interconsultations and corresponding frequencies (N=71).

Reasons for video interconsultation infeasibility[a]	Frequency, n (%)
Need for an in-person physical examination	27 (38)
Difficulty with remote auscultation	18 (25)
Limited visibility through digital camera	12 (17)
Limited visibility through video otoscope	10 (14)
Urgent consultation required	5 (7)
Lack of patient cooperation	2 (3)

[a]Multiple reasons were reported in 3 cases.

A bivariate analysis was conducted to identify demographic and clinical variables potentially associated with the feasibility of video interconsultations.

Categorical variables, including patient sex, age group, diagnostic adequacy, and the clinical category of the consultation reason, were compared between feasible and nonfeasible cases using the chi-square test. A *P* value <.05 was considered statistically significant. No significant associations were found between feasibility and the patient's sex or age group.

However, a statistically significant relationship was observed between feasibility and the clinical category of the consultation reason. Consultations related to gastrointestinal, musculoskeletal, and other conditions showed a higher proportion of nonfeasible cases, whereas those for dermatologic, ocular, and otorhinolaryngologic conditions demonstrated a higher proportion of feasible cases.

Diagnostic adequacy was also significantly associated with feasibility, as all cases classified as feasible presented correct diagnostic agreement (*P*<.001; Table 3).

Table . Bivariate analysis of main variables by feasibility of telemedicine visits.

Variables	Infeasible (n=71)	Feasible (n=129)	*P* value[a]
Patient sex, n (%)			.21
Male	30 (42.3)	68 (52.7)	
Female	41 (57.7)	61 (47.3)	
Patient age (y), n (%)			.19
0 - 2	15 (21.1)	23 (17.8)	
3 - 5	9 (12.7)	35 (27.1)	
6 - 8	20 (28.2)	28 (21.7)	
9 - 11	13 (18.3)	24 (18.6)	
12 - 14	14 (19.7)	19 (14.7)	
Diagnostic agreement, n (%)			<.001
Correct	35 (49.3)	129 (100)	
Incorrect	36 (50.7)	0 (0)	
Reason for consultation, n (%)			<.001
Respiratory	20 (28.2)	35 (27.1)	
ENT[b]	12 (16.9)	45 (34.9)	
Gastrointestinal	10 (14.1)	1 (0.8)	
Trauma	9 (12.7)	4 (3.1)	
Other	9 (12.7)	4 (3.1)	
Infectious	8 (11.3)	13 (10.1)	
Dermatology	3 (4.2)	20 (15.5)	
Ocular	0 (0)	7 (5.4)	

[a]*P* values calculated using the χ^2 test.

[b]ENT: ear, nose, and throat.

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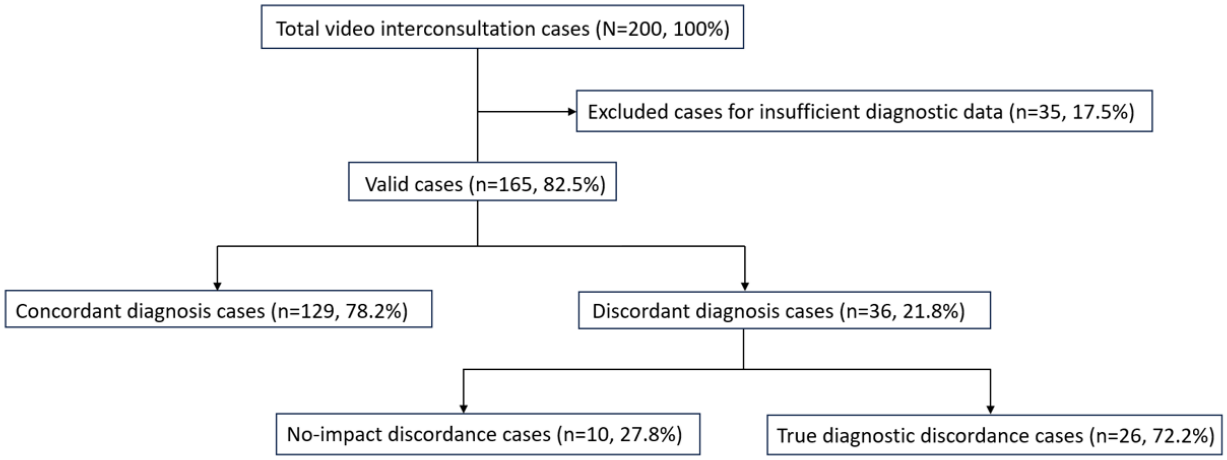
Accuracy

Regarding diagnostic accuracy, diagnoses were grouped by system, using the same eight categories as the reasons for consultation: respiratory, otorhinolaryngology, gastrointestinal, infectious diseases, dermatology, trauma, ocular, and other. In all 129 cases in which video interconsultation was feasible, diagnostic concordance with the in-person visit was observed, as this was considered inherent to the concept of feasibility.

In contrast, among the 71 nonfeasible cases, diagnostic discrepancies between the video interconsultation and the subsequent in-person visit were identified in 36 instances. To calculate diagnostic agreement, 165 valid cases were included, as 35 cases were excluded because of insufficient data for diagnostic evaluation. Diagnostic concordance between the video interconsultation and the in-person assessment was observed in 129 (78.2%) of 165 feasible cases. In the remaining 36 (21.8%) cases, the diagnoses differed between the 2 assessment modalities. Figure 3 shows the flow of participants through the study and the diagnostic concordance analysis.

Cohen κ coefficient for telematic–in-person diagnostic concordance was 0.36, indicating fair agreement. However, given the unbalanced distribution of diagnostic categories, Gwet's AC1 coefficient was also computed, yielding a value of 0.67, which indicates substantial agreement, according to the Landis and Koch scale.

Figure 3. Flow of participants throughout the study according to diagnostic agreement analysis. The different percentages for all subgroups are indicated in relation to the corresponding group.



Among the 36 (21.8%; total 165) cases of showing a diagnostic discrepancy between the telematic and in-person assessments, 10 (27.8%) cases were attributed to the need for a complete physical examination to establish an accurate diagnosis. The distribution of these cases was as follows: 5 involved the musculoskeletal system, 3 were related to the gastrointestinal system, 1 was related to infectious diseases, and 1 was related to other conditions.

Of the remaining 26 (72.2%) discordant cases, the type of diagnostic discrepancy and its distribution by organ system and specific diagnosis were analyzed (Table 4). Most discrepancies were underdiagnoses (23/26, 88.5%), while 5 (19.2%) cases represented overdiagnoses. The exact binomial test showed that the proportion of underdiagnoses was significantly greater than 50% (95% CI 69.8% - 97.6; P<.001).

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Table . Types and frequencies of diagnostic discrepancies between video interconsultations and in-person visits (n=26).

Discrepancy type (video interconsultation vs in person)	Cases[a] n (%)
Underdiagnosis of respiratory conditions	
Bronchospasm	6 (23.1)
Respiratory superinfection	4 (15.4)
Bronchiolitis	1 (3.8)
Overdiagnosis of respiratory conditions	
Bronchospasm	2 (7.7)
Underdiagnosis of ENT[b] conditions	
Acute otitis media	3 (11.5)
Herpangina	3 (11.5)
Otitis externa	2 (7.7)
Streptococcal pharyngitis	1 (3.8)
Dental abscess	1 (3.8)
Overdiagnosis of ENT conditions	
Acute otitis media	3 (11.5)
Underdiagnosis of dermatology conditions	
Atopic dermatitis	1 (3.8)
Scarlet fever	1 (3.8)

[a]One case involved both underdiagnosis in the respiratory system and overdiagnosis in ENT. Another case showed both underdiagnosis and overdiagnosis within ENT.

[b]ENT: ear, nose, and throat.

Of the 23 (88.5%; total 26) underdiagnosed cases in the video interconsultation assessment, 11 (%) corresponded to the respiratory system, 10 (%) corresponded to otorhinolaryngology, and 2 (%) corresponded to dermatology. The distribution of underdiagnoses by organ system did not differ significantly from a uniform distribution (Fisher exact test, P=.08).

Regarding overdiagnosis, of the 5 (19.2%) detected cases, 2 (%) involved the respiratory system, and 3 (%) involved the otorhinolaryngology system. Given the small sample size, no specific pattern could be confirmed or ruled out, and the Fisher exact test also showed no significant deviation from a uniform distribution (P≈.6).

In 2 cases, both underdiagnosis and overdiagnosis occurred simultaneously and were therefore classified in both categories. In 1 case, overdiagnosis involved an otorhinolaryngologic condition and underdiagnosis a respiratory one; in the other, both diagnoses were within otorhinolaryngology, where acute otitis media was incorrectly diagnosed instead of otitis externa during the video interconsultation.

The accuracy, sensitivity, and specificity of each diagnosis obtained via video interconsultation were estimated using the in-person diagnosis as the gold standard. Importantly, the mean diagnostic accuracy of video interconsultations across all conditions was 0.99 (95% CI 0.98 - 1.00). The mean overall specificity was 0.99 (95% CI 0.98 - 1.00), and the mean overall sensitivity was 0.90 (95% CI 0.84 - 0.95).

The diagnostic performance metrics for each clinical category, organized by organ system, are summarized in Table 5. A high level of diagnostic agreement was observed between video and in-person consultations across all categories, with accuracy values exceeding 0.92 and ranging from 0.93 to 1.00. Video interconsultations demonstrated the best performance for otorhinolaryngologic, dermatologic, and trauma-related conditions, which also showed high sensitivity and specificity. In contrast, respiratory diagnoses had lower sensitivity (0.68, 95% CI 0.51 - 0.82), suggesting a potential risk of diagnostic underestimation during video interconsultations. Detailed diagnostic performance metrics by specific condition, along with the corresponding frequency distribution, are provided in Multimedia Appendix 2. CIs should be interpreted with caution in categories with small sample sizes.

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Table . Diagnostic frequency by system in video and in-person consultations, with corresponding accuracy, sensitivity, and specificity (N=200).

Organ system	Video visit, n (%)	In-person visit, n (%)	Accuracy (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)
ENT[a]	106 (53)	96 (48)	0.92 (0.87 - 0.95)	0.97 (0.91 - 0.99)	0.88 (0.80 - 0.93)
Respiratory	28 (14)	38 (19)	0.93 (0.89 - 0.96)	0.68 (0.51 - 0.82)	0.99 (0.96 - 1.00)
Dermatology	21 (10.5)	22 (11)	0.99 (0.97 - 1.00)	0.95 (0.77 - 1.00)	1.00 (0.98 - 1.00)
Trauma	12 (6)	13 (6.5)	0.99 (0.97 - 1.00)	0.92 (0.64 - 1.00)	1.00 (0.98 - 1.00)
Gastrointestinal	10 (5)	9 (4.5)	0.99 (0.97 - 1.00)	1.00 (0.66 - 1.00)	0.99 (0.97 - 1.00)
Other	10 (5)	9 (4.5)	0.98 (0.96 - 1.00)	0.89 (0.52 - 1.00)	0.99 (0.96 - 1.00)
Infectious	7 (3.5)	7 (3.5)	0.99 (0.96 - 1.00)	0.86 (0.42 - 1.00)	0.99 (0.97 - 1.00)
Ocular	7 (3.5)	7 (3.5)	1.00 (0.98 - 1.00)	1.00 (0.59 - 1.00)	1.00 (0.98 - 1.00)

[a]ENT: ear, nose, and throat.

Professional Satisfaction

Professional satisfaction, assessed through the validated Catalan version of the Health Optimum Telemedicine Acceptance Questionnaire, was analyzed by comparing responses across three professional groups—receivers (pediatricians), assistants (nurses), and observers (residents and students)—using the chi-square tests (Table 6).

In terms of perceived quality, 74% (148/200) of professionals rated the video interconsultation as equal to or higher than in-person care, whereas 26% (52/200) perceived it as lower. This assessment differed significantly among professional groups (P<.001). Nursing assistants expressed the most favorable opinions (42/47, 89.4%, positive ratings), similar to observers (41/46, 89.1%), whereas receivers (pediatricians) were less favorable, with 50.5% (54/107) positive and 43% (46/107) negative ratings.

Overall, 94.5% (189/200) of participants believed that telemedicine could have a positive impact on patient health, 4.5% (9/200) thought it had no influence, and 1% (2/200) considered that it might worsen patient outcomes. When analyzed by professional group, receivers reported in 99.1% (106/107) of visits that telemedicine could improve patient health, compared with 78.7% (37/47) among assistants and 100% (200/200) among observers. Among assistants, 4.3% (2/47) indicated that telemedicine could negatively affect patients' health.

With respect to the continuity of telemedicine use, 83.4% (166/199) of professionals indicated that improvements were needed in infrastructure or organization. Receivers were particularly likely to request such improvements (96/107, 89.7%), compared with assistants (15/47, 31.9%) and observers (7/45, 15.6%; one observer did not provide a response to this item).

Differences among professional groups were statistically significant for both perceived quality (P<.001) and willingness to continue using telemedicine (P=.004).

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Table . Health care professionals' satisfaction with telemedicine and video interconsultation.

Opinion professionals	Total (N=200), n (%)	Assistant (nurse; n=47), n (%)	Receiver (pediatrician; n=107), n (%)	Observer[c] (other professionals[a]; n=46), n (%)	*P* value[b]
Perceived quality					<.001
Very good	63 (31.5)	25 (53.2)	12 (11.2)	26 (56.5)	
Good	74 (37)	17 (36.2)	42 (39.3)	15 (32.6)	
Fair	11 (5.5)	1 (2.1)	7 (6.5)	3 (6.5)	
Poor	35 (17.5)	3 (6.4)	31 (29)	1 (2.2)	
Very poor	17 (8.5)	1 (2.1)	15 (14)	1 (2.2)	
Perceived impact					<.001
No	9 (4.5)	8 (17)	1 (0.9)	0 (0)	
Yes, positive	189 (94.5)	37 (78.7)	106 (99.1)	46 (100)	
Yes, negative	2 (1)	2 (4.3)	0 (0)	0 (0)	
Intent to continue[c]					.004
Unchanged	33 (16.6)	15 (31.9)	11 (10.3)	7 (15.6)	
Improved	166 (83.4)	32 (68.1)	96 (89.7)	38 (84.4)	

[a]Other professionals included residents and students.

[b]*P* values were calculated using the χ^2 test.

[c]One observer did not provide a response to this item.

User Satisfaction

User experience, measured using a survey adapted from the Telehealth Network Questionnaire (Northern Saskatchewan Telehealth Network) and completed by the accompanying adults responsible for the child, was rated as very good in 74.5% (149/200) of the 200 cases and good in 20.5% (41/200). A total of 4.5% (9/200) of participants described the experience as poor, and 0.5% (1/200) of participants described the experience as very poor (Table 7).

In addition, 92% (184/200) of families reported that they would be willing to repeat the video interconsultation in the future (142/200, 71%, very likely, and 42/200, 21%, likely), whereas only 8% (16/200) expressed reluctance (12/200, 6%, unlikely and 4/200, 2%, very unlikely).

To explore whether these perceptions were shared by health care professionals, a correlation analysis between user and professional satisfaction for each visit revealed a weak but statistically significant positive correlation (r=0.182, 95% CI 0.044 - 0.312; P=.009).

Table . Users' satisfaction with telemedicine and video interconsultation (N=200).

Opinion users	Total, n (%)
Overall quality	
Very good	149 (74.5)
Good	41 (20.5)
Poor	9 (4.5)
Very poor	1 (0.5)
Willingness to repeat	
Very likely	142 (71)
Likely	42 (21)
Unlikely	12 (6)
Very unlikely	4 (2)

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Discussion

Principal Findings

This study evaluated whether a synchronous video consultation model—including remote physical examination guided by a pediatrician and supported by an onsite pediatric nurse—is a feasible, clinically appropriate, and well-accepted approach to managing acute pediatric conditions in rural primary care in Catalonia.

Feasibility was achieved in nearly two-thirds of cases, allowing completion of a safe and adequate remote assessment. Among feasible cases, diagnostic performance was high, with substantial agreement between telemedicine and in-person evaluations. Video consultations also demonstrated high diagnostic accuracy and sensitivity, along with near-optimal specificity. However, performance varied by clinical condition, suggesting that limitations inherent to remote assessment (eg, reduced ability to detect subtle clinical signs) may reduce sensitivity in certain scenarios.

Process outcomes further supported implementation: satisfaction was very high among families and positive among health care professionals, and consultation duration remained acceptable despite the inclusion of a remote physical examination.

Together, these findings indicate that—when appropriate feasibility and safety criteria are met—this telemedicine model can effectively complement, rather than replace, in-person pediatric care in underserved regions, thereby contributing to improved health equity and accessibility.

Furthermore, these findings could be applicable to other pediatric primary care settings with similar digital infrastructure and staffing resources. However, as this was an observational, single-center study without randomization, these findings should be interpreted with caution regarding their external validity.

Comparison With Prior Work

These results are consistent with the current literature suggesting that telemedicine in pediatrics can achieve high diagnostic validity when applied under well-defined conditions. That said, most previous studies were not conducted in primary care settings, did not address acute conditions, and primarily examined video consultations between professionals and patients, rather than between professionals themselves [22-24]. There is limited evidence on video consultations that incorporate physical examinations. In pediatrics, Wagner et al [25] found that remote physical examination using medical devices similar to those used in this study was comparable to in-person assessment. Their findings align with ours, showing high diagnostic accuracy for otoscopy, oropharyngeal evaluation, and dermatological examination, but lower accuracy for assessing abdominal pathology.

Several studies have found that the effectiveness of video consultations is particularly high for diagnoses that rely primarily on medical history and visual assessment, such as upper respiratory tract infections (eg, pharyngitis and otitis) or dermatologic lesions [26,27]. In contrast, conditions that require a full physical examination, such as abdominal pain, which necessitates palpation, or headache, which may call for a neurological evaluation, may show reduced sensitivity, as also observed in this study [25,28].

This limitation may increase the risk of incomplete or inaccurate diagnoses, as reflected in the 21.8% (36/165) of cases that showed diagnostic discordance between virtual and in-person visits. While most discrepancies were classified as underdiagnoses or overdiagnoses, some involved mixed errors. Several cases required referral to in-person care to complete the physical examination and establish a reliable diagnosis, underscoring the complexity of remote clinical assessment. Furthermore, in some cases classified as infeasible, the online and in-person diagnoses were consistent, and the infeasibility was attributed to other limitations. In pediatric care, particularly for younger children, a comprehensive physical examination is often performed regardless of the presenting complaint. These findings underscore the need for triage and feasibility criteria tailored to the specific characteristics of each patient and condition to optimize the safety and effectiveness of video interconsultations. They also highlight the importance of establishing clear clinical guidelines to ensure the safe, high-quality use of video interconsultations in primary care pediatrics.

Pediatric patients with specialty conditions, such as rheumatologic, cardiologic, or endocrinologic disorders, were not included, as no such cases were seen during the study period. However, a few neurology and gynecology cases were included in the “other” category due to their small number. It is worth noting that telemedicine has also proven useful for the follow-up of pediatric rheumatic diseases, particularly in rural areas and during the COVID-19 pandemic [29].

Regarding consultation duration, a 2022 review by the Catalan Agency for Health Quality and Evaluation reported that video or telephone consultations are typically 1.5 to 4 minutes shorter than in-person visits [30]. In contrast, in this study, video interconsultations lasted nearly twice as long as in-person visits, likely due to the inclusion of a physical examination, which extended the consultation time. Additionally, this model involved 2 health care professionals. While it may enhance accessibility, it also requires greater resource allocation in terms of time and staffing.

Regarding users’ perceptions of telemedicine, the findings of this study indicate a high level of satisfaction, consistent with previous research [31]. The main reasons families expressed concerns about remote interconsultations were technical issues related to sound, connectivity, and image quality, as well as fears that in-person care might be replaced by virtual services. Other reasons, such as a perceived lack of safety, were infrequent. In any case, it is essential to provide families with clear and transparent information so they can make informed decisions about using this technology. Ultimately, they remain at the center of care [32].

With regard to health care professionals’ perspectives on telemedicine, the results indicate that professionals acknowledge the value of pediatric video interconsultations, and most consider them beneficial for patient health. However, differences among

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professional groups suggest that perceptions vary depending on each participant's clinical role and expectations.

These findings are consistent with those of Martín-Masot et al [33], who analyzed the views of Spanish pediatricians following the rapid digitalization of health care delivery during the COVID-19 pandemic. In their study, most pediatricians regarded digital consultations as time-efficient and a valuable resource, aligning with the present results. Among nurses, the majority reported that the quality of video consultations was equal to or better than that of in-person visits. These results align with the findings of Navarro-Martínez et al [34], who reported that telenursing is positively perceived in routine clinical practice. However, most health care professionals in this study identified the need to improve the application of telemedicine in clinical settings, particularly in terms of technology, organizational processes, and bioethical considerations. This observation is echoed in a study conducted in Catalonia by Vidal-Alaball et al [35]. Similarly, other studies, such as that by Inoue et al [36] in Japan, have reached the same conclusions. In this context, it is essential to train professionals not only in the use of digital tools, but also in what Finkelstein et al [37] refer to as "webside manner," a more effective approach to online clinical communication.

Furthermore, although telemedicine can improve communication between doctors and patients and help reduce health care costs, it may compromise the quality of care, therapeutic effectiveness, and patient safety if not implemented properly [38]. Therefore, legislation and bioethical frameworks must evolve to accommodate these emerging models of care [39].

Limitations

This study has several limitations. First, there is a potential risk of diagnostic inaccuracy in video consultations compared with in-person visits, especially for conditions that require a direct physical examination, such as abdominal pain, trauma, or headache. Technical issues affecting image or audio quality may also hinder adequate remote assessment. Additionally, some diagnostic subgroups were small, which reduced the precision of accuracy estimates and widened the CIs.

Confirmation bias may have occurred because the same pediatrician conducted both the telemedicine and in-person evaluations. A role bias may also have occurred, as those receiving telemedicine may have different experiences from those delivering or observing it. If recipients represent the majority, as in this case, overall satisfaction may primarily reflect their perspective. Likewise, observers may have overemphasized methodological aspects while underestimating the actual user experience.

Another limitation is a possible social desirability bias, as the project was conducted by the patients' regular and trusted pediatrician and nurse. This relationship of trust may have influenced participants' responses, although no intentional intervention or influence was exerted during data collection.

Operational limitations should also be considered. Video consultations took longer than in-person visits and required the presence of both a pediatrician and a nurse, which may not be feasible in all settings and could increase the workload. Economic, organizational, and technological implications were not evaluated in this study, and the environmental impact of digital health equipment warrants further attention.

Finally, data were collected in a single rural primary care center, which may limit the generalizability to other health care settings. Despite strict data protection measures, concerns about confidentiality and the potential for digital care to reduce the human component of clinical interaction remain relevant considerations.

Future Directions

Future research should focus on defining evidence-based triage and feasibility criteria to select patients who can be safely and effectively managed through video interconsultation. Larger multicenter studies are needed to confirm diagnostic performance and satisfaction outcomes across broader pediatric populations and health care contexts. Evaluating economic, organizational, and environmental sustainability will be essential to inform real-world implementation. In addition, exploring strategies to streamline the workflow, optimize technical reliability, and maintain the human aspects of care will help ensure successful and responsible integration into routine pediatric practice.

Conclusions

The proposed model of synchronous video consultation between health care professionals, including physical examination, has proven to be a feasible option. It shows good diagnostic agreement with in-person visits and has been positively evaluated by both users and health care professionals.

This approach may serve as a valuable tool for managing acute pediatric conditions in rural primary care settings in Catalonia, provided it is implemented appropriately and maintains patient safety and quality of care. Although it cannot replace in-person visits, it can complement them within the ongoing reorganization of pediatric primary care, contributing to improved accessibility, territorial equity, and system efficiency.

The implementation of this model involves several challenges, including longer consultation times, training requirements, the development of standardized protocols, economic and environmental costs, and the management of data confidentiality.

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Data Availability

Data will be made available by the corresponding author upon reasonable request.

Authors' Contributions

MCR served as the principal investigator. CFC and JVA contributed the original idea. NSB assisted in case collection. AFC, QMC, and LSR contributed to the statistical analysis and provided support throughout the research process. JVA and FLS acted as supervisors and provided continuous guidance throughout the project.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Specific reasons for consultation for each organ system.
[DOCX File, 8 KB - pediatrics_v9i1e82133_app1.docx]

Multimedia Appendix 2
Frequencies and diagnostic performance metrics of video interconsultations by condition, with in-person diagnoses used as the gold standard.
[DOCX File, 12 KB - pediatrics_v9i1e82133_app2.docx]

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Abbreviations

CONSORT: Consolidated Standards of Reporting Trials
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

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Peer-Mentored Social Media Groups for Youth Vaping Cessation: Single-Arm Pilot Trial

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Abstract

Background: Using social media to deliver e-cigarette cessation interventions to young people is a promising approach, but low participant engagement and retention may undermine intervention efficacy. Peer mentoring holds great potential to address these issues.

Objective: This study aimed to understand the feasibility and acceptability of integrating peer mentoring into a social media–based intervention to help young people quit e-cigarette use.

Methods: We conducted a single-arm pilot trial with 24 e-cigarette users (aged 16 - 21 years). Participants were assigned to 1 of 2 Instagram groups, where they received an existing vaping cessation intervention, Quit the Hit (QTH), in which a trained counselor posted 1 to 3 evidence-based vaping cessation messages on weekdays over 5 weeks. As an adjunct to QTH, each group included 2 peer mentors of similar age as participants who had successfully quit vaping. The mentors provided social support and shared their quitting experiences. Participants completed a baseline survey and a follow-up survey at the end of the intervention (week 5) and were invited to participate in postintervention focus groups.

Results: Participants' mean age was 18.6 (SD 1.2) years, and 58.3% (14/24) were male. Most (20/24, 83.3%) identified as straight/heterosexual, 29.2% (7/24) identified as non-Hispanic White, and 45.8% (11/24) were high school students. On average, participants vaped e-cigarettes 5.1 (SD 1.7) days per week, and 33.3% (8/24) reported daily vaping. All participants (24/24, 100%) had made at least one quit attempt in the past year. Nearly all participants (23/24, 95.8%) engaged in the group by either posting or liking others' comments at least once. Mean program engagement was 28.8 (SD 27.3) posts or likes over the 5 weeks. The study retention rate was 91.7% (22/24) at week 5. Using an intent-to-treat approach, 66.7% (16/24) of participants were abstinent (7-day point prevalence abstinence) at week 5. On a 5-point Likert scale, participants rated peer mentoring as highly useful (mean 4.6, SD 0.3) and reported high levels of satisfaction (mean 4.7, SD 0.3). All participants who completed the follow-up survey said they would recommend the program to others. Focus group findings supported these results, highlighting positive feedback on both the quality and usefulness of peer mentoring and the peer-mentored version of the QTH program. Suggestions for future improvements were also discussed.

Conclusions: Integrating peer mentoring into social media–based e-cigarette cessation interventions for young people is feasible and acceptable. Participants engaged in the intervention and demonstrated strong retention. They rated both the peer mentoring and the overall program highly. Self-reported abstinence at 5 weeks was high. Larger trials are warranted to evaluate the efficacy of the peer-mentored intervention.

Trial Registration: ClinicalTrials.gov NCT07437196; https://clinicaltrials.gov/study/NCT07437196

(JMIR Pediatr Parent 2026;9:e46283) doi:10.2196/46283

KEYWORDS

peer mentoring; vaping cessation intervention; social media; adolescents; young adults

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Introduction

As cigarette smoking has declined after decades of tobacco control efforts, e-cigarettes have become the most commonly used tobacco product among adolescents and young adults [1,2]. Among US adults, young adults reported the highest rate of e-cigarette use, with 11% to 18% reporting vaping in the past 30 days [3-5]. According to the 2024 National Youth Tobacco Survey, 5.9% of middle and high school students (1.6 million) reported current e-cigarette use [6]. While the long-term effects of e-cigarette use are not yet fully understood, evolving evidence indicates an increased risk for respiratory and cardiovascular diseases [7-9]. In addition, early exposure to nicotine may increase the risk of addiction [10,11] and the likelihood of initiating cigarette smoking later in life [12-14]. A meta-analysis published in 2018 found that, after adjusting for established risk factors for cigarette smoking, youth e-cigarette users had nearly 4 times higher odds of subsequent cigarette smoking [15]. More recent meta-analyses of longitudinal studies have further confirmed the association between e-cigarette use and subsequent smoking among nonsmoking adolescents and young adults [14]. Quitting tobacco before age 30 reduces most tobacco-related health risks [16]; therefore, it is crucial to provide effective vaping cessation support for adolescents and young adults [17].

The growth of social media use among young people [18] makes it a potentially ideal channel for delivering vaping cessation interventions to adolescents and young adults [19,20]. Previous studies on social media–based smoking cessation interventions have shown feasibility, acceptability, and early efficacy [19]. However, despite these promising findings, social media interventions have reported large reductions in engagement over time and high dropout rates [19,20]. For instance, the Tobacco Status Project (TSP), a smoking cessation intervention for young adults delivered via Facebook groups, found that the number of participant comments decreased over time in each group despite variation between groups [21]. User engagement with cessation interventions has been found to be associated with retention and abstinence outcomes [22,23], highlighting the need to improve participant engagement to enhance the effectiveness of social media interventions.

The scientific literature suggests that peer mentoring may be a promising strategy to engage participants and address the issue of decreasing engagement and low retention in social media–based interventions. The model of supportive accountability [24], grounded in organizational psychology, motivation theory, and computer-mediated communication research, posits that human support from a trustworthy, benevolent, and competent source helps digital intervention participants stay engaged and adherent to interventions by offering social support and accountability. It also suggests that peer mentors can be especially effective because individuals often feel more at ease with those who are similar to themselves [24]. As a peer support strategy, peer mentoring is a process in which individuals with similar life experiences provide encouragement and assistance to foster health behavior change [25]. Previous studies with young people have shown that tobacco use is susceptible to peer influence [26-28]. Incorporating peer mentoring into vaping cessation programs may be effective because peers who have successfully quit are more relatable than health care professionals or adult facilitators [25,29]. Peers' personal experiences may show that cessation is achievable, and their social support may be more engaging for participants [30]. Peer mentoring has been adopted by various health promotion programs [31-33], including smoking cessation programs [34,35], yet it has not been used to address e-cigarette use in the context of social media. In this study, we aimed to evaluate whether integrating peer mentoring into social media–based interventions to support e-cigarette cessation among young people was feasible and acceptable.

Methods

We conducted a single-arm pilot trial that integrated peer mentoring into an existing Instagram-based vaping cessation program, Quit the Hit (QTH), to assess feasibility and acceptability quantitatively. Postintervention focus group discussions were conducted with participants to contextualize the quantitative findings.

Intervention Design

QTH is a 5-week program that delivers evidence-based vaping cessation content in groups via direct messages on Instagram. QTH was developed by a University of California, San Francisco research team in partnership with outside agencies (HopeLab and Rescue) and based on the TSP discussed above, which showed efficacy in delivering a smoking cessation intervention to young adults in private Facebook groups [36]. QTH convenes Instagram direct-message groups of 10 to 15 participants facilitated by a professional tobacco cessation counselor; the counselor delivers up to 3 posts per weekday. Content includes evidence-based vaping cessation strategies, incorporating skills from cognitive behavioral therapy and the transtheoretical model that have demonstrated efficacy for long-term smoking cessation [37]. Additional details about QTH have been published previously [38].

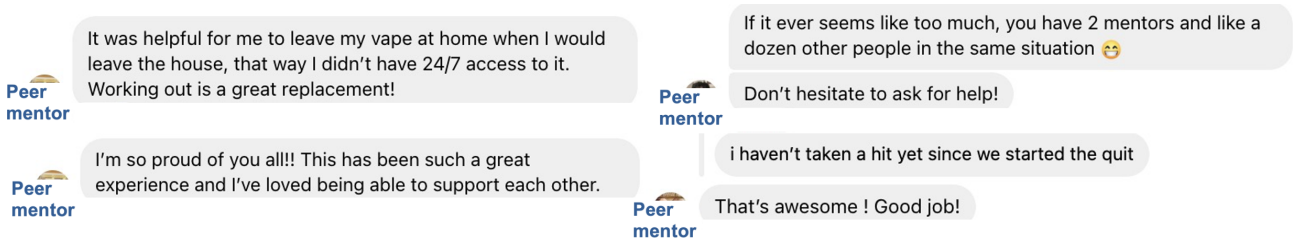
Peer mentoring was provided by young adults aged 18 to 29 years who had used e-cigarettes, had previously participated in QTH support groups, and had successfully quit vaping for more than 3 months. This 3-month threshold was used because abstinence at 3 months is a commonly reported benchmark in tobacco cessation research for "successful" short-term sustained cessation [39], although it does not eliminate the possibility of relapse. Peer mentors received a 4-module mentor training (basic information about e-cigarettes and health risks, mentoring relationships and skills, emotional intelligence, and boundary setting and confidentiality) and passed a posttraining qualification assessment that included a knowledge test and scenario-based questions. The mentoring relationships and skills module was a live Zoom training with a trained counselor, while the other modules were provided as recorded trainings that mentors completed on their own time. The training modules were adapted from a previous peer-mentored smoking cessation intervention and informed by our formative research on mentors' training needs and participants' expectations [35,40] and consultations with experts in vaping cessation, peer mentoring,

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and youth-serving programs, with the goal of preparing mentors to effectively fulfill their mentoring roles.

Peer mentors posted in the QTH groups to provide emotional support, often sharing their personal experience with quit attempts and offering encouragement. Figure 1 shows examples of peer mentor posts in the QTH groups. In each peer-mentored QTH group, there were 8 to 12 participants, 2 peer mentors, and a professional tobacco cessation counselor. Participants could direct-message their mentors to receive one-on-one peer mentoring if they were uncomfortable reaching out in the group setting. Peer mentors sent each participant a check-in message around the third week. Program features, such as the age range of peer mentors, group size, and mentor-mentee ratio, were informed by our formative study [40].

Figure 1. Screenshots of peer mentor posts in Instagram groups illustrating emotional support.



Participants and Recruitment

Participants were recruited through social media advertising (Meta Ads, including Facebook and Instagram, and TikTok advertising), recruitment messages distributed by youth-serving community organizations, and outreach to participants of a previous randomized controlled trial (RCT) testing QTH [38] who did not quit vaping by the end of the trial. The recruitment message included a link and QR code to the study's website, where eligibility was screened. Eligible participants were able to read English, aged 13 to 21 years, used social media at least 4 days per week, vaped at least once per week in the past 30 days, indicated that they were considering or interested in quitting within the next 6 months, and resided in California. Participants were asked to show photos of their ID and vape devices to verify their age and vaping status during study enrollment.

Study Procedures

After giving consent and completing a baseline survey, participants were assigned to one of the 2 support groups based on timing of enrollment. The first 12 participants were assigned to group 1, and the next 12 were assigned to group 2. After participants joined the group, we reviewed the ground rules with participants, including expectations for respectful behavior and confidentiality (ie, what is said in the group stays in the group). The intervention lasted 5 weeks. At the end of the intervention, participants were asked to complete a follow-up survey and were invited to participate in a 90-minute focus group via Zoom. The focus group discussion asked participants to reflect on their experiences with peer mentoring and the overall intervention and to provide suggestions for future improvements. Focus group discussions were video recorded and professionally transcribed.

Measures

Overview

Both baseline and follow-up surveys were administered online via Qualtrics (Qualtrics, Inc). Participants reported their sociodemographic characteristics, e-cigarette use, and quitting-related factors, such as quit attempts, desire to quit, and confidence in quitting. Measures of feasibility (including engagement and retention) and acceptability (including perceived usefulness of peer mentoring, satisfaction with peer mentoring, and evaluation of the program) were adapted for use in a vaping cessation context based on prior pilot trials for smoking cessation with and without peer mentors [35,38,41].

Feasibility

Feasibility was assessed by participant engagement in the Instagram group, as indicated by the number of likes and comments documented by study staff, which is consistent with previous social media interventions [41] and the retention rate. Retention was measured as the proportion of enrolled participants who completed the follow-up survey.

Perceived Usefulness of Peer Mentoring

Perceived usefulness was assessed in the follow-up survey with 9 items, measuring agreement on a 5-point Likert scale (1=disagree a lot to 5=agree a lot). Example items included the following: "The peer mentors helped me quit vaping," "The peer mentors shared useful information on quitting," and "The peer mentors increased my confidence that I can quit."

We calculated an index of the overall perceived usefulness as the mean of responses across all 9 items.

Satisfaction With Peer Mentoring

Satisfaction with peer mentoring was assessed in the follow-up survey with 6 items, measuring agreement on a 5-point Likert scale (1=disagree a lot to 5=agree a lot). Example items included the following: "I liked the peer mentoring in the program," "I felt comfortable with the messages I got from peer mentors," and "The peer mentors sent messages at convenient times of day."

Additionally, participants rated their satisfaction with the quantity of peer mentor posts on a 5-point scale by responding to the item, "Overall, the number of messages from peer mentors was …" (1=too few, 2=few, 3=about right, 4=many, and 5=too many).

Evaluation of the Program

The overall evaluation of the peer-mentored vaping cessation program was measured with 4 items, measuring agreement on a 5-point Likert scale (1=disagree a lot to 5=agree a lot). The 4

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items were the following: “I would recommend this program to others,” “The program gave me something new to think about,” “I thought about what I read in the program” and “The program was easy to understand.”

Data Analysis

We summarized descriptive statistics for participant characteristics, feasibility, and acceptability as indicated by perceived usefulness, satisfaction, and evaluation of the program, and other variables of interest. A series of comparisons about e-cigarette use were made between preintervention and postintervention data, but given the small sample size, no inferential statistics were used. All analyses were conducted using SPSS (version 26; IBM Corp).

We adopted a thematic analysis approach to analyze qualitative data from 2 focus groups (5 participants total), with the assistance of Dedoose software (SocioCultural Research Consultants). Using a data-driven inductive approach, one author (JCL) reviewed all transcripts from both groups and developed the initial coding guide. With this guide, 2 authors (JCL and KS) independently coded the transcripts and resolved any discrepancies through discussion. Analytic memos were written during the independent coding phase and later discussed to refine the coding guide. Given the focus of this study and limited number of focus group participants, thematic saturation was not the goal of the qualitative analysis; instead, we aimed to identify key points expressed by participants regarding their experiences in the program to contextualize the quantitative findings.

Ethical Considerations

This study received approval from WIRB-Copernicus Group Institutional Review Board (protocol T31IR1910). The trial was registered at ClinicalTrials.gov (NCT07437196). Participants completed online informed consent, consistent with standard care for adolescents in smoking cessation treatment [42]. Participants received electronic gift cards for completing the baseline survey and follow-up survey. They received US $10 for completing the baseline survey and US $20 for completing the follow-up survey, with a US $5 bonus per survey for completion within 24 hours of receiving the survey link. Participants who completed the 90-minute postintervention focus group received US $50. Peer mentors received US $30 for completing the saliva test for biochemical verification of abstinence and US $50 for completing peer mentor training and passing the subsequent assessment. They also received US $250 at the end of the 5-week program for their effort.

Results

Participant Characteristics

Among the 24 participants, 15 were recruited via TikTok ads and 9 were recruited from a list of prior QTH RCT participants who met eligibility criteria, including 7 from the control group and 2 from the intervention group. Table 1 shows the details of the participant characteristics. Participants were predominantly male (n=14, 58.3%). While participants aged 13 to 21 years were eligible, the enrolled participants ranged in age from 16 to 21 years, with a mean age of 18.6 (SD 1.2) years. Most participants (n=20, 83.3%) identified as straight or heterosexual, 7 (29.2%) identified as White, and almost half (n=11, 45.8%) were high school students. All participants reported vaping in the past 7 days, with an average of 5.1 (SD 1.7) days per week, and 8 (33.3%) participants reported vaping daily. On vaping days, the average number of puffs was 31.6 (SD 62.5). A total of 8 (33.3%) participants reported using e-cigarettes within 30 minutes of waking. Overall, participants reported strong motivation to quit. All participants (n=24, 100%) had made at least one quit attempt (ie, stopped vaping nicotine for 1 day or longer) within the past 12 months, and on a 1- to 5-point scale (5=very much), the average desire to quit was 4.5 (SD 0.6), and the average confidence in quitting was 4.0 (SD 1.0).

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Table . Participant characteristics (N=24).

Characteristics	Values
Sociodemographic characteristics	
Age (years), mean (SD)	18.6 (1.2)
Sex at birth, n (%)	
Female	10 (41.7)
Male	14 (58.3)
Sexual identity, n (%)	
Heterosexual	20 (83.3)
LGBTQ+[a]	4 (16.7)
Race and ethnicity, n (%)	
Hispanic	6 (25)
Non-Hispanic Asian	1 (4.2)
Non-Hispanic Black	1 (4.2)
Non-Hispanic White	7 (29.2)
Other or multiracial	9 (37.5)
Educational attainment, n (%)	
High school	11 (45.8)
Not enrolled	2 (8.3)
GED[b] classes or community college	6 (25)
4-year college or university	5 (20.8)
e-Cigarette use characteristics	
Puffs per day, mean (SD)	31.6 (62.5)
Days per week vaped, mean (SD)	5.1 (1.7)
Daily vaping, n (%)	8 (33.3)
Time to first puff after waking, n (%)	
Within 5 min	3 (12.5)
6 - 30 min	5 (20.8)
31 - 60 min	12 (50)
After 60 min	4 (16.7)
Quit-related characteristics	
Past-year quit attempts, n (%)	24 (100)
Desire to quit, mean (SD)	4.5 (0.6)
Confidence in quitting, mean (SD)	4.0 (1.0)

[a]LGBTQ+: lesbian, gay, bisexual, transgender, queer or questioning, or others.

[b]GED: General Educational Development.

Feasibility: Engagement and Retention

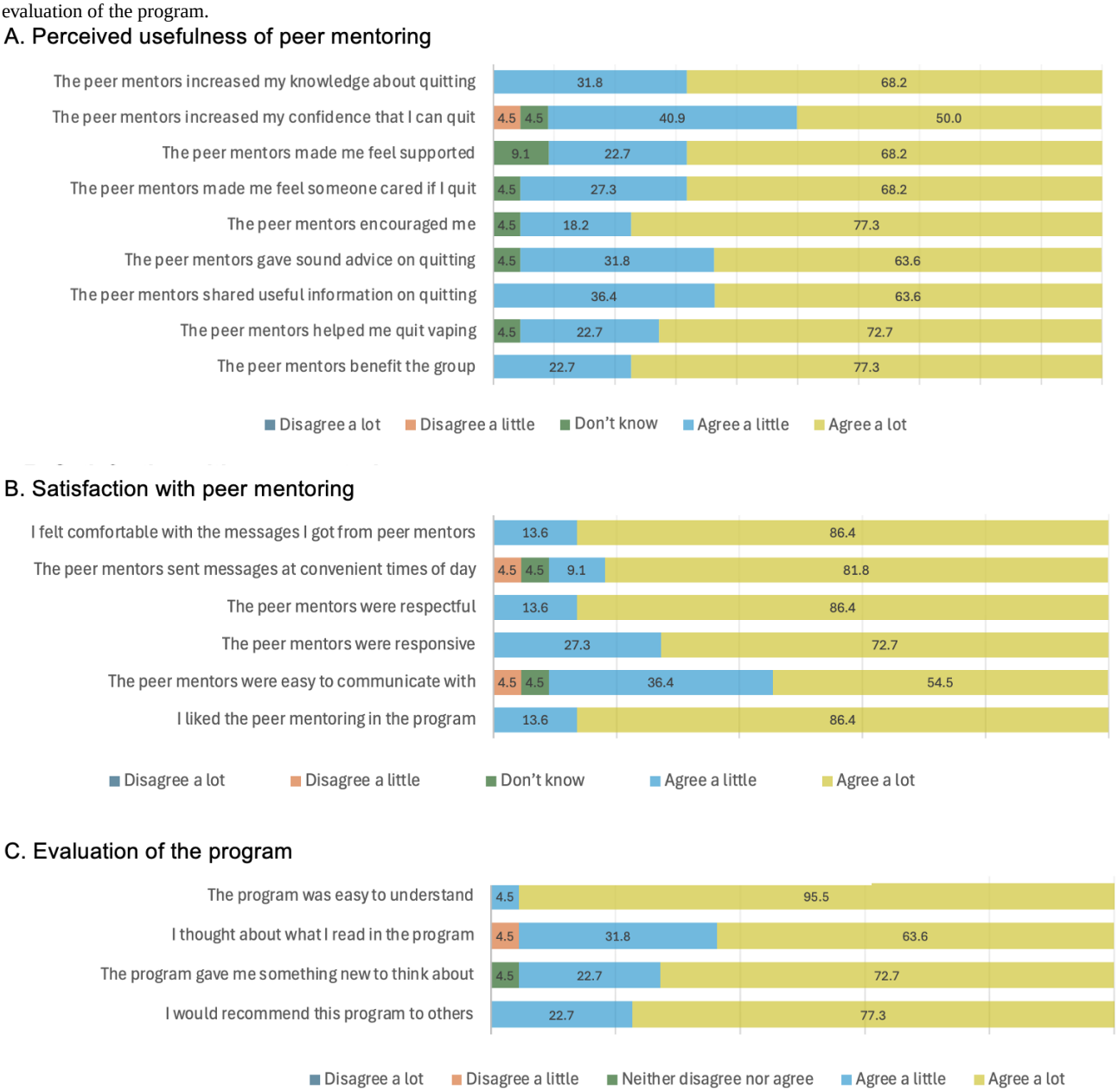
Almost all participants (23/24, 95.8%) engaged by posting or liking comments in the group at least once during the program. Combining posting and liking, participants engaged with the program a mean of 28.8 (SD 27.3) times and median 15.5 (IQR 9.0-44.8) times over the 5 weeks. There was no substantial difference between group 1 (median 18.0, IQR 9.3-61.3) and group 2 (median 13.0, IQR 9.0-44.3). Specifically, of the 24 participants, 23 (95.8%) posted at least once during the program. The mean number of posts per person was 18.6 (SD 18.5), and the median number of posts was 10.0 (IQR 8.0-26.3). Excluding the 1 participant who never posted, individual post counts ranged from 1 - 67. A total of 21 (87.5%) participants ''liked'' at least one post in the group. The mean of "likes" per person was 10.3 (SD 11.1). The median number of "likes" was 5.5 (IQR 1.0-18.8). Among those who "liked" at least once, individual "like" counts ranged from 1 - 38. At week 5, 22 (91.7%) participants remained in the group and completed the follow-up survey.

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Perceived Usefulness of Peer Mentoring

Peer mentoring provided in the group was perceived to be highly useful (Figure 2A). All participants agreed that their peer mentors increased their knowledge about quitting, provided useful information, and benefited their group. Nearly all participants (21/22, 95.5%) agreed that the mentors showed care, offered encouragement, gave good advice, and helped them quit vaping. A total of 90.9% (20/22) of participants reported that the mentors boosted their confidence in quitting and made them feel supported. Across the 9 items measuring perceived usefulness, the mean score was 4.6 (SD 0.3) out of 5.

Figure 2. Proportion (%) of responses for acceptability measures. (A) Perceived usefulness of peer mentoring; and (B) satisfaction with peer mentoring; (C) evaluation of the program.



Satisfaction With Peer Mentoring

The participants expressed very high levels of satisfaction with the peer mentoring they received in the group (Figure 2B). All participants agreed that they liked the peer-mentoring component, felt comfortable with the messages they received, and found the mentors respectful and responsive. Most (20/22, 90.9%) participants also agreed that the mentors sent messages at convenient times and were easy to communicate with. Across the 6 items measuring satisfaction with peer mentoring, the mean score was 4.7 (SD 0.3) out of 5. In addition, 86.4% (19/22) of participants felt the number of messages from peer mentors was "about right," 9.1% (2/22) thought there were "few," and 4.5% (1/22) thought there were "many." No participant selected the options of "too few" or "too many."

Evaluation of the Program

The participants evaluated the peer-mentored vaping cessation program highly (Figure 2C). All participants agreed with the statements "I would recommend this program to others," and "The program was easy to understand." Nearly all participants (21/22, 95.5%) agreed that "The program gave me something

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new to think about," and "I thought about what I read in the program."

Vaping Abstinence Outcomes

Using an intent-to-treat approach, 66.7% (16/24) of participants reported being abstinent at the end of the program based on 7-day point prevalence abstinence. Of the participants who completed the follow-up survey, 72.7% (16/22) reported being abstinent at 5 weeks. Among participants who had not quit, the average number of vaping days per week was 1.8 (SD 1.2) days, lower than the average of 5.1 (SD 1.7) days per week at baseline, and no participant reported daily vaping at follow-up. Similarly, the average number of puffs per vaping day decreased to 5.7 (SD 4.7) puffs, compared with 31.6 (SD 62.5) puffs at baseline.

Focus Group Findings

We conducted 2 postintervention focus groups with 5 participants from the 2 groups (1 female and 4 male). Three participants reported abstinence and 2 did not, and 3 had participated in a prior QTH group without peer mentors. The following themes were identified: appreciation of having peer mentors, communication with mentors, feedback on program setup, privacy and boundaries, advice for improvement, and willingness to be a future mentor.

All 5 participants expressed high satisfaction with the peer mentoring they received, valuing both mentors' approachable communication style, characterized by respect and responsiveness, and their steady support. One participant noted the following (theme: appreciation of having peer mentors):

> *I feel like they're the most helpful with just general support. I have the group as community support overall, but the peer mentors serve as kind of an anchor... I feel like the peer mentors were really stable source of support in the group and I feel like that was a benefit.*

Some participants who had previously participated in a QTH group without mentors recalled that a large number of participant posts off the topic of vaping cessation discouraged participation, and this was improved with peer mentors:

> *I had muted it around week two... every hour that I would get a notification of 99 plus messages... the actual topics of conversation were not beneficial to quitting and we're completely off of what should be discussed.*

By comparison, these participants felt that peer mentors' presence in the group discussions kept the group focused and on track (theme: appreciation of having peer mentors). They were also satisfied with the number of times their mentor messaged them and the wait time before receiving a response (theme: communication with mentors). The group size and ratio of mentors to mentees were considered acceptable, as noted by one participant (theme: feedback on program setup):

> *Both of my mentors were pretty active, so I always felt like they were around. So, I thought two was the perfect number.*

Participants appreciated being offered the options of peer mentoring both one-on-one and in the group setting (theme: feedback on program setup). They mentioned that the peer mentors fostered a welcoming environment in the group, which also facilitated comfort with one-on-one mentoring. Among the 5 focus group participants, 3 direct-messaged their mentors (themes: feedback on program setup and communication with mentors):

> *I feel like the way he interacted in the group chat first also made me feel comfortable to reach out. He seemed very open.*
>
> *It's like you get to know them and the DMs, it's a lot more personal, ... I like that we have both options instead of one.*

Although all participants agreed that one-on-one support was a valuable supplement to group discussions, they had mixed views on peer mentors proactively direct-messaging them. Most participants appreciated it and felt it increased their sense of connection to the group, with one participant noting the following:

> *I thought that this program and the group chat was very helpful, especially the mentors, especially when they DM me personally, so I never felt that way of leaving the program, and they really helped us quit.*

However, one participant felt pressured by the DM and said they might have considered leaving the group if they received more (theme: privacy and boundaries).

Participants in the focus group also affirmed core components of the QTH program and believed some helped with the mentor-mentee relationship (theme: feedback on program setup). For instance, the counselor posted Monday roll calls as brief check-ins in the group chat that invited members to respond to a fun question or prompt. Participants felt that these posts helped maintain engagement, and they described the group-based design as both supportive and motivating. As one participant explained:

> *I guess the motivation was just other people—seeing other people also trying to achieve the same goal as me. It just pushes you forward instead of relying on your own goals, so you get inspiration from other people.*

While participants wanted the program to focus on vaping cessation, they also appreciated that not all questions were strictly about vaping. For example, a question from QTH asked, "If you were a food what food would you be?" and a participant answered, "I'd be a grape because I want to be with my friends all the time." They felt that having nonvaping-related interaction questions once a week was just the right amount and helped keep them engaged and connected with both their peers and the mentors.

When asked for suggestions to improve the program, participants recommended incorporating more personal interactions, such as video messages, video meetings, and designated office hours for real-time support (theme: advice for improvement). Several noted that a mentor had used a video self-introduction, which was very well received. As one participant shared:

> *It seems like they sent you a personal message even though it's sent to everyone. I feel like that [sending*

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a video message] would help you get to know them just a little bit better.

They also suggested that the QTH counselor share more resources during the program, particularly on Fridays, so they could review the materials over the weekend when there were no messages from the counselor in the group. Additionally, a couple of participants expressed a desire for a longer intervention than 5 weeks to further support abstinence. Participants did not indicate any further concerns with the peer-mentored QTH program, participant safety, or privacy. Two participants also expressed interest in serving as peer mentors in future cohorts (theme: willingness to be a future mentor).

Discussion

Principal Findings

Our study found that integrating peer mentors who had successfully quit vaping into QTH, an Instagram-based vaping cessation program, was both feasible and acceptable. While the study was not designed to formally assess efficacy, using an intent-to-treat analysis, 66.7% (16/24) of participants reported 7-day point prevalence abstinence. Postintervention focus groups provided qualitative data confirming that participants highly valued the peer mentoring in the program, found the peer mentors helpful in their quit efforts, and endorsed a peer-mentored approach. Together, these findings underscore the promise of peer-mentored, social media–based vaping cessation interventions and the need for future trials to assess their efficacy.

Overall, engagement in the peer-mentored QTH intervention was encouraging. QTH was adapted from the Facebook-based TSP smoking cessation intervention for young adults that showed efficacy. We used the same engagement metrics (ie, number of comments and likes) as in the TSP pilot lasting 90 days. In the TSP pilot, 61% (48/79) of participants commented on at least one post and 51% (40/79) liked at least one post, compared with 95.8% (23/24) and 87.5% (21/24), respectively, in our peer-mentored intervention. The median number of comments was higher in our intervention than in TSP (15.5 vs 12), and the median number of likes was also higher (5.5 in our intervention vs 4 in TSP) [41]. TSP did not report mean overall program engagement, limiting direct comparison on this metric. However, mean program engagement in the peer-mentored intervention was 28.8 (SD 27.3) posts or likes, which was lower than the mean of 47.5 posts or likes in the QTH RCT [43]. This may partly be explained by the large number of nonvaping-related engagement, as noted by our postintervention focus group participants who had been recruited from the QTH RCT and did not successfully quit. It should also be noted that participants reported sending DMs to their mentors during the peer-mentored program; however, one-on-one peer mentoring via DMs was not captured as an engagement metric because the research team could not access these messages outside the group. Therefore, we may have understated participant engagement in the peer-mentored QTH program.

Regarding retention at the end of intervention, TSP reported 76% (60/79) retention [41], the QTH group in an RCT without peer mentoring reported 48.4% (124/256) retention [44], and our QTH group with peer mentoring achieved 91.7% (22/24) retention. However, the program durations differed (90 days in TSP vs 5 weeks in QTH), and recruitment strategies also varied across studies; therefore, the presence of peer mentoring may not fully explain the differences in study retention. The purpose of incorporating peer mentoring as a source of social support was to enhance participant engagement, which is a key driver of retention. Although we could not statistically establish the relationships among these factors, both the observed engagement metrics and qualitative feedback from postintervention focus groups suggest that peer mentoring is a promising and well-received strategy for increasing topic-focused engagement in social media–based interventions. Further research is recommended to clarify these relationships.

We also found high levels of satisfaction with and perceived usefulness of peer mentoring among the participants. Participants expressed high levels of satisfaction, as indicated by high mean values. All participants who completed the follow-up survey agreed that their peer mentors "increased [their] knowledge about quitting," "shared useful information on quitting," and "benefited the group." Focus group discussions echoed these findings, revealing that peer mentors benefited the group by keeping the conversation focused on quitting, compared with programs without peer mentoring. Participants also expressed strong satisfaction with the peer mentoring they received in the group, highlighting easy and comfortable communication, a respectful and responsive style, messages sent at convenient times and in appropriate amounts, and the effective combination of one-on-one and group mentoring. All participants agreed with the statement, "I like the peer mentoring in the program." Participants' positive responses to the current peer-mentoring approach reflect the success of incorporating our formative findings into program development and underscore the potential of this approach for future interventions [40]. Beyond the very positive perception of peer mentoring itself, participants also highly rated the peer-mentored version of the QTH program, with all indicating that they "would recommend this program to others."

One consideration for implementing peer mentoring is the additional resources required to train, support, and compensate peer mentors, which increase program cost and complexity. However, this model remains more efficient than in-person peer-mentoring programs, which require more substantial resources [34]. Our participants' strong evaluations of both the peer mentoring and the peer-mentored intervention as a whole highlight the potential of a geographically unrestricted, low-cost peer support model. Moreover, participants expressed interest in serving as peer mentors themselves, suggesting the potential to develop a large, sustainable mentor pool to support subsequent cohorts of individuals seeking to quit.

Though this pilot study focused on feasibility and acceptability, 72.7% (16/22) of participants who completed the follow-up survey reported abstaining at the end of the intervention. Using an intention-to-treat approach, the reported 7-day point prevalence abstinence rate was 66.7% (16/24), which is higher than the self-reported abstinence rate at the end of intervention in the QTH group without peer mentoring (67/256, 26.2%) [44]

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and TSP (9/79, 12% in its pilot test [41] and 23/251, 9.2% in its RCT [36]). Compared with the QTH RCT, participants in this study included fewer daily users, reported lower frequency of nicotine use, had lower levels of nicotine addiction as measured by time to first use upon waking, and showed higher motivation to quit. As a result, peer mentoring alone may not fully explain the observed differences in abstinence. While self-reported data from unblinded participants may not accurately reflect participants' actual quit status, these findings suggest that peer mentoring has the potential to improve abstinence from e-cigarette use and warrant further research to assess efficacy. Additionally, focus groups provided valuable insights for future peer-mentored intervention design, such as increased use of videos to enhance interaction, opportunities for real-time support, and ways to extend the intervention duration to help sustain abstinence.

Limitations

This study has several limitations. First, intervention participants were recruited from California only, and most had a strong desire to quit vaping. As a result, the findings of this pilot trial may not be fully generalizable to e-cigarette users in other regions or to those less motivated to quit. Second, abstinence data were self-reported and not biochemically validated. Third, the small number of pilot groups and focus group participants may not reflect the full range of participant experiences. The limited number of focus group participants also precluded the achievement of thematic saturation. Fourth, as a pilot study, the limited sample size does not allow the establishment of relationships between peer mentoring, engagement, and outcome variables. Future studies, such as RCTs or those using a multiphase optimization strategy design, are recommended to rigorously evaluate the efficacy of peer mentoring in supporting young people's e-cigarette cessation.

Conclusions

This study found that integrating peer mentoring into vaping cessation interventions delivered in groups on a social media platform is both feasible and acceptable. Participants rated both peer mentoring and the overall peer-mentored program highly. Self-reported 7-day point prevalence abstinence at the end of the intervention was very promising. These findings support a future full-scale trial to evaluate the efficacy of peer-mentored social media–based vaping cessation interventions.

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Data Availability

The datasets generated and/or analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

Conceptualization: JCL (lead), PML (equal), JSW (supporting)
Data curation: JCL, KS, AA
Formal analysis: JCL (lead), KS (supporting)
Funding acquisition: PML, JCL
Investigation: JCL
Methodology: JCL, PML
Project administration: JCL, PML
Resources: PML
Supervision: PML
Validation: JCL, PML
Visualization: JCL
Writing – original draft: JCL (lead), KS (supporting)
Writing – review & editing: JCL, JSW, KS, AA, PML

Conflicts of Interest

None declared.

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Abbreviations

QTH: Quit the Hit
RCT: randomized controlled trial
TSP: Tobacco Status Project

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Original Paper

Motivational Drivers for Teachers as Informal Health Educators to Initiate In-Class Discussions With Adolescents About Smoking: Moderated Mediation Study Using Attribution Theory

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Abstract

Background: Teachers have the potential to be influential figures in school-based health promotion as informal caregivers; yet little is known about what motivates them to initiate preventive conversations with students. Attribution theory offers a useful framework to explore how perceptions of responsibility shape communicative behavior, but it has rarely been applied in the context of teacher-student interactions around health risks such as smoking.

Objective: This study applies the attribution theory to explore the motivational drivers that lead teachers to initiate discussions with adolescents about smoking.

Methods: Data were collected from 101 middle schools in the Canton of Ticino, Switzerland, as part of a larger longitudinal study. The analysis focuses on 67 teachers who participated in the first wave. Responsibility attribution, concern, and previous classroom sanctions were examined in association with teachers' communication.

Results: Results from a moderated mediation model showed that teachers who attributed greater responsibility to the school (internal attribution) reported higher levels of concern (β=–0.41; *P*=.002) and engaged in more frequent in-class discussions on smoking (β=–0.26; *P*=.02). Although concern alone was not directly related to communication (β=–0.14; *P*=.22), its effect was significantly moderated by contextual sanctions (β=1.01; *P*<.001).

Conclusions: These findings highlight the motivational and contextual factors that shape teachers' communication with students on smoking behavior. By applying attribution theory in the novel context of health communication, this research contributes to understanding how perceived responsibility influences preventive communication in schools.

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KEYWORDS

attribution theory; in-class health communication; informal caregiver; smoking prevention; teachers

Introduction

Overview

Imagine being a teacher (if you are not already one) faced with the challenge of addressing the topic of health prevention with your students. Now imagine feeling directly responsible for these young individuals, knowing that their future may, in part, depend on what you teach them, and becoming aware of the weight your words might carry in shaping their behavior. It is reasonable to assume that such awareness, this sense of responsibility, would significantly influence what you say in the classroom to prevent adverse behaviors, especially if your class is known for behavioral issues or has previously faced disciplinary actions. Conversely, suppose that while looking at these 20 or so faces, you are convinced that students' health is

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entirely the responsibility of their parents. You are convinced that your role does not extend to teaching healthy behaviors, and you therefore feel no personal involvement in their long-term health. In such a case, you would likely be less inclined to engage with them in conversations aimed at preventing risky behaviors.

This is precisely the central focus of the research presented in this study: it concerns the motivational foundations of in-class teachers' communication on smoking and applies attribution theory, originally developed by Heider [1] within psychology, to the novel and previously unexplored domain of teachers' health communication with students in educational settings.

Research on the impact of communication on adolescent smoking has traditionally emphasized the influence of parents and peers [2]. Teachers, on the other hand, spend a similarly significant amount of time with adolescents but have received comparatively limited attention [3-5]. The school environment has been broadly considered in previous research [6,7]. What has been overlooked is the specific role of teachers in deterring adverse behaviors, with some early exceptions [8].

To address this gap, this research draws on the longstanding psychological framework of attribution theory to explore the mechanisms that may prompt teachers to initiate conversations about smoking. Although attribution theory has been successfully applied to explain pupil motivational drive or achievement evaluation in educational contexts [9-11], its use in communication research, particularly health communication, remains limited. Notably, in their contribution to the book *Communication and Learning*, Waldeck and Labelle [11] propose future research directions that include "extending its use to examine the relationship of instructor attribution of student behavior of corresponding communication behaviors both in and outside the classroom environment" (page 70). Although more than a decade has passed, this research cue has not yet been pursued. This study directly responds to this call by demonstrating the value of applying attribution theory to teachers' interactions with students in the context of smoking prevention, contributing to a sparsely developed body of literature on teachers as active agents in health-related communication.

The following sections provide a detailed exploration of the literature supporting this inquiry, including teachers' role in adolescents' health, the context of adolescent smoking, and, finally, past work that has applied attribution theory.

Teachers' Role

Schools have long been the focus of numerous intervention programs aimed at reducing adolescent smoking [12,13]; yet the specific role of the adults who share this environment with students—namely, teachers—remains understudied [2,8]. Anecdotal evidence highlights the potential influence teachers can exert on students; many can recall a particular teacher whose words or actions left a lasting impression. This influence is unsurprising given that adolescents spend approximately 5 to 7 hours per day in close interaction with teachers during critical developmental years. Moreover, teachers can impact learning across cognitive, affective, and behavioral domains [14,15].

Teachers play a central role in adolescents' lives, acting as a bridge between the adult world, represented by institutions and society, and the private, familial world of childhood [8]. Importantly, teachers are both accessible and cost-effective to involve in health-related initiatives, given that their professional role already encompasses a form of authority that is qualitatively distinct from that of parents [6]. Furthermore, their position grants them a dual role: as socializers guiding adolescents into adulthood and as communicators capable of voicing students' needs to other adults. This dual function highlights their unique capacity to mediate between adulthood and childhood [8].

The teacher-student relationship has been shown to significantly affect a variety of health behaviors [16]. For example, Voisin et al [17] found that students reporting high levels of teacher connectedness were less likely to engage in adverse behaviors such as gang membership, risky sexual encounters, and substance use. Communication, specifically, has been identified as a key factor in enhancing the efficacy of intervention programs. Effective teacher communication has been defined as a set of communicative behaviors that improve learning [18]; this concept can be extended beyond academic topics to include health-related behaviors. In the study by Mesman et al [19], clear communication from teachers improved outcomes in interventions targeting alcohol use and physical activity. These findings suggest that a similar influence may extend to other health behaviors, such as smoking, although further studies will need to confirm this relationship.

Understanding the motivational processes that drive teachers to engage with students in conversation about health behavior is crucial, as it opens the door to developing strategies that support and enhance teacher-led communication as a form of school intervention. This is precisely why the theoretical framework adopted in this study is particularly well suited: to effectively increase teacher engagement in preventive communication, efforts must target the motivational grounds for such communication. Among these, perceived responsibility for adolescent health can be a promising factor. By increasing the perception of responsibility, it could be possible to foster more frequent and meaningful communication, ultimately leading to a higher impact of prevention on adolescent smoking.

Adolescents' Smoking

The urgency of addressing adolescent smoking stems not only from its well-documented health consequences, such as respiratory disorders, cardiovascular diseases, and cancer, as highlighted by the review by Arafa et al [20], but also from its negative effects on cognitive development. Tobacco use during adolescence has been shown to hinder the development of brain networks and cognitive functions. Nicotine products are, without a doubt, toxic to the neurodevelopment of young people [21-23].

Beyond its impact on individual health, the global tobacco industry contributes significantly to environmental degradation, including deforestation, air and water pollution, biodiversity loss, and greenhouse gas emissions [24-26]. As such, smoking represents a critical behavior to target, not only for personal health but also for environmental protection. Preventing smoking initiation during adolescence is especially critical, as early

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smoking onset significantly increases the likelihood of long-term tobacco consumption [27].

Recent data confirm that adolescent smoking remains a pressing global public health issue, with notable prevalence rates reported even in high-income countries with strict regulations. For example, the Health Behavior in School-Aged Children study indicates that a substantial percentage of youth experiment with or regularly use tobacco products, with nearly a quarter of adolescents aged 15 years reporting having ever smoked [28]. Adolescent smoking is strongly influenced by psychosocial factors such as peer norms, social identity, and stress—factors that make this period especially critical [29-32].

This underscores why the timing of intervention is crucial: adolescence is a developmental window during which risk-taking increases [33]. In this context, teachers are unique figures who can influence adolescent health trajectories. Their presence and authority place them in a powerful position to support early prevention efforts. Moreover, addressing adolescent smoking cannot be left solely to families or health care systems. Schools represent a critical institutional setting for early prevention, not only because they welcome a great variety of young people but also because they provide opportunities for sustained interaction between students and educators, which can foster trust and influence over time.

Attribution Theory

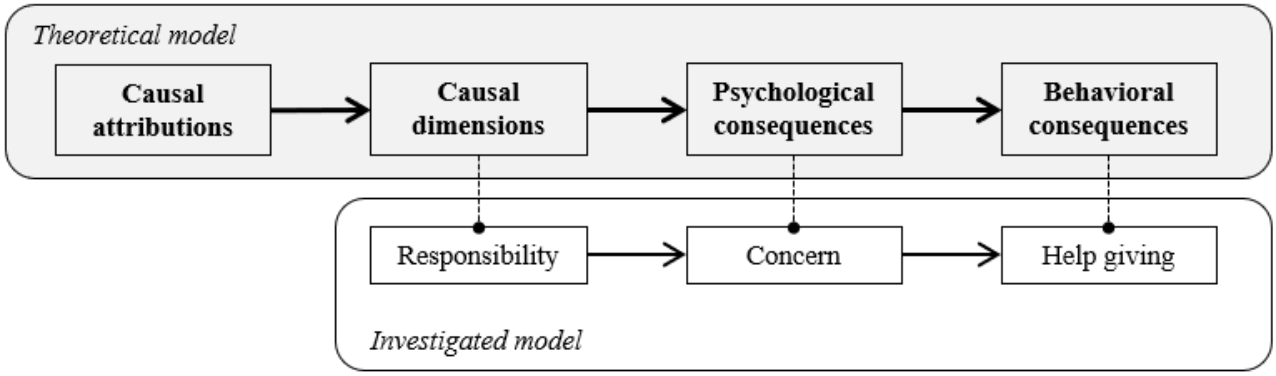
This study applies attribution theory, first developed by Heider [1] and further elaborated by Weiner [34]. It has been successfully used for decades in motivational research, social psychology, and educational psychology [35], but has rarely been applied in the context of health communication. According to this theory, individuals ascribe causality, and subsequently responsibility, to events and behaviors in their everyday lives [36]. These attributions, often made unconsciously, help understand why people do what they do and what motivates them to engage or disengage in specific behaviors [37].

Attributions are shaped in accordance with preexisting beliefs and are characterized by three distinct dimensions: (1) locus of causality, (2) stability, and (3) controllability [9,35,37-40]. The locus of causality refers to whether the cause of an event is attributed to personal characteristics within one's control (ie, internal attributions) or external factors beyond one's control (ie, external attributions) [38-41]. The stability dimension, as the name suggests, refers to the perceived consistency of the cause over time, whether it is a fixed trait or a fluctuating condition [38,39]. Lastly, the controllability dimension concerns whether the cause is perceived as subject to personal control and is closely tied to perception of personal responsibility [38]. Although this dimension was not part of the original formulation—as it was added by Fiske [42]—it has since been included as a "proximal critical cognitive consequence" of causal attribution [38,43]. This last dimension is the focal point of the research presented here.

In practice, individuals evaluating a situation unconsciously assess the cause of an event or behavior, including how responsible they feel in that situation [44]. This attribution directly shapes their behavioral response, as each evaluation elicits distinct psychological and behavioral consequences, such as help giving or help seeking [9,44].

The model tested in this paper is depicted in Figure 1 and shows the linear framework outlining the pathway from causal attribution to causal dimensions, then to psychological consequences, and lastly to behavioral consequences. The linear framework outlines the pathway from causal attribution to causal dimensions, then to psychological consequences, and lastly to behavioral consequences. This study focuses on the final 3 components of the model to examine their relevance within the teacher-student communication context. Specifically, the causal dimension triggered by the attribution is the feeling of personal responsibility; the psychological consequence is the rise of the social emotion of concern; and the behavioral consequence is help giving, through the form of communication [9].

Figure 1. Representation of the attributional model tested.



Exploring each component in more detail, the attribution of responsibility in educational contexts has been the subject of several studies, with both students and teachers as attributers [45-47]. In one section of the systematic review conducted by Wang and Hall [38] focused on teachers' attributions, the authors present 9 papers that specifically examine teachers' perceptions of responsibility. However, the studies presented are exclusively on responsibility in relation to academic performance, without addressing either health-related themes or the communicative behaviors between teachers and students.

Regarding the psychological consequences of the causal attribution, concern has been selected as a social emotion, consistent with the definition given by Burnett et al [48] as an emotion that involves mentalizing about other people. Concern arises in social contexts in which individuals affect one another's

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emotional state [49]. In the context of this study, the emergence of teacher concern for students is expected to be influenced by whether teachers feel responsible for their students' health behavior.

Lastly, help giving has been operationalized as communication: the first step in supporting students within the context of smoking prevention is the act of speaking to them about the issue and drawing their attention to its risks. Whether through advice, emotional support, or information sharing, communication can fulfill the function of helping others, particularly in contexts in which direct intervention is limited. This has been demonstrated in studies on doctor-patient communication and online support groups [50-52]. In the case of smoking prevention, the most accessible and powerful tool teachers possess—aside from disciplinary measures—is their ability to educate adolescents about the harmful effects of tobacco use. Teachers' communication skills have been consistently associated with more effective learning outcomes [53] and the success of intervention programs [19,54]. Moreover, training in communication is frequently identified as a strategy for improving teacher efficacy [55]. Together, these findings underscore the central role of communication as a vehicle for preventive action in school settings.

Building on the theoretical framework presented thus far, we can summarize the core logic: hypothetically, teachers who feel personally responsible for preventing smoking among their students should experience greater concern than those who place responsibility externally. This heightened concern should in turn increase their motivation to protect students through communicative engagement in the classroom. In this way, communication could become the behavioral outcome of an attribution-based emotional and cognitive process—bridging the sense of responsibility and the intention to help students. This framework highlights the relevance of attribution theory in explaining the motivational base for health-related communication.

Contributions of This Study

Based on the literature review, several gaps emerge that this study seeks to address. The first concerns the attribution of responsibility by teachers: no past research, to the best of the authors' knowledge, has uncovered who is deemed responsible in the eyes of teachers for smoking prevention. Furthermore, in the context of tobacco consumption, it is not known how the attribution of responsibility affects communicative behavior: the motivational drivers behind teachers' decisions to engage in conversations with students about smoking remain underexplored. While existing research provides some evidence of teachers' influence on adolescent health behaviors, little is known about their personal motivators or decision-making processes in initiating such communication. To address this, the study tests the linear model proposed by Graham [9], grounded in Weiner's [39] attribution theory, focusing on concern as a social emotion that mediates the relationship between attribution of responsibility and communication.

In addition to this theoretical contribution, the study introduces a novel contextual variable not previously discussed in the literature review: the smoking behavior of students. This variable has been operationalized in this study as the presence or absence of prior sanctions for smoking, considering that this information implicitly includes the teachers' perception of classroom smoking behavior. This element is hypothesized to moderate the relationship between teachers' concern and their likelihood of communicating about smoking. Specifically, the expectation is that highly concerned teachers will be less likely to initiate discussions in classrooms in which no sanctions have previously been applied compared with those teaching in classes with a history of disciplinary action related to smoking. This reflects the idea that contextual cues, such as prior disciplinary actions, may shape whether emotional concern is translated into communicative behavior.

These considerations lead to the development of the study's central research question and hypotheses, summarized in Table S1 in Multimedia Appendix 1. They aim to empirically test both the motivational and contextual factors driving teacher-student communication on smoking prevention.

Research Question and Hypotheses

The study was guided by the following research question (RQ) and hypotheses (HP):

- RQ1: To whom do teachers attribute responsibility for preventing students from smoking?
- HP1: Attributing responsibility to the school context (ie, internal locus of responsibility) is associated with engaging in more discussion on smoking with students compared with attributing responsibility to parents (ie, external attribution of responsibility).
- HP2: Concern about future problems resulting from smoking (M), as a psychological consequence, will mediate the link between responsibility attribution (X) and in-class communication (Y).
- HP3: The presence or absence of sanctions applied to the class will moderate the relationship between concern and communication. Specifically, higher concern is expected to be associated with more frequent communication when students have previously received sanctions for smoking.

Methods

Ethical Considerations

The study was conducted according to the guidelines of the Declaration of Helsinki. The questionnaire and methodology for this study were approved by the Cantonal Bureau for Education in the Canton of Ticino, Switzerland (September 2017). No exemptions from ethics review were applicable. Written informed consent was obtained from participating teachers at the beginning of data collection; participants were informed that their participation was voluntary and that they could withdraw at any time without explanation. To protect their privacy, all data were anonymized using alphanumeric codes. No financial or other compensation was provided.

Procedure

This research is part of a larger longitudinal study involving teachers, parents, and adolescents from a representative sample of 101 middle schools in the Canton of Ticino, Switzerland.

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The Canton of Ticino is located in the southern part of Switzerland, and the official language is Italian. As of 2024, the canton accounts for 4% of the total Swiss population (354,023 permanent residents), and the proportion of young people aged 15 years or younger has been steadily decreasing, reaching 12.6% of the total population in 2023 [56].

The study aimed to investigate the evolution of various health behaviors from the perspective of adolescents, their parents, and their teachers.

In September 2017, marking the beginning of data collection, a random sample comprising 66% of all first-year public school classes from the 5 areas of the canton was selected. The school sample was randomly selected to ensure representation of the broader school population. Private schools were also invited to participate; 1 of 3 agreed to participate, and 1 class was randomly selected. The final sample consisted of 101 classes from 36 schools (35 public and 1 private). Each class designated a reference teacher who could voluntarily participate in the study. The data analyzed in this study refer to the 67 teachers who voluntarily participated in the first wave of data collection, conducted at the end of the 2018 school year. The response rate was 66.3%, which is relatively high given that the questionnaire was administered at the end of the academic year, when teachers are usually engaged in closing activities and planning for the summer recess.

Paper questionnaires were distributed to all participating schools for completion by adolescents, parents, and teachers. Reference teachers were asked to complete the survey at the end of school board meetings, ensuring they had an up-to-date understanding of the classroom context. Once completed, they were asked to return the questionnaires to the university using a preaddressed, stamped envelope.

Participants

Of the 67 teachers who participated, 60% (40/67) identified as female, 30% (20/67) as male, and 10% (7/67) did not disclose their gender. In 88% (56/67) of the cases the role of reference teacher was assumed by the class teacher, a key figure in educational system of Ticino, responsible for mediating between the school and the families, as well as evaluating students' performance and workload [57]. The remaining respondents (11/67, 12%) identified themselves as members of management or as subject-specific lecturers. Participating teachers taught their class for a minimum of 2 hours and a maximum of 10 hours per week (mean 4.98, SD 2.10 hours), and more than three-quarters (41/67, 77%) had at least 5 years of teaching experience in middle school. Overall, teachers reported an average of 11.8 (SD 8.41) years of teaching experience and a mean employment rate of 81.3% (SD 22.90%).

Materials

Overview

The questionnaire used in the longitudinal study included both validated scales and ad hoc items developed specifically for this data collection. The following section describes the variables included in the model presented in this study.

Responsibility Attribution

Attribution of responsibility was measured using a set of 8 items covering both health-related and educational behaviors. For this study, only the item related to smoking was analyzed. Participants responded to the general prompt, "In your opinion, which of the following educational goals are the responsibility of the school, and which are the responsibility of the parents?" with 1 of the specific goals being: "Ensuring that children do not smoke." Responses were rated on a 7-point Likert scale, where 1 indicated full responsibility attributed to the school, 4 indicated shared responsibility, and 7 indicated full responsibility attributed to parents. Responses attributing responsibility to the school were considered an internal attribution, as teachers are part of the school context and their answers reflect both their own behavior and their awareness of institutional norms and practices. Conversely, attributing full responsibility to parents was regarded as an external attribution.

Concern

Teachers' concern was assessed with the following item: "How concerned are you that the following behaviors may lead middle school students to have problems in their future lives?" A list of 8 adverse behaviors was provided, including "cigarette consumption." Responses were recorded on a 5-point Likert scale (1=not at all and 5=very).

Sanctions

Teachers were asked to consider the past academic year and indicate "on how many occasions students in the class [insert class evaluated] were appropriately sanctioned if they performed any of the following behaviors." Sanctions could have been issued by the teacher himself or by a colleague. For this study, only the responses for smoking cigarettes were used. The response option was a 6-point Likert scale (0=this type of incident never occurred and 6=always). As the item, in its original formulation, contained two types of information—(1) the presence or absence of sanction and (2) the appropriateness of the sanctions—the researchers dichotomized the variable to isolate the first type of information. In this recoding, a response of 0 was retained as reference category to indicate that no sanctions were applied, while all other response options (1 through 6) were recoded to 1, signifying that a sanction was given to the class.

Communication on Smoking

The amount of communication in the classroom regarding health issues was measured with the following item: "During this school year, how often have you or other teachers discussed the following issues with the class [insert class evaluated]?" A list of 4 topics was presented, including tobacco use. Teachers could respond on a 4-point scale (1=never and 4=often).

Hours of Teaching (Covariate)

To control for time spent with the students, teachers were asked to indicate the number of hours they taught each week in the classroom being evaluated. This variable was treated as continuous.

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Data Analysis Plan

The required sample size was determined using G*Power (version 3.1.9.7) [58]. A minimum of 51 participants would be needed with 95% power at α=.05 (2-tailed). The final sample for the analysis included n=59, exceeding the requirement.

Using SPSS Statistics (version 29; IBM Corp), descriptive statistics were applied to analyze the variables under consideration. Means, frequencies, percentages, and SDs were used to describe the data, as well as to answer the first research question (RQ1). Pearson correlations were conducted to assess the relationship between the variables, and a 2-tailed *t* test was performed to examine differences in the continuous variables by the dichotomous variable of sanctions.

The hypothesized regression paths (HP1, HP2, and HP3) were tested using Model 14, a moderated mediation model, of Hayes PROCESS macro in IBM SPSS Statistics (version 29), with 10,000 bootstrap samples [59]. The analysis consisted of a regression test on the effect of responsibility attribution on communication frequency, as well as a test on the role of concern in mediating this relationship at the 2 levels of reported sanctions (ie, no sanctions and presence of sanctions). The mediator (concern) was mean centered prior to analysis. The variable "hours of teaching spent in the classroom" was used as a control variable. The model was tested with the addition of several teacher-level variables (ie, gender and years of experience) but yielded nonsignificant results and deteriorated overall model fit. Therefore, the more parsimonious model was retained. The graphical representation of moderation was performed in R (version 4.5.0; R Foundation for Statistical Computing) using the package *interactions* [60].

Results

Descriptive Results

Descriptive statistics are reported in Table 1. Following the recommendations of VanderWeele [61], descriptive statistics stratified by sanction level are reported to facilitate interpretation of interaction effects. Correlations and additional information are provided in Table S2 in Multimedia Appendix 1. Information on the variable responsibility attribution will be discussed in the next section, as it directly relates to RQ1. The variable concern had a mean of 2.97, indicating a moderate level of concern for future problems due to smoking. The distribution appears approximately normal, with minimal skewness (0.17) and kurtosis (–0.70). A similar pattern was observed for in-class communication on smoking, for which the mean score was 2.09, reflecting a low to moderate frequency of communication, and the variable appears normally distributed (skewness=0.41 and kurtosis=–0.92). Sanctions were given in 20% (14/67) of cases.

Table 1. Descriptive statistics for continuous variables, stratified by sanctions.

Variable	Frequency, n	Mean (SD)	Range	Sanctions, mean (SD)	
				Yes (n=14)	No (n=53)
Responsibility attribution	65	4.77 (1.07)	3-7	4.43 (0.85)	4.86 (1.12)
Concern	67	2.97 (1.18)	1-5	3.43 (0.94)	2.85 (1.22)
Communication	67	2.09 (0.98)	1-4	2.71 (1.32)	1.92 (0.81)
Hours of teaching (covariate)	61	4.98 (2.10)	0-10	5.46 (2.18)	5.07 (1.86)

Regarding correlations, communication frequency was significantly associated with all variables: it was positively correlated with concern (r=0.25; P<.05) and negatively correlated with responsibility attribution (r=–0.26; P<.05). The independent-samples 2-tailed *t* test revealed a significant difference in communication scores between sanction condition (mean 2.71, SD 1.33) and the no-sanction condition (mean 1.92, SD 0.80); t_{65}=–2.82; and P=.003. Concern and responsibility attribution were not differently distributed in the 2 conditions of sanctions. In other words, higher levels of communication were associated with greater concern, a more internal attribution of responsibility, and the presence of sanctions.

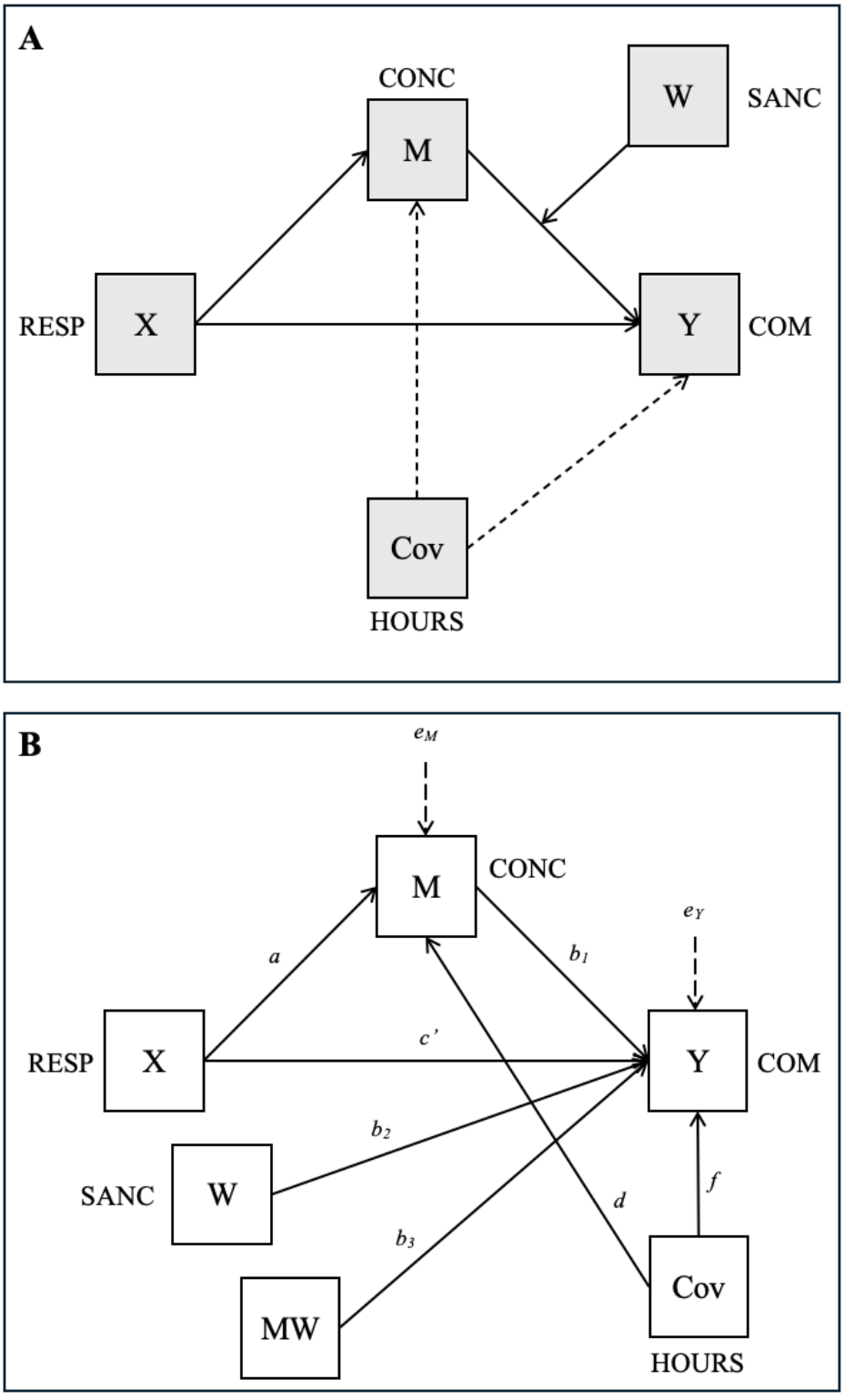
Main Results

Most teachers in the sample (36/67, 54%) attributed a shared responsibility for smoking prevention, and the descriptive statistics offer further insight into this pattern (RQ1). The mean of 4.77 (SD 1.07) suggests that, on average, teachers tend to lean toward attributing more responsibility to parents than to the school, as higher scores reflect external attribution. The distribution is slightly skewed, indicating more teachers score toward the higher end of the scale (Table 1). Notably, no participant attributed full responsibility to the school alone, while 10% (7/67) of participants stated that smoking prevention would solely involve parents.

Using Model 14 of the PROCESS macro [59], it was possible to test the 3 hypotheses. The conceptual and statistical diagrams of the tested model are shown in Figure 2, while the results of the analysis are presented in Table 2. In terms of model fit, a moderate amount of variance was explained, particularly for the outcome variable communication (39%). Controlling for weekly hours of teaching did not change the direction, strength, or significance of the main effects. Both the mediator (M; concern) and the dependent variable (Y; communication) were significantly predicted by the model, as indicated by the respective *P* values.

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Figure 2. The (A) conceptual and (B) statistical representation of the moderated mediation model. COM: communication; CONC: concern; M × W: interaction effect; M: mediator; RESP: responsibility attribution; SANC: sanctions. W: moderator; X: independent variable; Y: dependent variable.



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Table 2. Model coefficients for the moderated mediation model.

Antecedent	Consequent							
	Path	M[a] (CONC[b])[c]			Path	Y[d] (COM[e])[f]		
		Coefficient	SE	*P* value		Coefficient	SE	*P* value
X[g] (RESP[h])	a	–0.41	0.13	.002	c'	–0.26	0.11	.02
M (CONC)	—[i]	—	—	—	b_1	–0.14	0.12	.22
W[j] (SANC[k])	—	—	—	—	b_2	–2.56	0.95	.01
M × W[l]	—	—	—	—	b_3	1.01	0.27	<.001
Constant	i_M	4.26	0.74	<.001	i_Y	3.17	0.76	.001
Covariate (hours)	D	0.11	0.07	.13	f	0.07	0.06	.25

[a]M: mediator.

[b]CONC: concern.

[c]R^2=0.19; $F_{2,56}$=6.71; *P*=.002.

[d]Y: dependent variable.

[e]COM: communication.

[f]R^2=0.39; $F_{5,53}$=6.83; *P*=.001.

[g]X: independent variable.

[h]RESP: responsibility attribution.

[i]Not applicable.

[j]W: moderator.

[k]SANC: sanctions.

[l]M × W: interaction effect.

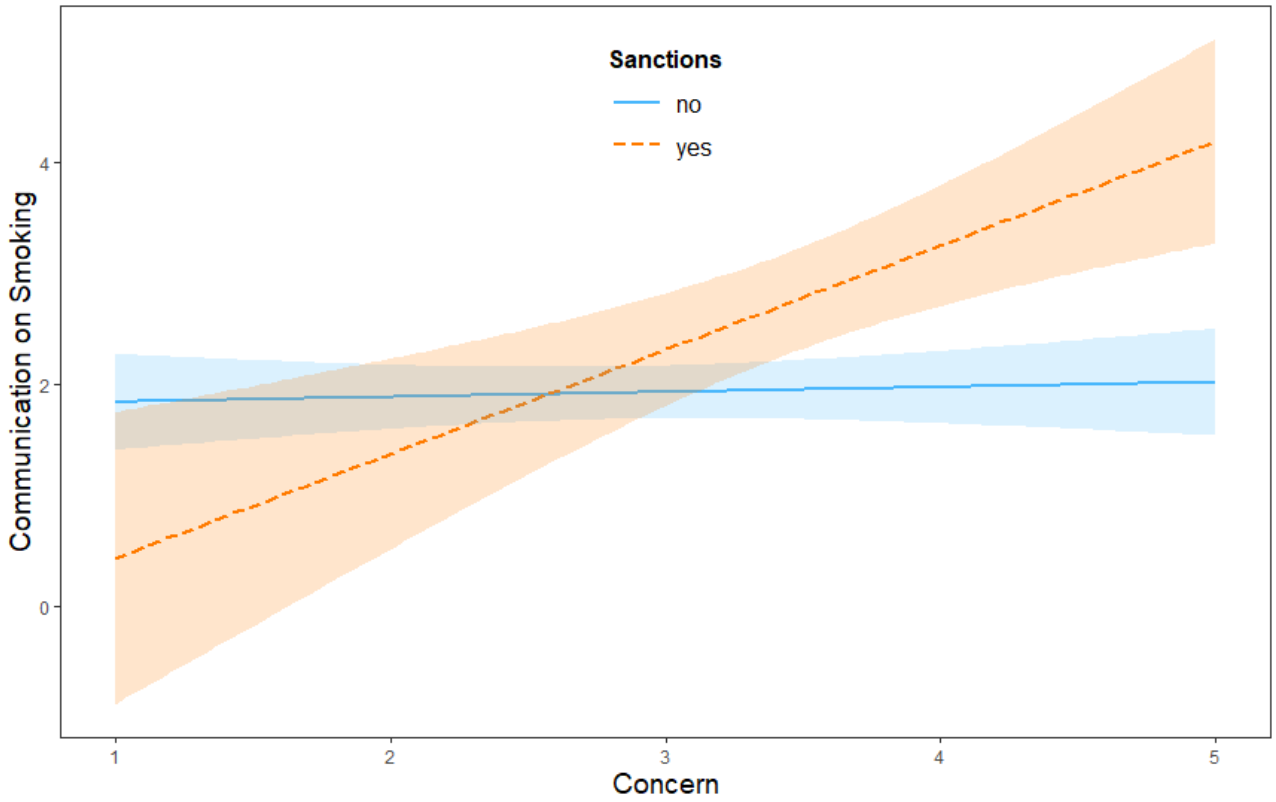
Before delving into hypotheses testing, it is important to note that, because the data are cross-sectional, the directionality of the observed relationships cannot be established. HP1 was supported: the path from responsibility attribution (X) to amount of communication (Y) showed a significant negative direct effect (β=–0.26; *t* value=–2.35, df_1=5, df_2=53; *P*=.02; 95% CI –0.47 to –0.04), even when controlling for concern and interaction effects. The outcome model accounted for a substantial proportion of variance in communication (R^2=0.39; $F_{5,53}$=6.83; *P*=.001). In practical terms, teachers who reported higher scores on responsibility attribution (ie, with an external focus, attributing more responsibility to parents) were also associated with lower rates of in-class discussions on smoking.

The mediation effect (HP2) was not confirmed in the main effect but supported under contextual moderation. As a matter of fact, the effect of responsibility attribution (X) on concern (M) was significant and negative (β=–0.41; *t* value=–3.22, df_1=2, df_2=56; *P*=.002; 95% CI –0.66 to –0.15), indicating that external attribution was associated with lower teacher concern. However, the main effect of concern (M) on in-class communication (Y) was not significant (β=–0.14; *t* value=–1.23, df_1=5, df_2=53; *P*=.22; 95% CI –0.38 to 0.09). In other words, unloading the feeling of responsibility to parents was linked to teachers being worried about the future of their students, but this was not directly associated with a decreased communication effort. Concern alone was not significantly related to communication.

In contrast, HP3 was confirmed: the effect of concern (M) on communication (Y) was indeed moderated by the contextual factor of sanctions (W). The interaction was statistically significant (β=1.01; *t* value=3.74, df_1=5, df_2=53; *P*<.001). When no sanctions were present, the indirect effect was not statistically significant (effect=0.06, 95% CI −0.02 to 0.16). In contrast, when sanctions were present, the indirect effect was significant and negative (effect=−0.35, 95% CI −0.64 to −0.07), indicating that external attribution reduced concern, which in turn reduced communication in sanctioned classrooms. This revealed how concerned teachers talked significantly more in classes where students had been punished for smoking in the previous academic year, compared with students in classes with no sanctions. Further information on the direct and indirect effects is available in Tables S3 and S4 in Multimedia Appendix 1. The indirect effect of responsibility attribution on communication through concern was significant only when past sanctions were present. When no sanctions were applied, the indirect effect was nonsignificant. Practically speaking, when the class had been sanctioned for smoking, the path connecting responsibility attribution to concern and finally to communication was significant (Figure 3).

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Figure 3. Graphical representation of the moderation effect on communication.



Discussion

Overview

This study explored the motivational and contextual factors that influence teachers' decisions to engage in classroom discussions about adolescent smoking, using attribution theory as its framework. Before delving into the discussion of the results, it is important to note that this is the first study to investigate the effect of responsibility attribution on communicative behavior. Given the absence of directly comparable studies in the existing literature, this section is primarily devoted to discussing the implications of the findings and proposing avenues for future research.

Findings related to the first research question, regarding whom teachers view as primarily tasked with deterring students from smoking, revealed that teachers generally attribute slightly more responsibility to parents than to the school. Considering parents are still seen by teachers as the reference figures for adolescents, this is not surprising [62]. The result is nevertheless promising and suggests that public efforts to involve teachers in health prevention are well aligned with teachers' perceptions. While teachers do feel slightly less responsible than parents, the difference is minimal. This finding indicates that, in Switzerland, the role of health educator is appropriately positioned in the hands of teachers: they are expected to lead projects on health education and promotion, and several initiatives directly involve them in targeting adolescent populations [63]. Their role in prevention is therefore participatory and includes, but is not limited to, enforcing no-smoking policies in the school perimeter and applying sanctions when rules are broken [64]. The first key finding somewhat reflects this institutional commitment of being involved in children's health prevention. The teachers' feeling of responsibility is expected to vary across health topics, depending on how these issues are addressed in school programs. For example, topics such as sexual or mental health have been more explicitly and widely integrated into curricula through structured programs [65]. Testing their attributions and evaluating their differences when tackling health behaviors is therefore the first main further direction of research to pursue.

The results support the first hypothesis: teachers who attributed greater responsibility to the school (internal attribution) were more likely to communicate with students about smoking. This key finding has both theoretical and practical implications. Theoretically, it establishes the successful use of attribution theory to explain teachers' communicative behavior and supports the idea that perceived responsibility is a key driver of preventive communication [9]. Practically, it highlights the motivational force behind such communication. Considering the model accounts for 39% of the variance, responsibility attribution appears to be a meaningful factor to consider in preventive efforts. A next step would be to examine how parents attribute responsibility and compare their patterns to those of teachers. Questions remain open on situations in which parents' and teachers' perception diverge. Furthermore, exploring adolescents' perspective could offer interesting insights on who they recognize as authoritative and trustworthy figures in health communication. Perceptions of authority and trustworthiness will most likely impact the way adolescents perceive and respond to preventive efforts. In the case of teachers, future research could explore whether increased teacher communication correlates with reduced smoking rates, and

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under which relational circumstances this effect is most pronounced.

The relation between attribution and feeling of concern, which is the first part of the mediation process shown in Figure 2A, was confirmed: internal attributions were indeed associated with heightened apprehension about students' future well-being. This finding aligns with the idea that such emotion is a social one: it arises in response to others and is shaped by relational context. Experiencing this form of emotional engagement appears to be a response to perceived responsibility. This supports the first stage of Graham's [9] model, and highlights the potential value of testing other social emotions in future applications, such as pity, guilt, pride, or embarrassment [49,66]. The second hypothesis is, however, only partially confirmed, as concern alone was not significantly linked to communication, suggesting that further contextual clues, such as past sanctions, are needed.

Specifically, the moderated mediation is significant only in the "sanctioned" condition (Figure 2A): concern is associated with communication only when the class has a history of sanctions. Practically speaking, concerned teachers communicated more in classes where students had previously been sanctioned for smoking. This finding is not surprising, as it is reasonable to expect that prevention efforts are more likely to be directed toward students who have already exhibited problematic behavior. In contrast, in classes where smoking is not perceived as an issue, teachers may not feel the need to engage in preventive communication. These results show that classroom dynamics can shape how concern translates into action. The result prompts 2 considerations. First, teachers may not always be fully aware of their students' health behaviors, potentially overlooking those who smoke but have not been caught. Second, reduced communication in such cases may leave students more vulnerable to a future smoking threat. As inoculation theory has demonstrated, consistent communication efforts help protect adolescents from smoking onset [67]. This opens the door to exploring other contextual variables that may shape this relationship, such as school norms or the nature of teacher-parent relationships.

Implications

The research has 2 key implications, 1 related to theory and the other to practice. Theoretically, it successfully applies a psychological theory to the novel field of health communication, identifying attribution theory as a promising framework for studying the drivers of communicative behavior. Communication can be influenced by individuals' responsibility attributions, and this approach is promising because it could be applied to various health-related communication involving multiple actors (eg, parents).

Practically, the findings underscore the vital role of teachers in smoking prevention, positioning them as key figures in adolescents' lives. As previous research has consistently shown, adolescents are shaped by their surroundings—be it their neighborhoods, home environments, or schools—but particularly by the individuals who share these spaces with them [35,68,69]. By actively engaging teachers and empowering them to feel invested in their students' futures, healthier behaviors in adolescents can be fostered.

Limitations and Strengths

This study is not without limitations. First, the sample size of the participating teachers was relatively small, which may limit the statistical power of the findings. However, it is important to note that two-thirds of the schools in the Canton of Ticino were involved and randomly selected—a region that, to begin with, comprises a relatively small number of schools. Among these, the response rate was 66%, which is not low considering the questionnaire was administered at the end of the school year, when teachers were beginning their summer vacation. Second, the use of self-reported data introduces the possibility of social desirability or recall bias. Additionally, variables were measured with single-item scales, due to the constraints of the dataset, as the data analyzed in this study were originally collected for different research purposes. While the use of single-item measures can potentially reduce reliability, their application is not without precedent. Wanous et al [70], in their review of job satisfaction measures, concluded that although multi-item scales are generally preferable, single-item measures may be acceptable when justified by the research context. Furthermore, some items referred also to the school context and not to the individual teacher. We argue, however, that this approach is still valid. Teachers are embedded in the broader context of schools, and their responses likely reflect not only their own behavior but also their perception of institutional practices. Preventive initiatives are often implemented at the school level, and individual teachers' perceptions may be shaped by what their colleagues are doing. The application of multilevel modeling techniques was considered but not implemented due to sample size constraints (ie, limited number of teachers per school). Future research should address this limitation by using larger samples that allow for such modeling.

A further limitation lies in the fact that the study was conducted within the specific sociocultural and educational context of the Canton of Ticino, which may limit the generalizability of the results to other regions or countries. Finally, due to the nature of the cross-sectional data, it is not possible to infer causality or directionality in the model tested.

Despite these limitations, the study offers several notable strengths. It presents a novel application of attribution theory to the field of communication, extending its use into educational settings to explain teacher-student interactions. This theoretical lens provides insights into the motivational drivers behind teachers' communicative efforts regarding adolescent smoking. Moreover, the study draws on a representative sample of schools. Lastly, by focusing on teachers (an often overlooked yet influential population in prevention research), this work contributes to filling an important gap in the literature and opens new directions for theoretical exploration.

Future Directions

This study opens several promising avenues for future research in applying this theoretical framework. First, future research may consider involving a more diverse sample of teachers to examine how variations in role, teaching experience, or

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educational context may influence perceived responsibility. A further direction would be to apply attribution of responsibility theory to other health-related topics, such as sexual health, to assess whether the strength or nature of the association differs across issues. To establish causal relationships, the current findings should be replicated using longitudinal data. Finally, the link between attribution of responsibility and communicative behavior could be explored in relation to other key actors, beginning with parents and extending it to the impact on adolescents' behavior, to broaden the scope of this theoretical application.

Conclusions

Let us once again imagine ourselves as teachers facing a classroom of students and talking to them about adverse health behaviors, precisely smoking. According to the results of this study, our level of perceived responsibility will influence our behavior, leading us to speak more frequently with our students when we feel directly responsible for their health. This will happen especially in cases in which concern is high and the class has previously shown issues related to tobacco use.

These findings are particularly significant because they show not only that acting on the perception of responsibility is a valid and effective way to increase classroom conversations about health topics, but also that this theoretical model has the potential to explain communicative behaviors across a range of contexts. A broader assumption of responsibility has the potential to increase communication on sensitive topics and thereby raise awareness on adverse behaviors in the minds of young adolescents.

Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request.

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Authors' Contributions

AJR contributed to conceptualization, methodology, formal analysis, writing the original draft, and visualization. AB contributed to conceptualization, methodology, data curation, and writing—reviewing and editing. PJS contributed to conceptualization, methodology, writing—reviewing and editing, supervision, and project administration.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Data on research question and hypotheses investigated and distribution statistics for continuous variables.
[DOCX File , 106 KB - pediatrics_v9i1e81959_app1.docx]

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Abbreviations

HP: hypotheses
RQ: research question

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Original Paper

Online Search Trends on Child Abuse During the COVID-19 Pandemic Using the Most Widely Used Search Engine: Retrospective Observational Study

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Abstract

Background: Child abuse is an important issue that threatens child development. The COVID-19 pandemic had psychological, social, and economic effects, and concerns were raised about a possible increase in child maltreatment.

Objective: This study aimed to describe online search trends on child abuse in Japan during the COVID-19 pandemic.

Methods: We conducted a retrospective observational study on the online search volume of terms related to abuse, such as “abuse,” “psychological abuse,” “physical abuse,” “neglect,” “sexual abuse,” “I might become abusive,” “I am scared I might become abusive,” and “I cannot stop abusing,” in Yahoo! Japan. Search volumes were compared with trends in the number of reported cases of COVID-19.

Results: The number of searches for “neglect” increased during periods of social change caused by the COVID-19 pandemic and when waves of the pandemic coincided with the summer vacation period. Searches for terms suggesting abuse, such as “I might become abusive” and “I am scared I might become abusive,” increased in 2020 followed by a decrease from 2021 onward. Most of the searches were conducted by women aged 20 to 49 years.

Conclusions: Online searches related to “neglect” increased during periods of major social change during the COVID-19 pandemic. Searches suggestive of concern about perpetrating abuse were conducted predominantly by women aged 20 to 49 years. Online search data may serve as a useful tool for identifying trends in child abuse–related search interest.

(JMIR Pediatr Parent 2026;9:e93215) doi:10.2196/93215

KEYWORDS

abuse; child abuse; COVID-19 pandemic; infodemiology; online search trend

Introduction

The COVID-19 pandemic started with an outbreak of pneumonia of unknown cause in Wuhan, China, in December 2019, eventually reaching Japan. Considerable knowledge has been accumulated on the symptoms of COVID-19, and diagnostic, therapeutic, and preventive methods have been established. However, the COVID-19 pandemic has not only had a devastating negative impact on health but has also had negative psychological, social, and economic effects [1,2], with an increase in the incidence of mental illness, suicide, and abuse of children and older adults [3-7]. Child abuse is a social

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problem that requires national countermeasures because of its serious adverse effects on children's mental and physical health and personality development [8].

In Japan, according to Article 2 of the Child Abuse Prevention and Treatment Act, child abuse encompasses not only physical and sexual abuse but also neglect and psychological abuse [9]. According to the Ministry of Health, Labor, and Welfare and the Children and Families Agency, the number of consultations and responses to cases of child abuse has been increasing every year and reached a record high of 225,509 cases in 2023 [9]. The number of cases of abuse may have been underreported during the COVID-19 pandemic owing to school closures and voluntary lockdowns [4,10].

A previous study of online search trends during the COVID-19 pandemic compared the number of searches for "long COVID" with the number of new COVID-19 cases and found that online search trends were associated with real-world events [11]. The online search trends for changes over time in child maltreatment during the COVID-19 pandemic are unclear and, to our knowledge, have not been studied previously. Some studies suggest an increase in child abuse during the pandemic [4,10], whereas other studies suggest a decrease [12]; therefore, the actual situation is unclear.

The purpose of this study was to investigate the trend in online searches on child abuse in Japan and compare it with trends in the number of cases of COVID-19 reported.

Methods

Data Sources

To examine the patterns of online searches on abuse during the COVID-19 pandemic, we obtained data on online searches extracted from Yahoo! Japan, one of the most widely used search engines in Japan. Yahoo! Japan is the most accessed website in the country. According to Japanese data, the total number of accesses was 1.18 billion in November 2021.

Data on the monthly number of abuse-related online searches were available for the period from December 2019 to November 2023. Annual rankings of abuse-related search terms were available up to the top 500 terms for each year from 2019 to 2023.

Search volume data were obtained from Yahoo! Japan Corporation via DS.INSIGHT with legitimate access (last accessed on May 29, 2025). Yahoo! Japan DS.INSIGHT can be accessed by people working at educational and research institutions by obtaining a log-in ID. It is a tool that enables analysis of all Yahoo! Japan big behavioral data, such as keywords, period, gender, age, and prefecture and the transitions and trends in specific searches over time. The user manual is available [13]. The number of internet users in Japan was calculated based on the Communications Usage Trend Survey by the Ministry of Internal Affairs and Communications.

The number of new cases of COVID-19 in Japan was obtained from open access COVID-19 notification data on the Ministry of Health, Labor, and Welfare website. Comprehensive case count data were available only for the period from January 2020 to May 2023.

To compare with the monthly data on online searches related to abuse, the number of new COVID-19 cases was also aggregated on a monthly basis. Monthly search trend data were available for the period from December 2019 to November 2023, and visual comparisons of the monthly number of searches with monthly COVID-19 case counts were conducted from January 2020 to May 2023, the period for which both types of data were available.

Search Queries Used in the Analysis

To investigate the trends in the number of online searches on abuse, we conducted an observational study using the volume of search terms obtained from Yahoo! Japan. We used the search terms "abuse," "psychological abuse," "physical abuse," "neglect," and "sexual abuse" to evaluate online interest in abuse based on monthly data available from December 2019 to November 2023, with the last 4 terms corresponding to the 4 categories of child abuse used on the official website of the Administration for Children and Families under the Law Concerning the Prevention of Child Abuse. In addition, to clarify the trends in the parties conducting searches related to abuse, we analyzed the top 500 search terms including "abuse" in 2020, the year in which the COVID-19 pandemic began, and for each query, we observed the trends for each year from 2019 to 2023 for which top 500 data were available.

Queries related to anticipated or ongoing perpetration of abuse were extracted independently by 2 evaluators (NT and KI), and a third evaluator (MO) also provided an assessment to minimize the effect of observer bias. The search terms "I might become abusive" and "I am scared I might become abusive," which suggest anticipated perpetration of abuse, and "I cannot stop abusing," which suggests perpetrating abuse at the time of the search, were identified. We also identified the query "I have abused"; however, this query was excluded from the main trend analysis because its Japanese equivalent is semantically and temporally ambiguous and may indicate either an abusive act committed in the past with continuity to the present or regret over an abusive act committed in the past without continuity to the present and the annual search volume did not show a clear temporal pattern.

The designation as "Out of ranking," which is shown in the Results section, indicates that a query was not ranked in the top 500 searches for that period and that the search volume was lower than that of the 500th-ranked query.

Statistical Analysis

Details regarding Yahoo! Japan's internal statistical processing were not disclosed owing to concerns that individual data might be identified. Internet users were stratified by age, gender, and year on the day of the search. Categorical variables were summarized as frequencies and percentages. Descriptive statistics were compiled using Microsoft Excel 2019.

Ethical Considerations

This study adhered to Chapter 1, Part 3, Section 1, under category (C), item (iii) of the Ethical Guidelines for Medical

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and Biological Research Involving Human Subjects of the Ministry of Health, Labour and Welfare of Japan [14]. In accordance with this guideline, since this study used previously anonymized and de-identified data, an ethical review was waived, and patient informed consent was not required.

Results

Between 2019 and 2023, between 50.3% (49,883,262/99,252,024) and 51% (48,512,132/95,187,232) of all internet users in Japan were men, and the user population was evenly distributed among different age groups (Table 1). The number of online searches related to abuse decreased between 2019 and 2023, with fluctuations from year to year. The gender distribution showed that online searches related to abuse were more commonly conducted by women (40,600/59,200, 68.6%-48,100/66,200, 72.7%) than by men (18,100/66,200, 27.3%-18,600/59,200, 31.4%), and the age distribution showed that the 30- to 49-year age group conducted more online searches related to abuse than other age groups, with 18.2% (10,800/59,200) to 28.1% (32,200/114,600) of searchers aged 30 to 39 years and 22.2% (16,200/73,100) to 24.3% (27,800/114,600) aged 40 to 49 years (Table 1).

Table 1. Number of online searches using the Yahoo! Japan search engine that included the term "abuse" by gender, age, and year (2019 to 2023).

	2019		2020		2021		2022		2023	
	Internet users[a], n (%)	Search term "abuse"[b], n (%)	Internet users[c], n (%)	Search term "abuse"[d], n (%)	Internet users[e], n (%)	Search term "abuse"[f], n (%)	Internet users[g], n (%)	Search term "abuse"[h], n (%)	Internet users[i], n (%)	Search term "abuse" [j], n (%)
Gender										
Man	51,488,428 (50.4)	33,900 (29.6)	48,512,132 (51)	18,100 (27.3)	49,333,623 (50.6)	20,700 (28.3)	49,883,262 (50.3)	19,600 (28.9)	50,267,774 (50.6)	18,600 (31.4)
Woman	50,755,843 (49.6)	80,700 (70.4)	46,675,100 (49)	48,100 (72.7)	48,155,775 (49.4)	52,400 (71.7)	49,368,762 (49.7)	48,300 (71.1)	49,099,369 (49.4)	40,600 (68.6)
Age group (y)										
<20	13,497,868 (13.2)	13,700 (12)	13,304,833 (14)	9800 (14.8)	13,686,376 (14)	12,300 (16.8)	13,467,288 (13.6)	8900 (13.1)	13,376,729 (13.5)	6700 (11.3)
20-29	12,281,904 (12)	16,700 (14.6)	12,291,295 (12.9)	9700 (14.7)	12,293,873 (12.6)	9600 (13.1)	12,406,690 (12.5)	7500 (11)	12,228,406 (12.3)	5400 (9.1)
30-39	13,715,342 (13.4)	32,200 (28.1)	13,721,738 (14.4)	18,600 (28.1)	13,364,445 (13.7)	16,800 (23)	13,293,144 (13.4)	14,700 (21.6)	13,037,003 (13.1)	10,800 (18.2)
40-49	17,603,599 (17.2)	27,800 (24.3)	17,368,194 (18.2)	15,100 (22.8)	17,150,128 (17.6)	16,200 (22.2)	16,718,688 (16.8)	15,600 (23)	16,143,714 (16.2)	13,700 (23.1)
50-59	15,496,656 (15.2)	12,800 (11.2)	15,320,558 (16.1)	7400 (11.2)	15,934,650 (16.3)	10,300 (14.1)	16,398,504 (16.5)	11,300 (16.6)	16,873,071 (17)	11,600 (19.6)
60-69	13,792,110 (13.5)	6300 (5.5)	12,116,356 (12.7)	3600 (5.4)	12,497,583 (12.8)	5100 (7)	12,735,846 (12.8)	6300 (9.3)	12,920,129 (13)	7000 (11.8)
≥70	15,856,792 (15.5)	5100 (4.5)	11,064,258 (11.6)	2000 (3)	12,562,343 (12.9)	2800 (3.8)	14,231,864 (14.3)	3600 (5.3)	14,788,091 (14.9)	4000 (6.8)

[a]n=102,244,271.

[b]n=114,600.

[c]n=95,187,232.

[d]n=66,200.

[e]n=97,489,398.

[f]n=73,100.

[g]n=99,252,024.

[h]n=67,900.

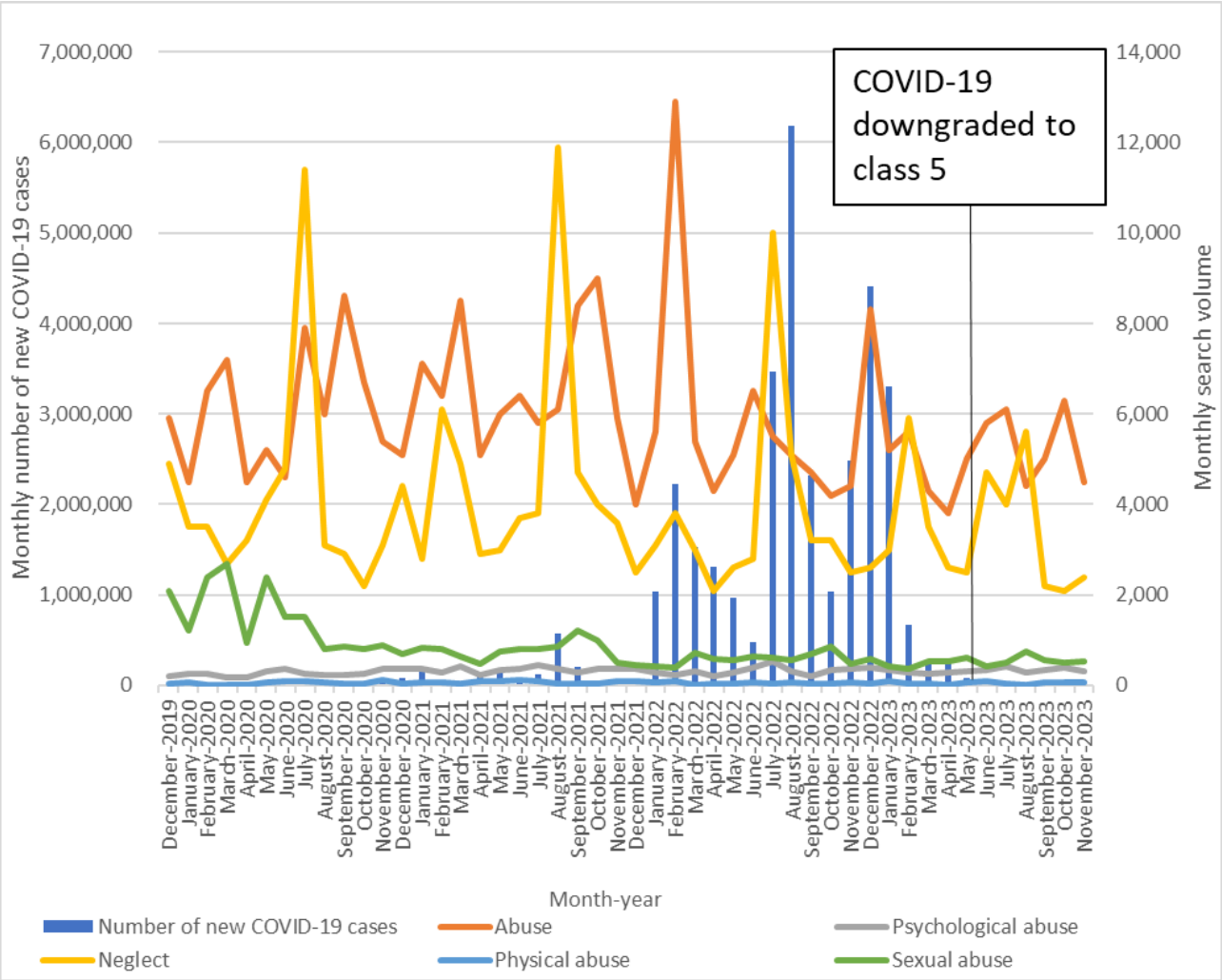
[i]n=99,347,143.

[j]n=59,200.

On visual comparison of monthly trends, no clear relationship was apparent between the number of new COVID-19 cases and the search volume for "abuse," "psychological abuse," "physical abuse," "neglect," and "sexual abuse"; however, the number of searches for "neglect" increased during the early phase of the COVID-19 pandemic (from March 2020 to August 2020), the fifth wave (June to November 2021), and the seventh wave (June to October 2022). During the study period, the number of new COVID-19 cases increased from year to year, but the number of searches for "neglect" did not (Figure 1).

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Figure 1. Monthly number of new COVID-19 cases (January 2020 to May 2023) and monthly search volume using the terms “abuse,” “psychological abuse,” “neglect,” “physical abuse,” and “sexual abuse” (December 2019 to November 2023). On May 8, 2023, the Japanese government reclassified COVID-19 as a class 5 infectious disease according to the Infectious Diseases Control Law, placing it on the same level as seasonal influenza and syphilis.



Next, we extracted data on searches that suggested perpetration of abuse and found that the search volume for “I might become abusive” increased from 1300 in 2019 to 1500 in 2020 (a 15.4% increase) and then decreased to 1100 in 2021 (a 26.7% decrease from 2020). For “I am scared I might become abusive,” the exact 2019 search volume was unavailable because the term was reported as out of ranking (≤410 searches); therefore, a percentage change could not be calculated. However, the search volume was 460 in 2020, indicating that the number of searches for this term also increased from 2019 to 2020. It then decreased to 310 in 2021 (a 32.6% decrease from 2020). Women accounted for 94% and 96% of those searching for “I might become abusive” and “I am scared I might become abusive,” respectively, in 2020, and internet users aged 20 to 49 years accounted for 96% and 89% of those searching for “I might become abusive” and “I am scared I might become abusive,” respectively, in 2020 (Table 2). Of those searching for “I cannot stop abusing,” suggesting ongoing abuse, women accounted for 88% of the searchers by gender, and internet users aged 20 to 49 years accounted for 92% of searchers by age. The annual number of online searches for “I cannot stop abusing” decreased by 12.6% in 2020 compared with 2019 and by 6% in 2021 compared with 2020, indicating a decrease in the number of searches conducted during the COVID-19 pandemic.

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Table 2. Number of searches related to committing abuse by gender, age, and year (2019 to 2023). Since Yahoo! Japan uses expanded statistics, this table lists only the total number of searches and the percentage.

Search term and year	Search volume (persons), n	Man (%)	Woman (%)	10s and below (%)	20s (%)	30s (%)	40s (%)	50s (%)	60s (%)	70s and older (%)
"I might become abusive"										
2019	1300	5	95	1	24	60	10	1	1	3
2020	1500	6	94	1	21	62	13	1	1	1
2021	1100	4	96	4	20	60	13	1	1	1
2022	880	6	94	2	18	62	15	1	1	1
2023	810	6	94	2	15	63	17	1	1	1
"I am scared I might become abusive"										
2019	Out of ranking: search volume (persons) of 410 or less	Out of ranking: search volume (persons) of 410 or less	Out of ranking: search volume (persons) of 410 or less	Out of ranking: search volume (persons) of 410 or less	Out of ranking: search volume (persons) of 410 or less	Out of ranking: search volume (persons) of 410 or less	Out of ranking: search volume (persons) of 410 or less	Out of ranking: search volume (persons) of 410 or less	Out of ranking: search volume (persons) of 410 or less	Out of ranking: search volume (persons) of 410 or less
2020	460	4	96	7	20	54	15	2	2	0
2021	310	6	94	0	19	59	19	3	0	0
2022	Out of ranking: search volume (persons) of 290 or less	Out of ranking: search volume (persons) of 290 or less	Out of ranking: search volume (persons) of 290 or less	Out of ranking: search volume (persons) of 290 or less	Out of ranking: search volume (persons) of 290 or less	Out of ranking: search volume (persons) of 290 or less	Out of ranking: search volume (persons) of 290 or less	Out of ranking: search volume (persons) of 290 or less	Out of ranking: search volume (persons) of 290 or less	Out of ranking: search volume (persons) of 290 or less
2023	Out of ranking: search volume (persons) of 280 or less	Out of ranking: search volume (persons) of 280 or less	Out of ranking: search volume (persons) of 280 or less	Out of ranking: search volume (persons) of 280 or less	Out of ranking: search volume (persons) of 280 or less	Out of ranking: search volume (persons) of 280 or less	Out of ranking: search volume (persons) of 280 or less	Out of ranking: search volume (persons) of 280 or less	Out of ranking: search volume (persons) of 280 or less	Out of ranking: search volume (persons) of 280 or less
"I cannot stop abusing"										
2019	950	11	89	3	18	55	19	2	2	1
2020	830	12	88	5	18	52	22	1	2	0
2021	780	8	92	3	17	51	24	3	1	1
2022	660	9	91	0	17	49	27	3	2	2
2023	650	9	91	5	12	46	26	5	3	3

Discussion

Principal Findings

To contribute to the understanding of the epidemiology of child abuse in Japan, this study characterized the trends in online searches related to child abuse during the COVID-19 pandemic.

According to information on the Administration for Children and Families website, the number of consultations on child abuse at Child Guidance Centers in Japan has been increasing each year; however, this increase was not reflected in the number of online searches related to child abuse during the 5-year study period. Furthermore, the number of searches for "psychological abuse," which accounted for 59.6% of all consultations on child abuse at Child Guidance Centers in 2022 (according to information on the Administration for Children and Families website), was small, whereas the number of searches for "neglect," which accounted for only 16.2% of all consultations on child abuse at Child Guidance Centers in 2022, was the largest of the 4 child abuse categories considered, showing a discrepancy between the number of consultations related to specific types of child abuse and the volume of online searches for the corresponding type of abuse. Possible reasons for this discrepancy may be that online searches are influenced by news reports of prominent cases and that online searches include searches for cases that are not clearly abusive because the general perception of what constitutes abuse among internet users is broader than the legal definition of abuse. In this study, on visual comparison of monthly trends, no clear relationship was apparent between the number of new COVID-19 cases and the search volumes for the terms "abuse," "psychological abuse," "physical abuse," "neglect," and "sexual abuse."

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The observed increase in searches for "neglect" may be interpreted in the context of social changes during the COVID-19 pandemic. Previous studies have identified economic factors, mental and physical health problems of parents and children, and parenting stress as risk factors for neglect [15]. The COVID-19 pandemic led to increased parenting burden owing to parents' economic difficulties, worsening mental health, and social isolation [16-19]. Previous studies on child abuse during the COVID-19 pandemic have reported mixed findings [20], and no consistent trend has been established for specific types of abuse. Although this has not been a conclusion consistently supported across the existing literature, some studies have suggested an increase in the incidence of neglect [21,22].

In Japan, during the period of voluntary curfew, worsening of physical and mental symptoms was especially noticeable among young adults aged 18 to 29 years; women; people with a history of treatment for mental illness; and people with socially disadvantaged backgrounds, including those with an annual income of less than ¥2 million (US $12,400; ¥1=US $0.0062 as of June 8, 2026) [23]. In another study of pregnant women and mothers less than a year post partum conducted during the COVID-19 pandemic [24], 38% reported "decreased income," 77.2% reported "fear of COVID-19," and 18.1% reported "experiencing criticism for taking my child to a public place." Of these, "decreased income" and "experiencing criticism for taking my child to a public place" were associated with a higher risk of perinatal depression [24]. These prior findings suggest that some factors associated with neglect may have worsened during the COVID-19 pandemic, providing a possible context for interpreting the observed increase in neglect-related searches.

In Japan, COVID-19 began to have an impact on daily life in March 2020. All elementary, junior high, and high schools in Japan were temporarily closed during spring break starting on March 2, 2020, and on April 7, 2020, a state of emergency was declared, requiring voluntary restraint from going out and holding events and restricting the use of facilities, which changed the way of life. The state of emergency was lifted on May 25, 2020, and the restrictions were gradually lifted in June 2020, but the number of cases of COVID-19 began to increase, leading directly to the second wave. The number of searches for "neglect" gradually increased starting in March 2020 followed by a decrease starting in August 2020, when the second wave began to subside. During the fifth wave (June to November 2021) and the seventh wave (June to October 2022), the number of searches for "neglect" increased markedly and then decreased as the number of new COVID-19 cases declined. Both the fifth and seventh waves occurred during the summer vacation period in Japan. During school vacations and natural disasters, children are isolated from their communities and schools, and programs to prevent child abuse are canceled; therefore, abuse is less likely to be reported despite an increased incidence [25,26]. Nevertheless, the results of this study show that online interest in "neglect" increased even during such periods.

During the seventh wave, the number of new cases of COVID-19 was higher than that during the fifth wave, but the number of online searches using the term "neglect" was lower. Changes between the fifth and seventh waves included a shift from the Delta variant to the less virulent Omicron variant and the holding of traditional festivals in various parts of Japan for the first time in 3 years, which eased the mood of self-restraint and led to a recovery in socioeconomic activities. Furthermore, in September 2022, the government introduced a shortened isolation period for individuals with COVID-19. After the eighth wave, on visual comparison, the number of searches for "neglect" did not appear to increase to the same extent as that observed during the early phase of the COVID-19 pandemic and during the fifth and seventh waves.

With each successive lockdown in Japan, the tendency for exacerbation of physical and mental symptoms was less marked owing to adaptation to the environmental changes brought about by the COVID-19 pandemic [23]. This study demonstrates that, although the annual number of new COVID-19 cases increased from thousands in 2020 to hundreds of thousands in 2022, the number of searches for "neglect" did not show a corresponding increase. Although the number of searches for "neglect" was not proportional to the number of new cases of COVID-19, the number of searches for "neglect" increased during periods of changes in living environments due to the COVID-19 pandemic, such as during the period of state emergency declarations and measures to prevent the spread of the disease and summer vacation periods coinciding with the COVID-19 pandemic waves.

These results are consistent with those of previous studies [15-19] that identified economic factors, mental and physical health problems of parents and children, and parenting stress as risk factors for neglect, all of which were amplified during the COVID-19 pandemic.

As searches for "abuse," "psychological abuse," "physical abuse," "neglect," and "sexual abuse" include searches from searchers with diverse intentions, we investigated searches that may reflect concern about potential or ongoing perpetration of abuse taking advantage of the anonymity of online searches.

We focused on searches from 2020 to 2021, the period immediately after the onset of the COVID-19 pandemic, and found that the number of searches for "I might become abusive" and "I am scared I might become abusive," which may reflect concern about potential perpetration of abuse, increased in 2020 and decreased in 2021 compared with 2019 and 2020, respectively. These searches were mainly conducted by women in their 20s to 40s, an age group likely to include mothers. In 2020, shortly after the onset of the COVID-19 pandemic, when lifestyle changes were most marked, the number of searches on the fear of perpetrating abuse increased the most among young adults, the age group most likely to include parents of young children.

According to the surveys conducted by the Japan Institute for Labor Policy and Training in 2012 and 2014, a total of 12% of mothers in Japan are worried that they may be abusing their children even during normal times, and 40.5% of those who worry about being abusive engage in excessive physical punishment or neglect [27]. These tendencies may have intensified in 2020. However, searches for "I cannot stop abusing," which suggests ongoing abuse-related concern at the time of the search, were predominantly by women aged 20 to 49 years, an age group likely to include mothers, but the increase

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did not correspond to the COVID-19 restrictions or to waves of the COVID-19 pandemic. On the basis of these findings, we assume that, at the onset of the COVID-19 pandemic in 2020, which led to marked changes in lifestyle, the number of women aged 20 to 49 years who searched for terms suggesting concern about becoming perpetrators of abuse increased, whereas searches suggesting ongoing abuse did not show a corresponding increase. However, based on these results, the possibility of changes in the degree or type of abuse during the COVID-19 pandemic cannot be ruled out.

This study found that the internet was also a means of accessing information for women in their 20s to 40s, an age group that may include mothers, who were concerned about perpetrating abuse. According to the World Health Organization handbook on measuring and monitoring national prevalence of child maltreatment, the results of surveys of parents regarding abuse are influenced by denial of socially undesirable behavior, leading to underreporting and inconsistencies with surveys of children; therefore, anonymity in fact-finding surveys is important [28]. Because anonymity is ensured, monitoring online search trends may be a useful tool for understanding changes in online interest in or concern about abuse-related issues during a pandemic.

Limitations

This study has several limitations. First, Yahoo! Japan was the sole data source, and online searches conducted using other search engines were not considered; therefore, the results may not be generalizable beyond the specific population from which the sample was drawn. Second, data obtained from online search engines may be subject to nonrepresentative sampling and methodological biases specific to search platforms. Third, no consideration was given to other factors that affect online interest in abuse, such as large media coverage, school closures, seasonal factors, and broader help-seeking behavior, because this was not possible. Fourth, the available data were limited in temporal scope, and comparisons across data sources were restricted to the period in which they overlapped. Fifth, annual rankings of abuse-related search terms were available only for the top 500 terms for each year, which limited the ability to follow some terms continuously across the 5-year study period. Furthermore, potentially relevant but less frequently searched terms may have been excluded.

Conclusions

On visual comparison, the observed increase in searches for the term “neglect” during the COVID-19 pandemic may be interpreted in the context of social changes during this period. Although no direct causal relationship could be established, this pattern may reflect the influence of factors identified in previous studies, including psychosocial stress, economic hardship, and social isolation. Previous studies have shown that, during school vacations and natural disasters, children are more isolated from society, making reporting of abuse less likely, but online interest in neglect increased during school vacations and during periods coinciding with waves of the COVID-19 pandemic. In addition, searches by women in their 20s to 40s, an age group that may include mothers, suggesting concern about perpetrating abuse also showed an increase in 2020 at the onset of the COVID-19 pandemic. Monitoring online search data is useful for understanding patterns of online interest in abuse as such searches can be conducted anonymously.

Data Availability

The raw dataset supporting the conclusions of this paper is available from the corresponding author upon request.

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Authors' Contributions

NT, KI, TM, MS, AK, MO, and TN contributed to study conceptualization, study design, and data collection. NT and KI contributed to analysis and interpretation of the data. NT wrote the manuscript and prepared all figures and tables. KI revised and edited the manuscript. TM, MS, AK, MO, and TN reviewed the final manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Mindfulness-Based Psychoeducation App to Improve the Well-Being of Parents and Caregivers of Children With Autism: Development and Usability Study

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Abstract

Background: Autism spectrum disorder (ASD) not only affects a person's social communication and behaviors, but also has an impact on their parents, who encounter different challenges during caregiving. Interventions developed for parents of children with ASD often focus on improving child outcomes and seldom consider the well-being of parents and families. Interventions leveraging mindfulness-based approaches have been developed to support parents of children with ASD, but the costs, inflexibility, and scarcity of resources may limit their accessibility. App-based interventions can be an accessible, scalable, and economical way of providing interventions at a primary health care level.

Objective: The aim of this study was to develop an evidence-based digital intervention that complements existing, overloaded psychiatric services, to provide mindfulness-based psychoeducation for parents of children with ASD to improve their mental well-being.

Methods: The app development process follows the systematic approach of intervention mapping. Needs assessment was first conducted through semistructured qualitative interviews with health care professionals. Performance and change objectives were specified; theory-based and practical application methods were selected, followed by the design of the curriculum for a structured intervention. A pilot waitlist randomized controlled trial was conducted to evaluate the feasibility, acceptability, and preliminary efficacy of the app with parents of children with ASD recruited from a tertiary child psychiatric service in Hong Kong.

Results: The resulting intervention, the TRIP app, is a 6-week structured intervention consisting of 6 sessions per week (each session lasting 15 - 20 minutes), covering topics on ASD parenting skills and mindfulness practices. The six weekly themes include (1) cultivating curiosity in parenting, (2) mindfulness of the breath and body, (3) management of core and associated features of ASD, (4) managing conflicts and setting boundaries, (5) perspective taking, and (6) cultivating self-compassion. The curriculum was designed to target the determinants of parental stress, including parents' knowledge, skills, emotions, and attitudes. App content and features were designed to incorporate behavioral change techniques, social cognitive theory, and elaboration likelihood model, to enhance efficacy and promote long-term usage. The app was found to be feasible and acceptable in the pilot randomized controlled trial (n=40), with greater long-term usage among parents of children on the waiting list who were yet to receive diagnostic assessment and clinical management, when compared with parents of children who have already been receiving clinical care.

Conclusions: The TRIP app was developed based on knowledge and expertise across psychiatry, public health, behavioral science, and implementation science. It caters to the unmet needs for improving caregiver well-being in the holistic care model for families of children with ASD. The clinical efficacy of the TRIP app is yet to be evaluated through clinical trials.

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Trial Registration: ClinicalTrials.gov NCT05927207; https://clinicaltrials.gov/study/NCT05927207

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KEYWORDS

mindfulness; digital intervention; autism; caregiver stress; mental wellbeing

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that can affect individuals throughout their lifetime, as persistent deficits and behavioral challenges can lead to functional impairments [1], and may also have a vast impact on their parents and families. Current interventions for ASD are primarily focused on improving adaptive functioning and ameliorating maladaptive behaviors [2], often comprising a combination of behavioral interventions, social communication training, and sensorimotor therapy. The delivery of these interventions is often brief and infrequent, limited by both the capacity of health service providers and the costs of the interventions. As a result, parents and caregivers inevitably take on a role in delivering interventions. Parent training programs (eg, the widely known Triple P Positive Parenting Program [3] and the Incredible Years Parent Training program [4]) were adapted to equip parents of children with ASD with the required skills for independent implementation of interventions with minimal or no support from therapists. While parent training for ASD is effective in improving child development [3,5,6], most of these trainings focused on improving children's behaviors and functioning, with a lack of emphasis on alleviating parental stress or enhancing their mental well-being and quality of life. As parents tend to shoulder a great deal of stress with limited professional support, taking care of parents' own mental well-being is essential when supporting parents in implementing interventions for their children [7].

In terms of the approaches used in interventions developed for supporting parents, mindfulness-based interventions (MBIs) were found to have positive effects in reducing parental stress and depressive symptoms and improving psychological well-being in parents of children with ASD [8,9]. Interventions tailored to integrate mindfulness into parenting for ASD have been developed, such as the Mindful Parenting program, which has the following aims: (1) to reduce parental stress, negative bias, and reactivity; (2) to break the cycle of intergenerational continuity of maladaptive parenting; (3) to promote self-nourishing attention and self-compassion; (4) to improve marital relationships, functioning, co-parenting; and (5) to reduce interparental conflicts [10]. The Mindful Parenting program was later extended into the MYmind program for ASD, delivering parallel, concomitant mindfulness training for adolescents with ASD and their parents, which was found to improve parenting style and competence, and increase quality of life for both adolescents and their parents [11].

Although MBIs have promising outcomes, the fixed 8-week structure of the courses may not fit into parents' busy schedules and could be costly, especially for families of lower socioeconomic status. App-based interventions can overcome these barriers and provide an accessible, flexible, and affordable platform for education and lifestyle changes. Furthermore, digital platforms can enable easier and quicker access to intervention content. Prompts through navigation, notification, and gamification can also encourage access to content compared with traditional web-based interventions [12]. A recent meta-analysis demonstrated that app-based mindfulness interventions were efficacious in reducing perceived stress and improving symptoms of depression and anxiety across diverse samples, including the general adult population and clinical populations suffering from major medical illnesses [13]. Some randomized controlled trials (RCTs) even showed comparable effects between app-based and face-to-face interventions [14]. Recent studies also found that app-based mindfulness interventions were effective for parents, as studies reported improvements in mindful parenting in the general population [15] and increased positive parent-child interactions and reduced parenting stress among parents of children with ASD [16]. Therefore, app-based interventions can be an accessible and economical way of providing a feasible alternative to in-person interventions for improving parental well-being.

While the market is not deprived of generic smartphone apps for improving mental health or mindfulness, attrition and non-adherence are common in unguided app-based interventions [17,18]. As app-based interventions were found to be more efficacious when complementing current care and being customized to users' goals and needs [19], tailored content is a crucial element in maintaining motivation for continual use. To date, the only app-based intervention developed for parents of children with ASD is the Smartautism app, a mobile app developed in France that uses ecological momentary assessment (EMA) to provide feedback for parents of children with ASD (aged 3 - 16 y) to adapt parents' educational behavior between medical appointments [20,21], and no app-based interventions have been developed for delivering MBIs tailored for parents of children with ASD. Therefore, considering the limited resources and inadequate provision in public health care for ASD, the aim of this study was to develop an app for mindfulness-based psychoeducation for parents and caregivers of children with ASD, and to evaluate the feasibility, acceptability, and preliminary efficacy of the app. Specifically, while the prevalence of ASD in Hong Kong is comparable to that of Western countries [22], clinical services for ASD in Hong Kong have seen a rapid increase in attendance by 162% over the past decade, with a 3-fold increase in average waiting time from 23 weeks in 2012 - 2013 to 80 weeks in 2019 - 2020 [23]. As such, we would like to explore whether the preliminary efficacy of the app is different for parents of children who were still on the waiting list to be seen by a psychiatrist for diagnostic assessments and clinical management, and hence are receiving lower levels of care and support when compared with parents of children who have already been receiving clinical care.

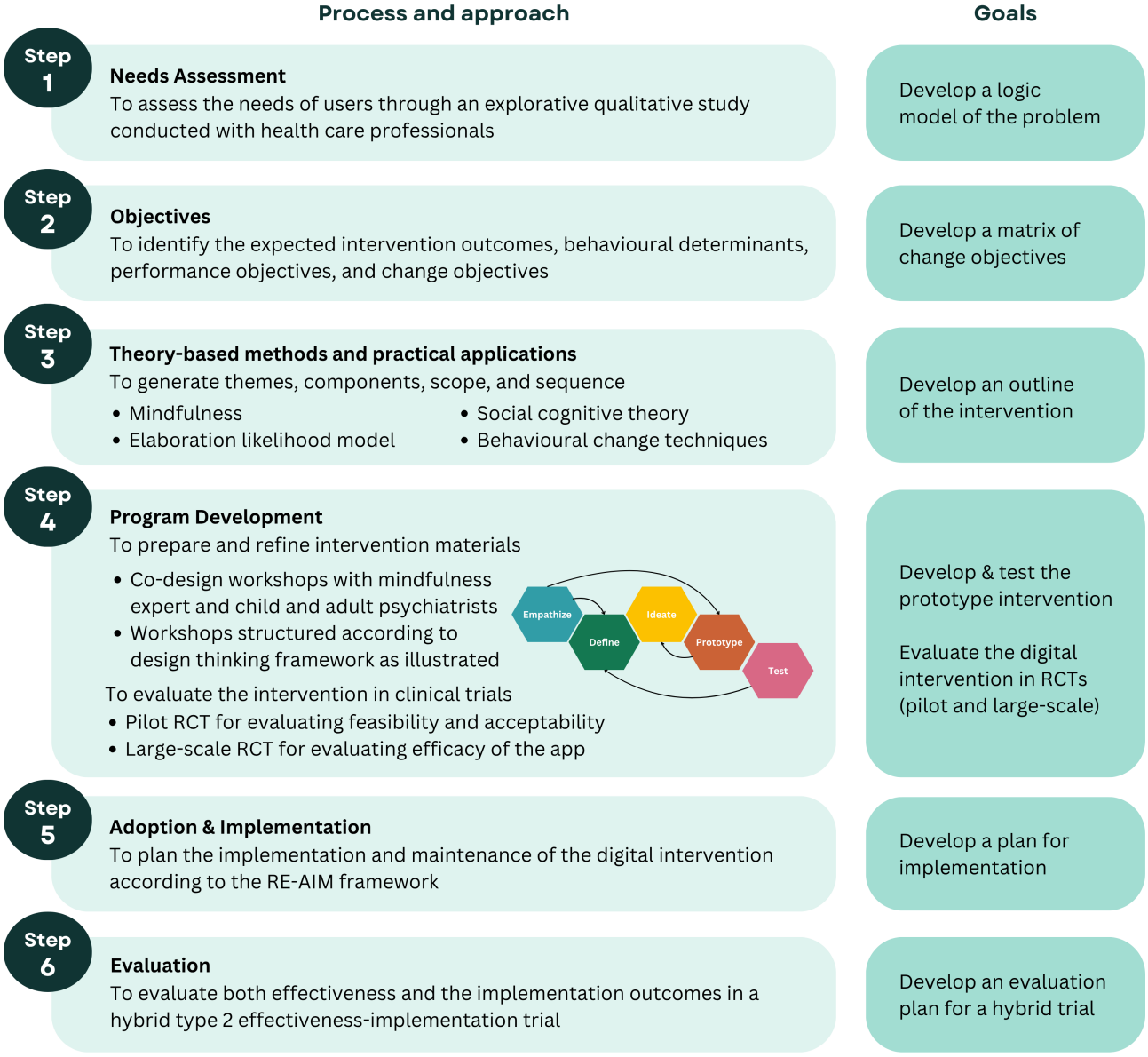
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Methods

Overview

The app development process follows a systematic, evidence-informed approach according to intervention mapping (IM) [24,25], a protocol for intervention development that fulfills the UK Medical Research Council framework for developing complex health care interventions [26]. IM is an iterative, 6-step method that is well-established and widely used (Figure 1). This article focuses on reporting the results of steps 1 - 4 of the IM process, including the development and usability testing of the app. Steps 5 - 6, which involve intervention implementation and evaluation, are planned but will be reported separately when completed. This report follows the Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth (CONSORT-EHEALTH) checklist (V.1.6.1).

Figure 1. Systematic development of the TRIP app using intervention mapping. RCT: randomized controlled trial; RE-AIM: Reach, Effectiveness, Adoption, Implementation, and Maintenance.



Ethical Considerations

Ethical approval was obtained from The Joint Clinical Research Ethics Committee established by The Chinese University of Hong Kong and New Territories East Cluster (qualitative study in step 1: Ref 2021.591; pilot RCT in step 4: 2022.586). Informed consent was obtained from all participants according to the Declaration of Helsinki. Data were anonymized and securely stored to ensure participant confidentiality. Upon the completion of the study, health care professionals in step 1 did not receive any financial compensation, whereas parents in step 4 received vouchers valued at HKD $100 (approximately US $12.50).

Step 1: Needs Assessment

The needs of parents and caregivers of children with ASD were assessed through an explorative qualitative study conducted with health care professionals to understand the underlying sources of challenges faced by ASD caregivers and recommendations to support parents in overcoming these

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challenges, complementing the lived experiences of parents and families that are already well-documented in the literature. Health care professionals providing tertiary specialist clinical services for ASD were purposively sampled via referral by professional acquaintances, and the sample size was guided by the principle of information power [27]. Semistructured interviews were conducted according to an interview guide developed with input from psychiatrists based on clinical experiences (Multimedia Appendix 1). Topics included management of ASD symptoms, impact of ASD on family dynamics, experiences of stigma around ASD, and responses toward the diagnosis. Open-ended questions and supplementary probing were used to allow any explorative, spontaneous, and in-depth discussions that may emerge during the conversation [28]. Interviews were first transcribed verbatim and checked for accuracy. Qualitative data then underwent inductive coding [29,30]. Codes were then mapped onto an adapted social ecological model (SEM), which considers multiple levels of influence on health and well-being, including individual, interpersonal, institutional, community, and societal levels [31]. Codes were then compiled to create a logic model based on the PRECEDE model (ie, Predisposing, Reinforcing, and Enabling Constructs in Educational Diagnosis and Evaluation), which provides a comprehensive framework for assessing the different determinants of health through an educational diagnosis before developing and implementing interventions for health promotion [32]. The PRECEDE model comprises 4 phases, beginning with a social assessment, followed by an epidemiological assessment, a behavioral and environmental assessment, and an educational and ecological assessment. Detailed methods and findings from the subsequent thematic analysis of this qualitative study were published separately [33].

Step 2: Matrices of Change Objectives

Based on the results from step 1, intervention outcomes and relevant, modifiable behavioral determinants were identified. This was used for specifying the performance objectives, which are specific actions required to achieve the intervention outcome. A matrix of change objectives was then created, which specifically identifies behaviors or thought processes that needed to be changed in order to achieve the target outcomes.

Step 3: Theory-Based Methods and Practical Applications

Theory-based methods and practical applications were selected to achieve behavior change in parents and caregivers of children with ASD. As there is considerable evidence in the existing literature for the effectiveness of MBIs in supporting ASD caregivers, mindfulness was selected as the basis for content development. The elaboration likelihood model (ELM) [34], which posits a dual process theory of attitude change through central and peripheral processing requiring varying levels of cognitive efforts, was selected as the basis for curriculum development. The social cognitive theory (SCT) [35], which suggests that people can learn to change, achieve, and maintain goal-directed behaviors over time through different constructs, including behavioral capability, outcome expectations, observational learning, self-efficacy, and reinforcements, was selected as the basis for the design of app content and features. Behavior change techniques (BCTs) based on an extensive taxonomy of 93 distinct techniques across 16 different group categories by Michie and colleagues [36] were mapped onto different SCT constructs for practical application to target specific change objectives.

Step 4: Program Development

App Development and Evaluation Process

The digital intervention was developed by a collaborative team of researchers, psychiatrists, mindfulness experts, software engineers, graphic designers, and text editors. The app development process involves the parallel, iterative development of app curriculum and content, content production and refinement, and software design and development. App curriculum and content were developed through 10 co-design sessions (each lasting around an hour) with an experienced mindfulness teacher (EWYW), a child psychiatrist (OWHW), an adult psychiatrist (SSMC), a doctoral researcher with a psychology background (KKYM), and our project manager (OC). Co-design sessions were structured according to the design thinking framework [37], with a focus on iterative cycles of define, ideate, and prototyping for the design of the app curriculum and content. Content production and refinement was done in collaboration with a text editor for editing and proofreading, a mindfulness expert for audio recording of mindfulness practices and voice-over narrations for animations, and a graphic designer for illustrations and animations. Software design and development was actualized by software engineers and graphic designers, respectively. The prototype of the app underwent alpha and beta testing with health care professionals and parents before it was officially launched. A prospectively registered pilot waitlist-RCT [38] was then conducted to evaluate the feasibility, acceptability, and preliminary efficacy of the app. This was followed by an ongoing large-scale RCT for evaluating the efficacy of the app (n=700) [39], which will be reported separately when the trial is completed.

Participant Recruitment

Participants were 40 parents or caregivers of children with ASD (aged ≤12 y) diagnosed by clinicians according to the *DSM-5* (*Diagnostic and Statistical Manual of Mental Disorders* [Fifth Edition]) criteria [40]. Only parents who can understand spoken instructions in Cantonese and texts written in traditional Chinese were eligible. Parents who were not primary caregivers, or those currently receiving psychological interventions or undergoing mindfulness training, were excluded. Participants were recruited from a university-affiliated tertiary hospital providing the sole public child and adolescent psychiatric service in a region of >1.2 million population in Hong Kong. In the clinic, parents were recruited from either the triage service (where the child had gone through initial triage assessment by nurses but were still on the waiting list to be seen by a psychiatrist for diagnostic assessments and clinical management), or the psychiatrist-led clinic (where ASD diagnosis was already made and the child was receiving active treatment and training from the hospital), therefore representing 2 different groups of parents whose children were receiving different levels of care and support.

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Potential participants were approached individually in a short call via videoconferencing, where they were given information about the study and had their questions addressed. Eligibility of interested participants was screened through a brief screener survey. Written informed consent was obtained from all eligible participants who agreed to participate. Participants were randomly allocated to either the immediate intervention group or the waitlist-control group, using the Qualtrics randomizer with a 1:1 allocation ratio through stratified block randomization (block sizes of 4, stratified according to the level of support received [waiting list vs clinical care] and child age [≤6 y, 7-9 y, and 10 - 12 y]). Participants in both groups received the intervention: the intervention group received the intervention immediately after allocation, whereas the control group received the intervention after 6 weeks of treatment as usual.

Sociodemographic and Clinical Characteristics

Sociodemographic information (including parents' sex, age, and educational level, and child's sex and age) and clinical characteristics were obtained at baseline. Child clinical characteristics were considered by parent-reported measures, including the Social Responsiveness Scale, second edition (SRS-2) for ASD core symptoms [41], as well as the Anxiety Scale for Children-ASD questionnaire [42] and the externalizing and attention problems subscales of the Child Behavior Checklist (CBCL-Ext and CBCL-Attn) [43] for common co-occurring psychopathology. Age-appropriate versions of SRS-2 and CBCL were used for preschool and school-aged children, respectively.

Outcome Measures

The primary outcomes of the pilot study were feasibility and acceptability of the app. Feasibility was measured by app usage during the intervention period, including usage patterns (day of week and time of day), user engagement (number of usage days, number of logins, and time spent per day), program participation (number of sessions completed and curriculum completion rate), and retention rates in terms of current use (participants who used the app during a given week) and last use (the last time the app was used by participants). Acceptability was assessed immediately post intervention by the 10-item System Usability Scale (SUS-10) [44], assessing the usability of products and apps, and the 20-item User Version of the Mobile Application Rating Scale (uMARS) [45], measuring engagement, functionality, aesthetics, and information quality of health apps.

The secondary outcome was preliminary efficacy, including parental mental health, parenting capabilities, and levels of mindfulness measured at baseline, preintervention, postintervention, and at 2-month follow-up. The selection of outcome measures was informed by the social and epidemiological assessment in step 1. Parental mental health was assessed by the 7-item General Anxiety Disorder scale (GAD-7) [46] and the 9-item Patient Health Questionnaire (PHQ-9) [47], and parenting stress was measured by the 36-item Parenting Stress Index-Short Form (PSI-SF) [48]. Parenting capabilities were considered in terms of parenting competence and satisfaction, which were measured by the 17-item Parenting Sense of Competence scale (PSOC) [49], the 6-item parenting efficacy subscale of the Parenting Self-Agency measure (PSA-PE) [50], and the 7-item warmth subscale of the Parenting Styles and Dimensions Questionnaire (PSDQ-W) [51]. Levels of mindfulness were assessed by the 15-item Mindful Attention Awareness Scale (MAAS) [52,53] and the 31-item Interpersonal Mindfulness in Parenting questionnaire (IM-P) [54,55].

Statistical Analysis

Analysis of covariance (adjusting for baseline values) was used to investigate the intervention effect and outcome changes from preintervention. Analyses were conducted according to the intention-to-treat principle, with last observation carried forward for any missing data. Analyses were stratified by the source of recruitment (triage service or psychiatrist-led clinic), as this represents different levels of support received by parents of children with ASD (waiting list vs clinical care). Intervention effect on all efficacy outcomes was analyzed separately with the same procedures, with outcome scores as the dependent variable, randomization group as a factor, and baseline values of the outcome and child clinical characteristics (SRS-2 and CBCL-Ext) as covariates (based on previous findings from the literature [56,57]). A similar procedure was used to compare changes in outcomes from preintervention to postintervention and 2-month follow-up, with assessment timepoint as a factor, and adjusting for preintervention value of the outcome, child clinical characteristics at baseline (SRS-2 and CBCL-Ext), and randomization group, to account for any potential confounding effects in intervention participation as a result of delayed intervention [58]. All analyses were performed in jamovi (version 2.6.2; The jamovi project) [59].

Results

Step 1: Needs Assessment

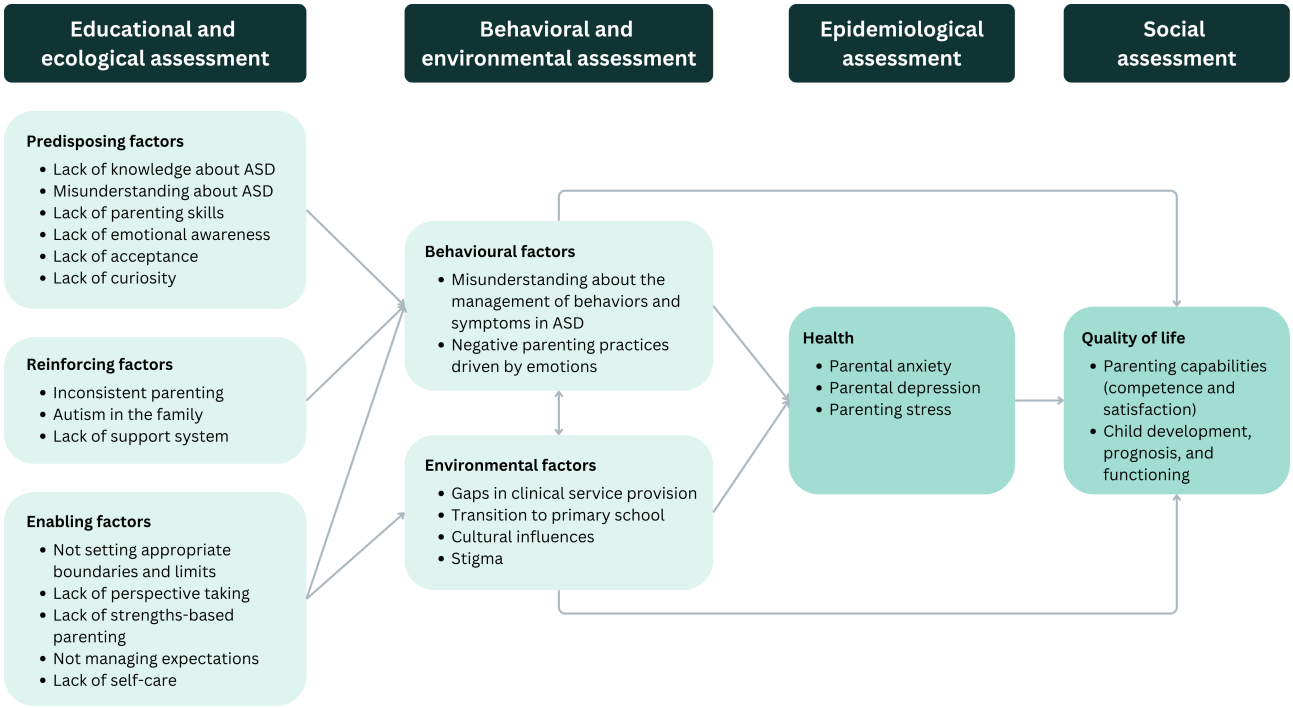
We conducted 10 interviews, including 7 individual interviews and 3 group interviews, with 16 health care professionals working in different roles, including psychiatrists (n=2), psychiatric nurses (n=9), clinical psychologists (n=2), an occupational therapist (n=1), a hospital-based teacher (n=1), and a social worker (n=1). We identified 4 key areas at the individual level of the SEM where parents faced challenges during caregiving, namely knowledge, skills, emotions, and attitudes. The key caregiving skills needed were broadly categorized into skills for managing specific child behaviors, skills during daily interactions with children, and skills for self-care. Moreover, health care professionals also shared their perspectives on wider contextual and environmental factors within the SEM that pose challenges for parents when caring for children with ASD. These include interpersonal factors such as inconsistent parenting and autism in the family, institutional factors such as the transition from kindergarten to primary school and gaps in clinical service provision, community factors such as support systems and cultural influences, and societal factors related to stigma surrounding ASD. Detailed codes and examples are provided in Multimedia Appendix 2. Detailed findings from the subsequent thematic analysis of this qualitative study were published separately [33].

Figure 2 shows a logic model for caregiver challenges faced by parents of children with ASD. Social assessment identified aspects of quality of life impacted by caregiving for ASD,

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including parenting competence and satisfaction, and children's development, prognosis, and functioning. Epidemiological assessment suggested that caregiver challenges affect parents' health through parenting stress, anxiety, and depression. Parallel analyses of behavioral and environmental factors revealed that misunderstanding about the management of behaviors and symptoms and negative parenting practices driven by emotions were the main challenges faced by parents, which were influenced by various environmental factors, including service gap, school transitions, cultural influences, and stigma. Educational and ecological diagnosis identified the main needs of parents in terms of predisposing factors related to parents' knowledge, skills, attitudes, and emotions, reinforcing factors in parents' social environment, and enabling factors related to varying levels of relational skills for parenting.

Figure 2. Logic model for caregiver challenges faced by parents of children with autism spectrum disorder. ASD: autism spectrum disorder.



Step 2: Matrices of Change Objectives

Based on the findings from the needs assessment in step 1, the overall intervention outcome was to reduce parental stress, anxiety, and depression, whereas the behavioral outcome was to improve parents' management of children's behaviors and symptoms. The specific performance objectives for the behavioral outcome were to (1) improve parents' understanding of behaviors and symptoms, and (2) improve parents' emotional regulation. A matrix of change objectives for parents of children with ASD based on the specific performance objectives is presented in Table 1.

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Table . Matrix of change objectives for parents of children with ASD[a].

Performance objectives	Change objectives categorized by determinants[b]			
	Knowledge	Skills	Emotions	Attitudes
To improve parents' understanding of behaviors and symptoms	• Improve knowledge about ASD around sensory issues and academic abilities (1.1.1) • Address misunderstandings about ASD related to social communication, repetitive behaviors, emotional expression, and comorbidity (1.1.2) • Learn about specific skills for toilet training, communication skills training, and organizing play (1.1.3)	• Use effective instructions and commands when parenting (1.2.1) • Avoid misconstrued behavioral reinforcement and encourage parents to make use of children's stereotyped interests (1.2.2) • Adopt an investigative mindset during parent-child interactions and take children's perspective to understand their underlying intentions and motivations for their behaviors (1.2.3)	• Avoid emotionally-charged parenting, especially when trying to understand children's behaviors (1.3.1)	• Increase curiosity in children's behaviors and characteristics (1.4.1)
To improve parents' emotional regulation	• Understand the negative effects of unhelpful parenting practices on the parent-child relationship and children's development (2.1.1) • Understand how inconsistent parenting can be confusing and unhelpful for children (2.1.2)	• Avoid emotionally-charged parenting and other negative parenting practices and adopt strengths-based parenting (2.2.1) • Manage own expectations about children's progress and development (2.2.2) • Balance between showing love and setting limits (2.2.3) • Reserve time for self-care through cultivating parents' own interests and hobbies (2.2.4)	• Improve emotional awareness (2.3.1) • Increase self-compassion (2.3.2)	• Acknowledge the presence of ASD diagnosis (2.4.1) • Increase acceptance toward ASD (2.4.2)

[a]ASD: autism spectrum disorder.

[b]Codes (eg, 1.1.1, 1.1.2, and so on) are with reference to Multimedia Appendix 3.

Step 3: Theory-Based Methods and Practical Applications

Mindfulness

As mindfulness is underpinned by key mechanisms of decentering and self-compassion, mindfulness practices for training attention control, decentering, and self-compassion, alongside practices that were further contextualized to parenting for ASD, were included in the app. This is important, as decentering can shift one's cognitive perspective to help reduce rumination [60,61], whereas self-compassion can increase positive affect and emotions for improving psychological well-being [62-64]. According to the warp and weft framework [65] that outlines the core essential elements and adaptable variable elements in MBIs, we preserved as many of the core essential elements in the curriculum and the content of the app. As direct inquiry is not possible in a self-taught format, the experiential, inquiry-based learning process was adapted by including debriefs that were intended to help parents reflect on their experiences and develop insight and understanding following the completion of guided mindfulness practices. Home practice was supported through convenient options for revisiting mindfulness practices through the intervention.

ELM

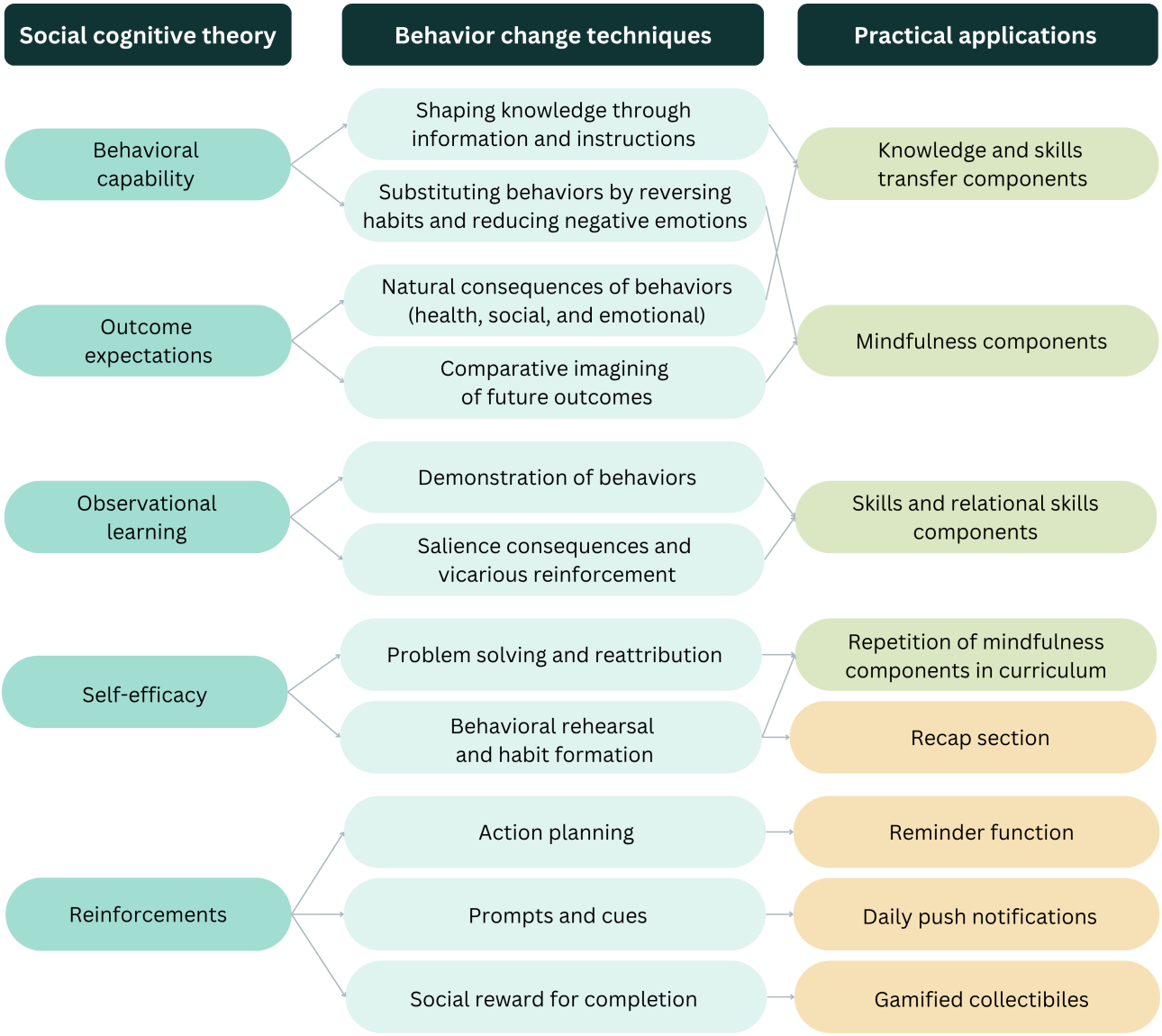
As ELM emphasizes how information processing may be done through the central or peripheral route depending on one's motivation and can lead to varying degrees of attitude changes, we developed intervention content on mindfulness and parenting for ASD that varied in depth and complexity (and therefore required different levels of cognitive efforts) to accommodate parents with different levels of motivation and cognitive abilities. For mindfulness content, gratitude practices, self-compassion practices, and attentional control training require less cognitive effort, whereas decentering practices, cognitive exercises, and relational skills require more cognitive effort. For psychoeducation content on parenting for ASD, knowledge transfer components require less cognitive effort, whereas skills transfer components, especially those explaining fundamental principles in psychological and behavioral science, require more cognitive effort.

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SCT

Figure 3 illustrates how BCTs were selected and applied to different SCT constructs (with details of how they map to specific change objectives provided in Multimedia Appendix 3). Intervention content for mindfulness and parenting for ASD was designed to target behavioral capability, outcome expectations, and observational learning. App features were designed to facilitate self-efficacy and reinforcements. For instance, we dedicated a section of the app to hold the entire collection of learning components to allow convenient revisiting and repeated practice. We also included a reminder function to help users set aside a specific time for completing the intervention, at which daily push notifications were sent to prompt users to log in and complete a session.

Figure 3. Social cognitive theory constructs mapped onto behavior change techniques for practical application.



Step 4: Program Development

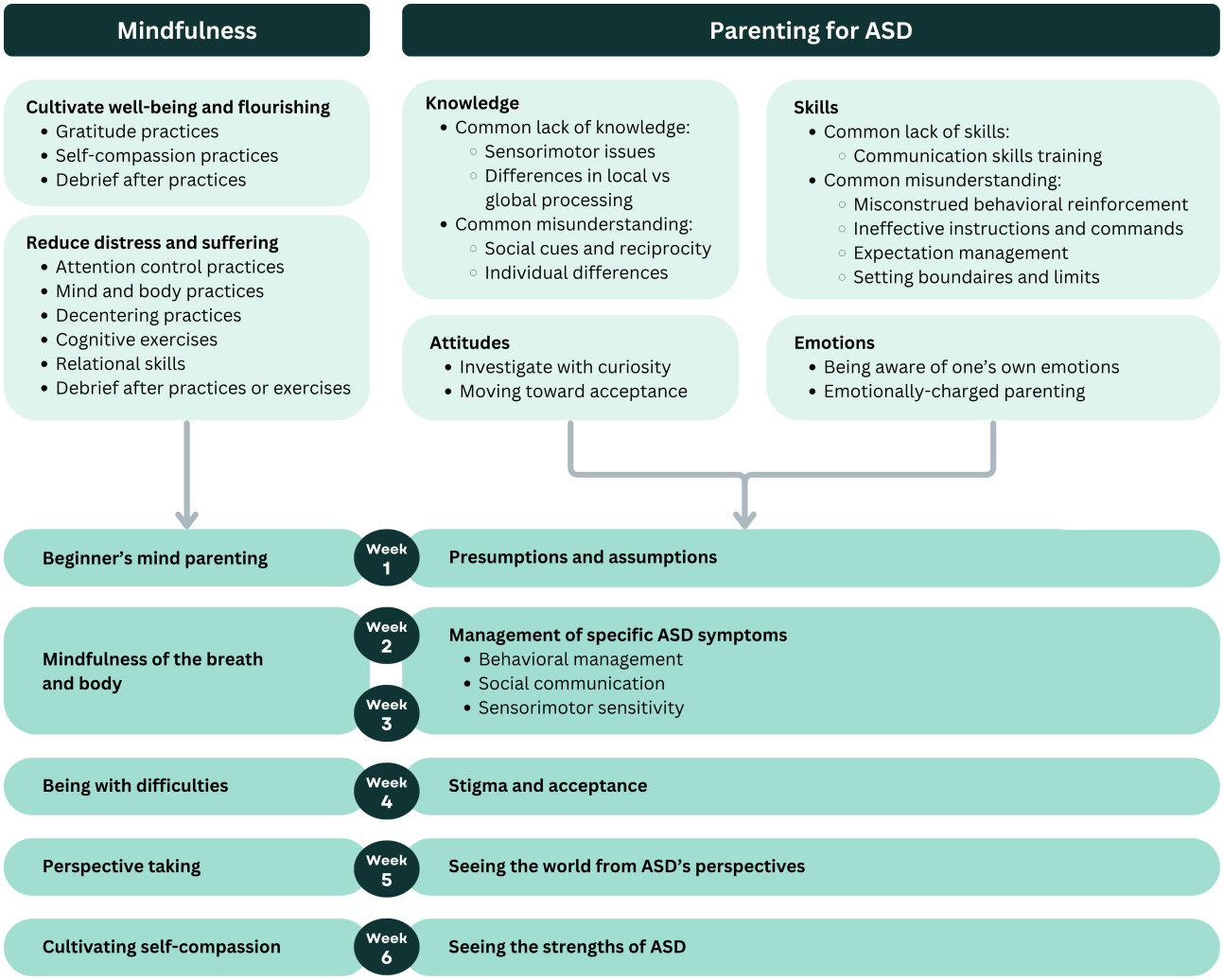
As “investigating with curiosity” was a recurring theme across interviews with health care professionals in step 1, the app was named TRIP and was designed as a journey for parents to learn more about themselves and their children through the cultivation of mindfulness and curiosity. The TRIP app is a 6-week structured intervention, with each week featuring a specific theme on mindfulness and parenting for ASD. Each week consists of 6 sessions, each session lasting 15 - 20 minutes; core and optional sessions are delivered on alternate days, with core sessions covering new content in greater detail, whereas optional sessions reinforce key messages of the week through self-directed learning. Within each session, learning components were delivered in different formats, including narrated animations (total duration=31 min, 7%), audio-guided meditation practices (total duration=307 min, 69%), and short articles (total duration=107 min, 24%). Each learning component focuses on either mindfulness practices, exercises, debriefing, and relational skills, or knowledge, skills, emotions, or attitudes in parenting for ASD, corresponding to the selected determinants of ASD caregiver challenges as identified in step 2. The app is currently available on App Store and Google Play in Chinese, with texts written in traditional Chinese characters and audio spoken in Cantonese, a popular Chinese dialect widely spoken in Hong Kong. Figure 4 illustrates the main screens of the TRIP app, and Figure 5 illustrates an outline of the themes and the intervention.

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Figure 4. Main screens of the TRIP app translated into English.



Figure 5. Outline of the themes and components of the TRIP app. ASD: autism spectrum disorder.

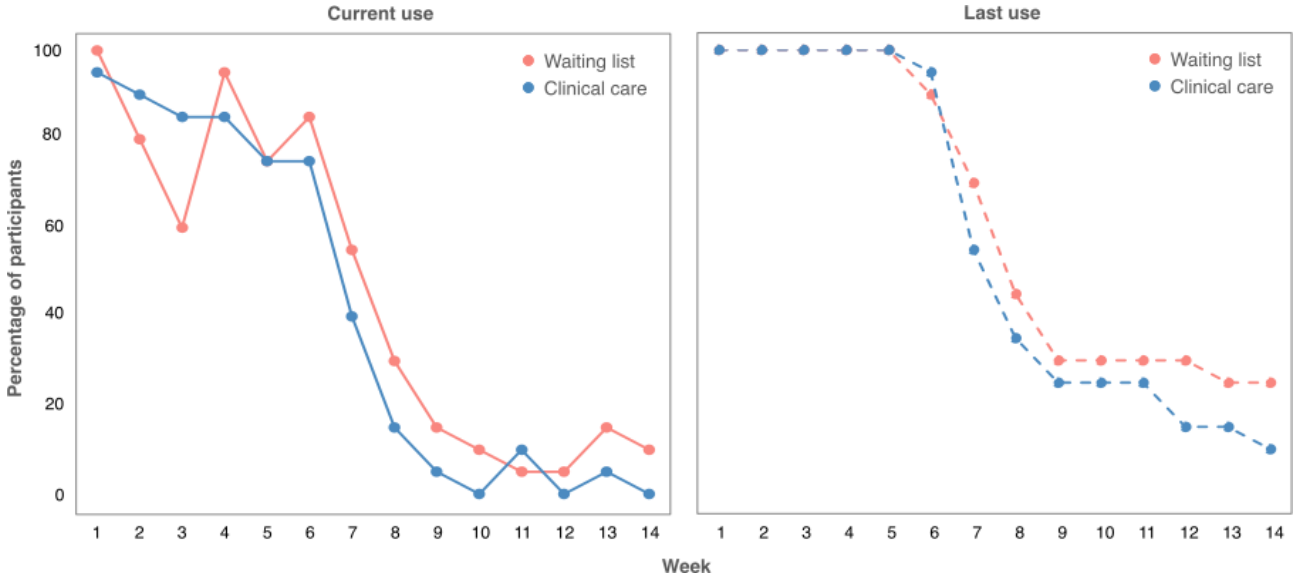


In the pilot RCT, 117 participants were screened for eligibility. A total of 77 parents were excluded, as they did not meet the eligibility criteria (n=5), declined to participate (n=24), or did not respond to the screener survey (n=48). In total, 40 parents (90% female; 20 parents of children on the waiting list and 20 parents of children already receiving clinical care) were enrolled and randomized, with 20 allocated to the intervention group, and 20 allocated to the control group (2 parents dropped out

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during follow-up, both were parents of children already receiving clinical care, and one allocated to the intervention group and the other to the control group). Most participants were female (n=36, 90%), while their children with ASD were mostly male (n=30, 75%) with a mean age of 5.18 (SD 2.46) years. There were no significant differences in participants' characteristics between the intervention and control groups (*P* values>.05). Multimedia Appendix 4 shows the CONSORT-EHEALTH flow diagram of the study, participants' characteristics at baseline, and detailed results for feasibility, acceptability, and preliminary efficacy outcomes.

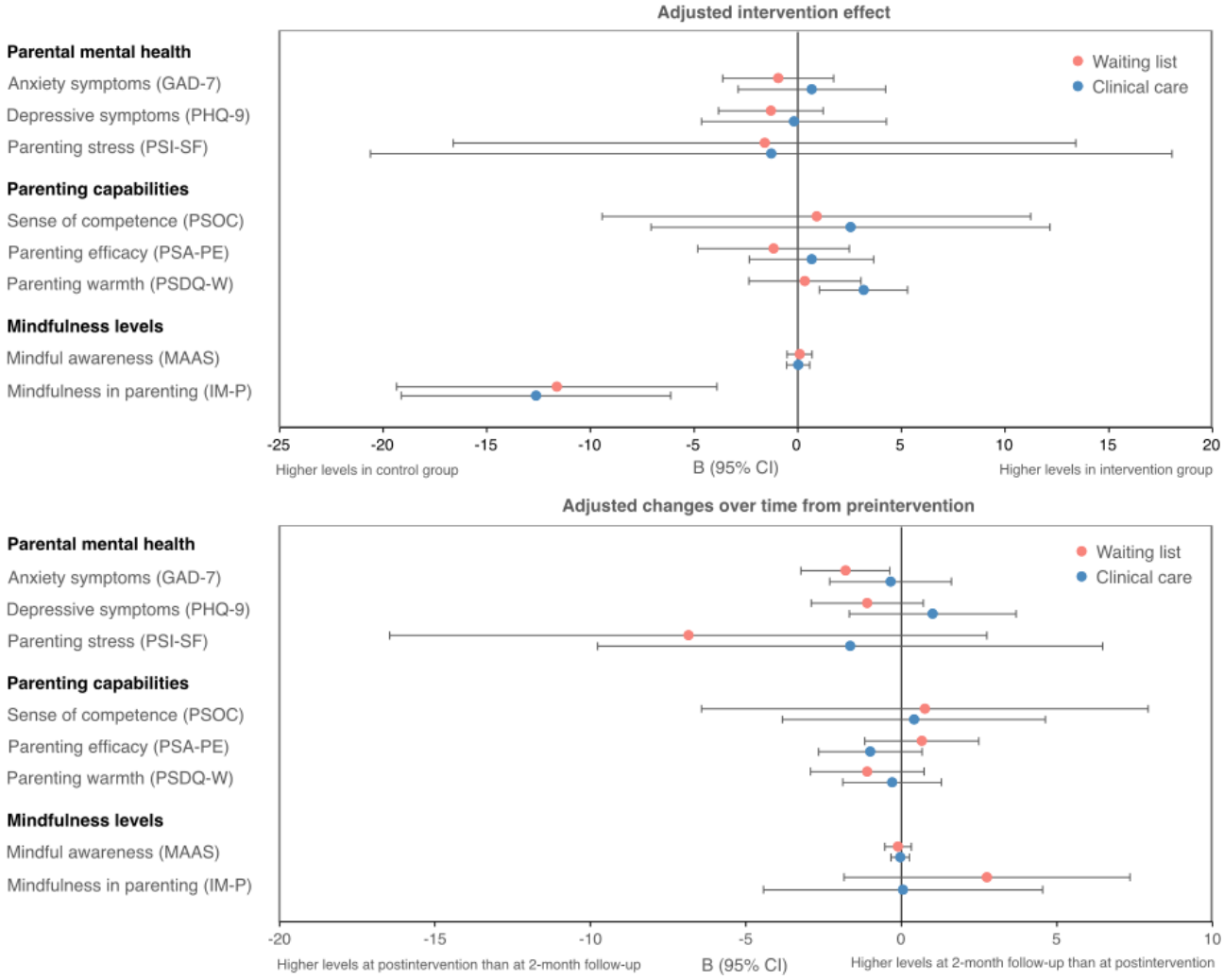
Figure 6. Week-by-week representation of participants' usage pattern during the active intervention period (weeks 1 - 6) and 2-month follow-up period (weeks 7 - 14).



For primary outcomes of feasibility and acceptability, the 6-week app-based structured intervention was both feasible and acceptable for supporting parents of children with ASD. Overall, the usage pattern is similar for parents receiving different levels of support during the active intervention period, whereas parents of children on the waiting list had a greater level of continued usage in the 2-month follow-up period than parents of children already receiving clinical care (Figure 6). All participants used the app during weeks 1 - 4, 92.5% (37/40) were still using the app at week 6, and 17.5% (7/40) continued using the app after the active intervention period. On average, participants completed 78.7% (65.3/83 unique components, SD 11.51) of the curriculum and 93.9% (16.9/18, SD 2.48) of the core sessions in the active intervention period, although the completion rate for optional sessions was rather low at 13.3% (2.4/18, SD 2.60). The overall usability of the system received a mean SUS score of 79.1 (SD 9.76) out of 100, reflecting "good" usability on the scale. The overall app quality based on the mean uMARS score was 4.09 (SD 0.41) out of 5. The app is highly rated for information (mean 4.52, SD 0.43), functionality (mean 4.43, SD 0.42), and aesthetics (mean 4.12, SD 0.55), whereas the rating for engagement is slightly lower (mean 3.29, SD 0.56).

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Figure 7. Intervention effect and outcome changes over time from preintervention to postintervention and 2-month follow-up for efficacy outcomes, stratified by the levels of support received (waiting list vs clinical care). GAD-7: 7-item General Anxiety Disorder scale; PHQ-9: 9-item Patient Health Questionnaire; PSI-SF: 36-item Parenting Stress Index-Short Form; PSOC: 17-item Parenting Sense of Competence scale; PSA-PE: 6-item parenting efficacy subscale of the Parenting Self-Agency measure; PSDQ-W: 7-item warmth subscale of the Parenting Styles and Dimensions Questionnaire; MAAS: 15-item Mindful Attention Awareness Scale; IM-P: 31-item Interpersonal Mindfulness in Parenting questionnaire.



For the secondary outcome of preliminary efficacy, the intervention effect and outcome changes from preintervention to postintervention and 2-month follow-up are illustrated in Figure 7 (refer to Multimedia Appendix 4 for full results). There was no evidence of intervention effects on parents' mental health (GAD-7, PHQ-9, and PSI-SF), parenting capabilities (PSOC, PSA-PE, and PSDQ-W), and mindfulness levels (MAAS and IM-P) at 6-week postbaseline for parents receiving different levels of support, except for increased parenting warmth (PSDQ-W) among parents of children already receiving clinical care (B=3.17, 95% CI 1.04-5.30). Moreover, improvements in parenting warmth (PSDQ-W) were more favorable among parents of children who have already been receiving clinical care, whereas reductions in parental anxiety (GAD-7) and depression (PHQ-9) were more favorable among parents of children on the waiting list who were yet to receive diagnostic assessment and clinical management. Unexpectedly, there was a greater increase in the levels of mindfulness in parenting (IM-P) in the control group (parents of children on the waiting list: B=−11.62, 95% CI −19.34 to −3.90; parents of children already receiving clinical care: B=−12.63, 95% CI −19.13 to −6.13), although the CI was wide and, therefore, suggests uncertainties in the precision of these estimates. Comparing the outcome changes from preintervention to postintervention and 2-month follow-up, there were no notable continual improvements in most outcomes, except for a further decrease in parental anxiety (GAD-7) among parents of children on the waiting list (B=−1.80, 95% CI −3.23 to −0.37). Nonetheless, trends in outcome changes over time showed favorable reductions in parental depressive symptoms (PHQ-9) and improvements in parenting efficacy (PSA-PE) at 2-month follow-up for parents of children on the waiting list when compared with postintervention, whereas there were few changes in these outcomes from preintervention to 2-month follow-up for parents of children already receiving clinical care.

Discussion

Principal Findings

In this study, we used a systematic, evidence-informed approach according to IM to develop an accessible and scalable digital intervention to support parents and caregivers of children with ASD. To our knowledge, this is the first project of its kind in the field of autism, creating a family-centered intervention to

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be implemented in primary care that complements existing clinical services and helps bridge service gaps in addressing unmet needs in the overloaded public specialist service system. This project is particularly intended to support families of children who are still on the waiting list to be seen by a psychiatrist for diagnostic assessments and clinical management. The digital format of the intervention also has great potential in reaching and providing an alternative avenue of care for those who are reluctant to seek conventional treatment due to concerns over privacy or mental health stigma. As the potential impact of improved parental mental well-being extends beyond parents themselves, this project can contribute to the effective management of elevated levels of parental stress in families of children with ASD and is potentially beneficial to both family functioning and child development in the long-term.

Through the IM process, the TRIP app was developed based on evidence-based research, incorporating existing findings from the literature and novel results from the explorative qualitative study with health care professionals conducted for needs assessment. Compared with MBIs developed for face-to-face or online synchronous delivery, the format of a digital platform posed constraints on the app content that can be covered, which may be limited in terms of depth and intensity to minimize the risk of harm or adverse events beyond the common, expected discomfort associated with meditation. For example, when exploring the theme of rupture and repair, instead of the more emotionally intense imaginary exercises in the Mindful Parenting program that may be potentially triggering, we created case studies of lower emotional intensity for observational learning to bring out the same learning points. In a similar vein, while research has emphasized the importance of partner relationships in parenting, it was not practical to address sensitive or highly individualized issues within an app-based format. As such, we have avoided the topic of partner relationships in the app, due to concerns about potential misuse between parents, including the possibility of parents undermining one another, or exacerbating conflicts between parents or separated coparents. Finally, the absence of a group learning environment, which is typical of MBIs, may limit the emergence of themes that often arise through collaborative exploration, such as the recognition of shared experiences of distress as part of our common humanity. This is because the sense of mutual understanding that arises in group settings can be particularly helpful for processing difficult emotions and realizations. Therefore, it would be interesting to implement app-based interventions within a group context, such as through peer support groups or similar networks in community settings, which is planned for later steps.

Feasibility and Acceptability of the App

Results from the pilot study suggest that the TRIP app is a feasible and acceptable way of delivering self-guided mindfulness-based psychoeducation for parents of children with ASD. All participants were actively engaged in the first 5 weeks of the active intervention period, with a low attrition rate of 7.5% at the end of the 6-week intervention, compared with a weighted meta-analytic attrition rate of 24.7% from 78 RCTs of mindfulness apps [66]. During the follow-up period, more than half of the participants revisited some learning components, and just under a third remained active users, with higher engagement among parents of children on the waiting list than parents of children already receiving clinical care. This is somewhat comparable to the engagement in mindfulness-based meditation apps in individuals awaiting psychological services [67]. Likewise, the completion rates of core sessions were substantially higher than those of optional sessions, likely because participants viewed optional sessions as nonessential, akin to the follow-up period. These observed usage patterns may be due to intrinsic factors related to the intervention structure, as the fixed course of core sessions for participants to progress through may have encouraged engagement and compliance, whereas optional sessions positioned outside of the core course scheduled with similar frequencies may have induced fatigue. Similarly, the learning components being available for revisiting in the follow-up period may have created decision-paralysis, thereby contributing to attrition from regular use. However, it is also possible that participants did not have the time to complete optional sessions during the week or did not feel the need to revisit any of the learning components in the follow-up period; therefore, spacing out optional sessions in the intervention period or releasing new learning components regularly in the follow-up period may increase engagement. On the other hand, extrinsic factors such as the study context, including support from research staff during the intervention period, may have acted as both a reminder and a source of accountability, thereby accounting for the increased app usage in the intervention period, as well as the decline in app usage in the follow-up period. This is in line with findings from a rapid scoping review suggesting that improved engagement with digital MBIs may be associated with additional support and encouragement from therapists, researchers, significant others, or other participants [68]. As such, this has been incorporated in the implementation plan, with staff across different settings included as implementers.

Preliminary Efficacy of the App

While we found that the app is feasible and acceptable for parents, there is little evidence for the preliminary efficacy of the app beyond the significant increase in parenting warmth among parents of children already receiving clinical care. An obvious explanation is that the pilot RCT is underpowered for detecting any intervention effects as a result of its small sample size. That said, trends observed in the data suggest that the app may potentially have different effects depending on the level of support children were receiving, as the app may be effective in reducing anxiety and depression in parents of children on the waiting list and increasing parenting efficacy in parents of children already receiving clinical care (in addition to a significant increase in parenting warmth). Moreover, the intervention effects may be delayed in parents of children on the waiting list, which was evident for further decrease in parental anxiety from postintervention to 2-month follow-up and indicated by similar trends observed for reductions in parental depression and improvements in parenting efficacy. This might be due to parents of children on the waiting list receiving minimal clinical support and, therefore, taking more time to understand and apply the knowledge and skills learned in the app to their everyday parenting. However, this means

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that any intervention effects beyond the active intervention period may not be detected, as comparisons with controls were only made during the active intervention period. Trends for outcome changes from postintervention to 2-month follow-up also suggest that the app may bring greater changes to parents of children already receiving clinical care during the intervention period, as reductions in parental depression and improvements in parenting efficacy reverted to preintervention levels at 2-month follow-up. It will be interesting to further investigate this through conducting subgroup analyses with an adequately powered sample in the ongoing large-scale RCT.

Moreover, it may also be possible that the TRIP app may have effects that were not assessed by the outcome measures used in this study. We included measures of parental mental health and parenting capabilities in terms of parenting competence and efficacy, which were selected based on results of the explorative qualitative study. While outcomes selection in this study was in line with established frameworks for integrating parents and family into research and practice [7], measures of parenting behaviors, family interactions, or family quality of life were not included in this study and could be incorporated in the future to provide a more comprehensive evaluation of intervention efficacy and effectiveness. Also, while validated measurement tools were developed for measuring knowledge about ASD in the general population [69] and knowledge of parenting strategies [70], no instruments have been adapted to measure knowledge or skills in caregiving for ASD beyond autism-specific parenting self-efficacy [71]. As such, we did not examine whether there were increases in knowledge or skills for caregiving for ASD, as it would have been difficult to operationalize these changes in a valid and reliable manner in the absence of appropriate psychometric tools.

With regard to the unexpected effects of the app attenuating the natural increase in the levels of mindfulness in parenting, a plausible explanation for this draws on the conscious-competence learning model for the process of experiential learning [72]. As this outcome was measured by self-report, it is possible that participants were in the unconscious-incompetence stage at preintervention, in which they may not be aware of how little they know, and thus have unknowingly inflated their estimations of their levels of mindfulness in parenting. Subsequently, through the TRIP app, they may have progressed to the conscious-incompetence stage as their understanding of mindful parenting improves, and they began to recognize that they might not be as mindful as they had previously thought, thereby explaining the stark decrease in levels of mindfulness in parenting in the intervention group from preintervention to postintervention. In other words, parents may have become more aware of their nonmindful parenting as a result of using the TRIP app. Subsequently, through increased practice and application of skills acquired from the app, parents may have progressed to the conscious-competence stage, which may explain the slight increase in levels of mindfulness in parenting from postintervention to 2-month follow-up. This highlights the need to consider how to best operationalize changes in skills that can be learned over time, especially in light of the individual differences in learning and awareness.

Strengths and Limitations

This study offers several strengths. The approach for app development is systematic, evidence-based, and the use of a clinician-led, co-design approach enables the resulting digital intervention to be family-centered and complement existing clinical services. Moreover, the randomized waitlist-controlled design for the pilot study has the merits of conferring high internal validity and maintaining the gold standard of evidence without withholding the intervention from participants in the control group, offering a more ethical way of intervention testing. Apart from taking into account several important confounding factors (eg, child age and clinical characteristics), careful consideration of the role of the source of recruitment (triage service vs psychiatrist-led clinic) allowed us to gain valuable insights into how families receiving different levels of support may interact with and use the app differently, potentially contributing to differential intervention effects. The inclusion of server-side documented data also allowed us to understand how the app was used, as assessed by objective measures.

While this project has many strengths, there are also various limitations that need to be acknowledged. First, the high nonresponse rates may introduce sampling bias and potentially limit the generalizability of our findings. Moreover, it was possible that parents of children who were on the waiting list may have attended their first appointment with a psychiatrist for diagnostic assessment and clinical management during the intervention period. While psychiatric care is typically a long-term process that may take more time than the 6-week intervention period to show observable effects, any emerging improvements could have confounded the outcomes measured in the pilot study. However, the sample size in the pilot study was too small to adequately explore whether results varied by changes in the level of support received during the study period (eg, transitioning from waiting list to clinical care) or whether results vary by ASD severity. Furthermore, due to time and resource constraints, it was not possible to adopt a mixed methods approach for the pilot study. It would have been interesting to obtain qualitative data from participants to explore the factors influencing their compliance, which may inform how the app can be better implemented in the future to promote continual use beyond the 6-week structured intervention. In a similar vein, it was not practical to extend the waiting period in the waitlist control group beyond the length of the structured intervention, which meant that intervention effects were only compared during the 6-week intervention period and did not allow for any delayed effects to be compared.

Direction for Future Research

To address the potential biases and confounders that may arise in the pilot study, the ongoing large-scale RCT should compare whether response rates differ across key subgroups within the sample, explore whether results varied by ASD severity and changes in the level of support received from clinical services, and adjust for these factors accordingly. To overcome the limitation of the lack of direct evidence on parents' lived experience and qualitative user feedback in the pilot study, factors associated with enhanced user experiences and long-term

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usage will be explored at the end of the ongoing RCT through qualitative interviews with parents and observations of naturalistic usage patterns beyond the active intervention period. Quantitative server-side documented data on app usage in the 6 months following the active intervention period will be analyzed to explore factors associated with long-term usage. Individual qualitative interviews (each lasting 30 - 60 min) will be conducted with parents to explore their user experience of the app, their subjective parenting experience, and their relationship with their children during the intervention period. The interviews will also seek feedback on how the content and delivery can be improved, and identify factors that may promote or hinder compliance with the intervention program. Results from the qualitative interviews will be used to refine the TRIP app before it is translated into English to complete the program development (step 4).

For adoption and implementation (step 5), we plan to implement the app according to a stepwise approach, commencing with implementation in clinical settings for families who are underserved by the public tertiary psychiatric services, followed by wider dissemination in the community through nonprofit organizations and local community centers, in order to be inclusive of those who may identify as neurodiverse but are unbeknownst to clinical services. A detailed implementation plan was devised as guided by the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework [73] (Multimedia Appendix 5).

For program evaluation (step 6), a hybrid type 2 effectiveness-implementation trial will be conducted to evaluate both effectiveness and implementation outcomes simultaneously [74]. Implementers at different sites will be recruited and randomized to either the early implementation group or the delayed implementation group. Those who are allocated to the early implementation group will receive training and support for the implementation of the app immediately after randomization, whereas those allocated to the delayed implementation group will receive the implementation intervention once they have recruited the target number of parents of children with ASD. Implementation outcomes assessing feasibility, acceptability, fidelity, and sustainability will be measured at the end of the implementation period for the early implementation group, or immediately after randomization for the delayed implementation group, as well as at 3-month and 6-month follow-up after the first measurement. Effectiveness outcomes for mental health and quality of life outcomes for parents of children with ASD will be assessed at preintervention, postintervention, and at 3-month follow-up.

Apart from the planned implementation and evaluation, future studies can focus on investigating the mechanisms of change brought by the app by including measures of intermediate outcomes, such as attention and self-compassion. Future research can also include objective psychophysiological measures of depression and mindfulness alongside self-report measures by incorporating EMA, which was found to be more sensitive than paper-and-pencil measures [75].

Conclusions

In this study, we created an evidence-based digital intervention for parents of children with autism with an interdisciplinary approach at the heart of psychiatry, public health, and behavioral and implementation science. We demonstrated how we can incorporate behavior change theories and techniques while leveraging the experiences of clinicians for the coproduction of a feasible and acceptable digital intervention that complements existing clinical services in addressing pressing clinical needs. The TRIP app has great potential to be an economical, first-tier intervention in the stepped-care model for the holistic management of autism, by bridging service gaps through supporting parents of children awaiting diagnostic assessment and clinical care, and by improving resource allocation within existing clinical services through freeing up capacity to focus on complex cases that require more specialized, individualized, and intensive input.

Acknowledgments

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Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request.

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Authors' Contributions

All authors have made conceptual contributions to the project design and procedures. KKYM, SSMC, EWYW, OC, GPCF, and OWHW contributed to the iterative development of the digital intervention. KKYM, SSMC, OC, and OWHW conducted the qualitative study for needs assessment and quantitative study for pilot evaluation. KKYM conducted all analyses and drafted the initial manuscript. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Qualitative study topic guide for semistructured interviews.
[DOCX File, 21 KB - pediatrics_v9i1e84224_app1.docx]

Multimedia Appendix 2
Qualitative study codes and examples mapped to an adapted socioecological model.
[DOCX File, 19 KB - pediatrics_v9i1e84224_app2.docx]

Multimedia Appendix 3
Practical application of social cognitive theory and behavior change techniques to achieve change objectives.
[DOCX File, 21 KB - pediatrics_v9i1e84224_app3.docx]

Multimedia Appendix 4
Pilot waitlist-randomized controlled trial recruitment flow, participants' baseline characteristics, and full results tables.
[DOCX File, 607 KB - pediatrics_v9i1e84224_app4.docx]

Multimedia Appendix 5
Implementation plan for different settings.
[DOCX File, 16 KB - pediatrics_v9i1e84224_app5.docx]

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Abbreviations

ASD: autism spectrum disorder
BCT: behavior change techniques
CBCL: Child Behavior Checklist
CBCL-Attn: Attention Problems Scale of the Child Behavior Checklist
CBCL-Ext: Externalizing Problem Scale of the Child Behavior Checklist
CONSORT-EHEALTH: Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth
***DSM-5*:** *Diagnostic and Statistical Manual of Mental Disorders* (Fifth Edition)
ELM: elaboration likelihood model
EMA: ecological momentary assessment
GAD: 7-item Generalized Anxiety Disorder Scale
IM: intervention mapping
IM-P: 31-item Interpersonal Mindfulness in Parenting Questionnaire
MAAS: 15-item Mindful Attention Awareness Scale
MBI: mindfulness-based intervention
PHQ: 9-item Patient Health Questionnaire
PRECEDE: Predisposing, Reinforcing, and Enabling Constructs in Educational Diagnosis and Evaluation

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PSA-PE: 6-item Parenting Efficacy Subcale of the Parenting Self-Agency Measure
PSDQ-W: 7-item Warmth Subscale of the Parenting Styles and Dimensions Questionnaire
PSI-SF: 36-item Parenting Stress Index-Short Form
PSOC: 17-item Parenting Sense of Competence Scale
RCT: randomized controlled trial
RE-AIM: Reach, Effectiveness, Adoption, Implementation, and Maintenance
SCT: social cognitive theory
SEM: social ecological model
SRS-2: Social Responsiveness Scale, second edition
SUS: 10-item System Usability Scale
uMARS: 20-item User Version of the Mobile Application Rating Scale

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Multidisciplinary Telehealth for Pediatric Developmental and Mental Health Care in Rural and Remote Australia: Interview Study Among Caregivers and Service Providers

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Abstract

Background: Geography and socioeconomic disadvantage impede access to appropriate services for rural and remote-dwelling children with complex developmental and mental health needs. Telehealth offers opportunities to increase access to essential health and well-being services for people with complex needs who live in rural and remote areas, whose experiences of mental ill-health are frequently compounded by social marginalization and economic disadvantage.

Objective: This study aimed to describe caregivers' and service providers' perspectives on the challenges and value of telehealth services for rural and remote children by drawing on experiences within a specialist service (Royal Far West; RFW) that provides mental and developmental health services to rural and remote-dwelling children and families in Australia.

Methods: Participants included a convenience sample of caregivers of children who use RFW services (n=11) and service providers from RFW (n=21). Deidentified interview transcript data were analyzed thematically using framework analysis.

Results: Caregivers were generally enthusiastic about telehealth but acknowledged potential technological limitations and challenges to effectively engaging some children. While acknowledging its value and importance, RFW service providers identified additional challenges with providing telehealth, such as limited capacity for some detailed clinical assessments and potential child and family risk and safety issues.

Conclusions: Telehealth remains a vital option within multidisciplinary services to improve access and outcomes for children in rural and remote communities who present with complex mental and developmental health needs. Despite challenges, rural and remote caregivers and RFW service providers identified telehealth as a beneficial, accessible, and effective component of multidisciplinary care for children with complex mental and developmental health needs. These caregiver and service provider perspectives will inform ongoing service development, research, and advocacy.

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KEYWORDS

rural; remote; developmental; pediatric; qualitative

Introduction

Background

Geography and socioeconomic disadvantage often make it difficult for rural and remote-dwelling Australian children with complex developmental and mental health needs to access appropriate services [1]. Clinical, family, and community complexity likely also influences service engagement for these families, whose experiences of mental ill-health are frequently compounded by social marginalization and economic disadvantage [2]. Although the prevalence of child and youth mental health problems is increasing across Australia [3], fewer than one-third of children currently receive the mental health services they require nationally [4]. Furthermore, although children and young people living in rural and remote communities experience poorer mental health [5] and developmental outcomes [6] than those in urban locations, their use of mental health services is considerably lower than that in urban areas in Australia [7] and internationally [8,9].

Telehealth offers opportunities to increase access to essential health and well-being services for children with complex mental and developmental health needs who live in rural and remote

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areas [10]. In this paper, "telehealth" refers to a combination of video consultations, telephone calls, and digital platforms used for client engagement, assessment, and therapy, which are sometimes supplemented with face-to-face consultations. A recent systematic review of telehealth screening, assessment, and diagnosis of autism spectrum disorder (ASD) found that telehealth facilitated the standardization, sensitivity, specificity, and efficiency of screening, assessment, and diagnosis of ASD [11]. Similarly, a systematic review of telehealth services to assess and treat neurodevelopmental disorders found that these services were clinically effective, cost-effective, and acceptable to caregivers [12]. Telehealth has been found to be convenient and cost-effective, as well as supportive for high-risk populations, given its ability to remove geolocation barriers [13]. Furthermore, telehealth as a psychological intervention for caregivers of children with neurodevelopmental disorders has been shown to improve mental health outcomes [14].

Telehealth is also acceptable to children and families seeking diverse and complex health and well-being care remotely [15]. For example, a recent systematic review of telehealth interventions for children with ASD found that telehealth programs are highly acceptable even when compared to face-to-face interventions and noted the vital role of telehealth for enhancing equitable access to interventions for rural and remote communities [16]. When facilitated through partnerships with Aboriginal community-controlled health services, telehealth services are also effective and acceptable to Aboriginal and Torres Strait Islander individuals and communities [17]. Furthermore, ease of use, improvements in outcomes and communication, and reductions in costs support patient satisfaction with telehealth [18].

However, most pediatric neurodevelopmental studies from Australia and abroad have reported telehealth benefits primarily in urban populations, providing limited data on rural and remote communities. Furthermore, they have not explored hybrid telehealth and face-to-face models. There is a need for studies focused on these populations and models of care to address knowledge gaps. Therefore, the aim of this study was to describe caregivers' and service providers' perspectives on the challenges and value of telehealth services by drawing on experiences within Royal Far West (RFW), a specialist service providing mental and developmental health services to rural and remote-dwelling children and families in Australia.

Study Context

RFW is a charitable, nongovernment, specialist child health service located in Sydney, New South Wales, Australia, that provides developmental, mental health, and disability support for children up to the age of 12 years in rural and remote settings using a mixed model of care that includes telehealth. Given its clientele, RFW was an early adopter of telehealth, using it for assessment and therapy in a range of clinical disciplines since 2015, well before the COVID-19 pandemic accelerated its use. RFW services have been adapted over time to integrate telehealth within their standard models of care, with telehealth becoming an integral modality to enhance and maintain engagement and reduce barriers to access.

Thus, telehealth is part of the standard assessment and therapy provided by RFW in all clinical services. Telehealth at RFW is provided by speech pathologists, occupational therapists, psychologists, social workers, nurses, pediatricians, and psychiatrists. It is used as both stand-alone care and to complement face-to-face care. For example, in the assessment-focused pediatric developmental service, telehealth is used before, after, and between face-to-face residential assessment visits in Sydney. Telehealth introduction consultations involve a pediatrician and allied health clinician connecting with the child and their caregivers, reviewing referral information, and assisting in planning for the upcoming visit. After the on-site or in-community (outreach) assessment with a multidisciplinary team, telehealth is used for diagnostic feedback from the multidisciplinary team and care planning with the caregiver. It is also used for ongoing care (eg, for medication management), interim progress reviews prior to further face-to-face assessments, and group parenting programs. Telehealth sessions are typically conducted with the child and caregiver at home, although for families with limited internet connectivity or other problems with access, sessions are conducted from the child's school or another service provider (eg, child protection or health service offices).

RFW's community-based disaster recovery service provides individual telehealth therapy sessions to children impacted by bushfires and floods. Telehealth is used for therapy (eg, eight 45-minute weekly sessions for psychological, occupational, or speech therapy) or for parent capacity building (eg, *Tuning in to Kids* parenting program). These programs supplement children's group programs or teacher capacity building programs that are delivered face-to-face during in-community (outreach) visits. Thus, at RFW, telehealth is integrated into all models of care and used for rapport building and service familiarization, diagnostic assessment, feedback and psychoeducation, therapy, care planning, progress review, and follow-up, as well as parenting programs, often to complement face-to-face care. Hence, telehealth can be an enabler of service engagement for rural and remote families along their care journey when used dynamically.

Methods

Study Design

The data presented in this paper were collected as part of a broader exploratory sequential mixed methods study. For the qualitative component of the study, a convenience sample of current RFW service providers and caregivers of children who had used RFW services within the 2 years prior to when the interviews were conducted were invited to participate in an interview. Semistructured interviews allow for detailed exploration of participants' experiences and perceptions, including the ability to ask follow-up questions. Interview questions were provided to participants in advance of the interview so they had time to prepare their thoughts. The interview questions focused broadly on challenges and enablers of service engagement throughout a family's service journey, with a substantial portion of the interview focusing specifically on experiences with telehealth. Questions were piloted with 2

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individuals and refined prior to participant recruitment, resulting in minor changes to question wording.

Data Collection

Interviews were conducted by a non-Indigenous female individual with extensive qualitative and mixed methods research experience who was employed as a postdoctoral researcher. Although the interviewer had presented the study outline earlier to many of the RFW service providers who later chose to participate, she had no prior relationship with caregiver interview participants. To facilitate rapport and relationship building, all interviews began with an invitation to ask the interviewer any questions about the study or the interviewer herself. All interviews took place online using Zoom teleconferencing software (Zoom Video Communications) and were audio recorded and transcribed using Zoom's verbatim transcription service.

Analysis

Once data saturation was reached, the interview data were analyzed thematically [19] using framework analysis [20], which includes the following 7 steps: (1) transcribing, (2) familiarizing oneself with the interview, (3) coding, (4) developing an analytical framework, (5) applying the analytical framework, (6) charting the data into a framework matrix, and (7) interpreting the data. Data were independently coded by 2 members of the research team, who identified emerging themes deductively using the Microsoft Word and Microsoft Excel software. Framework analysis allows for findings to be traced directly to primary data.

Ethical Considerations

This study was approved by the University of Sydney Human Research Ethics Committee (2024/HE000682) and all participants provided written informed consent before participating in an interview. Interview participants were provided with an AUD $30 (US $24.50) grocery voucher in gratitude for their time.

Results

Participants

Semistructured interviews were conducted with 11 caregivers, all of whom were female and 81.8% (9/11) of whom were non-Indigenous, and 21 RFW service providers, including psychologists (n=3, 14.3%), social workers (n=4, 19%), occupational therapists (n=3, 14.3%), speech pathologists (n=6, 28.6%), pediatricians (n=2, 9.5%), and operations staff (eg, bookings or caregiver support services; n=3, 14.3%). Findings from the caregiver interviews are presented first, followed by service provider interview findings.

Caregiver Findings

Three themes were identified within the caregiver interview data: (1) challenges with telehealth, (2) value of telehealth, and (3) settings for telehealth (Table 1). Some caregivers found telehealth to be a challenge, noting their children's resistance to engaging with telehealth; distractions in the household setting; the inconvenience of the timing of telehealth appointments; and technological issues such as satellite internet, which is vulnerable to weather changes. Other caregivers found telehealth very helpful, noting as strengths their own and their children's fluency with technology and the opportunity to access services that would otherwise be inaccessible. Finally, some caregivers recommended ensuring that the physical setting is conducive to telehealth.

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Table . Caregiver interview findings regarding the challenges and value of telehealth.

Theme	Illustrative quotes
Challenges of telehealth	• "We struggle with telehealth. [Child] just can't. He struggles with social interaction as it is, let alone being face-to-face with someone on a computer. It just didn't work for us. I don't think there was anything that [Royal Far West] could do to make it better. They did try their best. But yeah." [PDPF03] • "And with the telehealth visits, at times I'd have the other kids. So, they'd be in the background watching TV. And then [oldest child] gets distracted. [And] the first was a week of telehealth visits. [...] We've only got satellite Internet. So, the pings have got to physically go up 30,000 Ks and back down. So, sometimes I'm still talking, and then someone else starts. Like, it doesn't quite exactly work." [PDPF02]
Value of telehealth	• "I don't see many challenges with telehealth because I've been using telehealth for a few years. And as someone who lives regionally, where services are so limited face-to-face, and I'm time poor. I work full time; I'm a single parent to two kids. So, I guess the general challenges would be, yes, you're not seeing the person face-to-face, and that sort of stuff. But I don't really see a challenge with telehealth. Had that [parenting] course been done any other way, I wouldn't have been able to do it. Wouldn't have mattered weekend, daytime, afternoon, I simply would not have been able to do it. So, I think it's fantastic that we have a telehealth." [CRPF01] • "I'm very confident and capable with technology. So, I wasn't apprehensive. I found no challenges with that. [...] [Child] has no challenges with digital tech, either." [CRPF03] • "I don't remember there being any massive challenge [with telehealth]. I could see how someone a little bit more remote than me, or more rural than me could have internet issues, Wi-fi. Sometimes, if it's really windy here, we'll have trouble with our Wi-fi. But I think I was really lucky in a sense of I never really had any trouble like that." [CRPF02]
Settings for telehealth	• "Making sure the space is right. If you're a family and you're in a small house, like a lot of families have multiple people living in a house, it's too distracting for a child. You need to make sure the space for the telehealth session to actually go ahead [is] quiet. Are they going to be able to focus?" [PDPF04]

Service Provider Findings

Four main themes emerged from the service provider interview data: (1) the value of telehealth for rural and remote families, (2) implications of technology, (3) clinical challenges of telehealth, and (4) risk and safety (Table 2). Many service providers noted the value of telehealth, particularly in terms of its low cost to both families and RFW, facilitating access to care in the absence of other alternatives in local communities, and its demonstrable effectiveness for some disciplines. Others noted that some children respond really well over telehealth, whereas other children prefer face-to-face appointments. However, service provider interview respondents also noted several challenges with telehealth, including technological challenges for rural families, such as limited internet connectivity and difficulties accessing laptops or tablets for appointments.

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Table . Service provider interview findings regarding the value and challenges of telehealth for rural and remote families.

Theme	Illustrative quotes
Value of telehealth for rural and remote families	• "I think telehealth is amazing, because so many of those kids in rural, regional New South Wales, the waitlist is so long, or it's so expensive, or they just don't have any local services, or the local service is a two-hour drive away. So, telehealth is great in that we can offer them a service where they couldn't get it otherwise." [PDPS09] • "The evidence, particularly for speech pathology, a lot of the evidence says [telehealth] is just as effective as in-person therapy. [...] So, I think it's beneficial in terms of ease of access, cost, and we know that it's just as effective. We can meet goals." [PDPS13] • "From an [occupational therapy] perspective, I was...kind of surprised at how well you can go on telehealth in terms of running different OT activities, chatting to parents, building relationships over telehealth has been amazing. And that's the same for assessment as well." [PDPS08]
Implications of technology	• "The availability of technology. Some families might not have a laptop where they can sit down and have the zoom sessions and things like that. So that can be quite tricky, or they might not have good Internet at home, so that their availability of accessing telehealth can be tricky." [PDPS08] • "I think working on telehealth actually made me a much better [occupational therapist] in terms of me not being so reliant on equipment or games of those kind of things. Just thinking about, what can we do just with our bodies? Just being able to run an OT session with almost nothing. Very basic." [CRPS06]
Clinical challenges of telehealth	• "I find telecare incredibly challenging, for the social work role specifically.... I actually haven't found telecare assessments that clinically valuable because we're expected to do a [relatively] quick assessment. ...I think to build the rapport, to deep dive into your mental health, your relationship with your partner that you're parenting with, or the reason why you've separated your co-parenting, what choices or strategies do you use in your parenting? All these pretty significant personal topics. To get there via telecare can feel really challenging. ...I just don't ever think I get the same depth." [PDPS03] • "I do think telecare is a bit of a challenge. It certainly opens up doors in the sense of that means that we can check in with families, but it absolutely 100% does not replace a face-to-face assessment." [PDPS15]
Risk and safety	• "Challenges with telehealth and never knowing the full picture can put clinicians and the child at risk of child protection concerns—if child protection concerns are apparent [but] not able to be addressed, identified, and appropriately addressed." [CRPS01]

Another challenge noted by service providers was the limited depth of clinical assessments possible for some disciplines such as social work. Some service providers also found standardized assessments difficult to complete via telehealth, noting that, at times, it is difficult to engage children on-screen for adequate periods. Service providers also commented on risk and safety concerns for children and their families when using telehealth, particularly in relation to gauging off-screen activities. As one service provider expressed, "I just don't trust what I can't see on screen" (PDPS03).

Summary

In summary, although caregivers identified challenges, they also asserted the value of telehealth for multidisciplinary mental and developmental health assessments and treatment. Service providers reflected on both strengths and challenges associated with telehealth for multidisciplinary developmental and mental health assessment and treatment.

Discussion

Principal Findings

Caregivers and service providers articulated common themes when discussing the benefits and challenges of telehealth service delivery within a multidisciplinary pediatric developmental and mental health service for rural and remote children. Caregivers experienced challenges with telehealth yet valued it for its ability to facilitate access to otherwise inaccessible services. They also described the importance of ensuring that settings were conducive to telehealth assessment and treatment. Meanwhile, service providers reflected on the value of telehealth, particularly in terms of lower costs, easier access, and its demonstrable effectiveness for some clinical disciplines. Nevertheless, they

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also identified challenges with telehealth, including risk and safety; implications of technology; and depth of clinical assessments, particularly in relation to psychosocial evaluation. Importantly, while both caregivers and service providers expressed some concerns about telehealth, both groups shared an appreciation for how telehealth allows rural and remote children to access multidisciplinary developmental health services, especially given the dearth of appropriate services in rural and remote locations in Australia.

Cross-referencing caregiver and service provider perspectives on the challenges and value of telehealth for pediatric developmental and mental health reveals that multidisciplinary and multimodal telehealth can be an enabler of service engagement for rural and remote families along their care journey, particularly when used dynamically. For example, at RFW, telehealth is used for rapport building and service familiarization, diagnostic assessment, feedback, psychoeducation, therapy, care planning, progress review, and follow-up, as well as parenting programs. Thus, our findings suggest that telehealth can be effective for this range of activities when used to complement face-to-face consultations. Telehealth diagnostic assessment of complex developmental disorders elicited high levels of acceptance from caregivers and service providers despite limitations such as technical issues.

Our findings are consistent with those of international and Australian literature regarding telehealth in urban settings. For example, in an Australian metropolitan pediatric context, the use of telehealth in the diagnostic assessment of complex developmental disorders received high levels of acceptance from caregivers and service providers despite limitations similar to those observed in our study, such as technical issues, because it reduced costs, increased flexibility, and accommodated family needs [21]. Similarly, the international literature indicates that implementing telehealth in urban settings holds promise for greater accessibility of child mental health services [22], including pediatric psychiatry [23]. Our findings are also consistent with findings that telehealth supported increased rates of rural and remote patient satisfaction with allied health services such as occupational therapy and speech pathology [24].

Implications

Our study suggests several implications and recommendations for policy and practice in the field of telehealth for child mental and developmental health assessment and treatment. First, rural and remote communities without access to face-to-face services should have access to telehealth services that incorporate family, educational, and societal factors impacting the child. This would empower children and families with psychosocial or neurodivergent complexity to seek care and optimize access to government rebates for care needs that depend on multidisciplinary clinical assessment. Second, to be effective, digital literacy and internet connectivity must be assured. Finally, service provision staff must be supported to deliver telehealth services in integrated and dynamic ways.

Strengths and Limitations

One strength of our study is that it triangulates primary data from both caregiver and service provider interviews, facilitating comparisons of their experiences and perspectives. In addition, member checking of primary data before analysis, reflexivity throughout the analysis period, and an audit trail supported by the systematic stages of framework analysis strengthened the rigor and quality of data interpretation. However, this study had several limitations. For example, one potential limitation is self-selection bias because participants who voluntarily chose to take part represent only part of the client cohort. Similarly, caregiver interviewees were all biological mothers, omitting the perspectives of other caregivers (eg, fathers or grandparents). Another limitation relates to constraints on transferability given the relatively small sample sizes, as well as the fact that service clients (ie, children) were not engaged directly in the research. Despite these limitations, our qualitative findings provide important insights into the role of telehealth for rural and remote access to developmental and mental health services.

Directions for Future Research

Future studies should explore rural and remote children's experiences of telehealth and how it can inclusively engage and support neurodivergent or culturally diverse groups. Caregiver perspectives on unique aspects of telehealth clinician interactions, including supportive evaluation of child and family risk issues, could also be explored. Given the centrality of telehealth to rural and remote care, ongoing investigation of innovative telehealth neurodevelopmental assessment and therapeutic tools should be pursued, as well as comparison of care satisfaction, impact, and outcomes of telehealth vs hybrid telehealth and face-to-face care.

Conclusions

Although there are challenges with telehealth, it remains a vital option within multidisciplinary services to improve access and outcomes for children in rural and remote communities who present with complex mental and developmental health needs. Telehealth can be used to deliver a range of clinical services and offers opportunities to develop new clinical approaches. Future work should explore approaches that allow for the adaptation of in-person assessments to telehealth and improve service provider skills in engaging children using telehealth. As technology improves, so should the accessibility of telehealth-delivered care.

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Conflicts of Interest

None declared.

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Abbreviations

ASD: autism spectrum disorder
RFW: Royal Far West

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Woebot for Postpartum Mood and Anxiety: Randomized Controlled Trial Evaluating Feasibility, Acceptability, and Preliminary Efficacy of a Mobile Cognitive Behavioral Therapy Intervention

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Abstract

Background: Postpartum psychological distress, ranging from transient mood and anxiety disturbances to full-syndrome postpartum depression, is prevalent. Many postpartum individuals lack access to evidence-based interventions due to stigma and insufficient provider availability. The treatment gap is particularly pronounced among historically marginalized groups, including Black, Hispanic/Latina, and low-income mothers. Digital health interventions offer support to address this.

Objective: We aimed to evaluate the feasibility, acceptability, and preliminary efficacy of Woebot for Postpartum Mood and Anxiety (W-PPMA), a smartphone-based relational agent delivering cognitive behavioral therapy–informed psychoeducation to postpartum individuals.

Methods: This randomized controlled trial recruited participants from the PowerMom study, a digital platform for maternal health research. Eligible individuals (≥16 y, <3 mo post partum) were randomized to W-PPMA or a waitlist control condition. W-PPMA, an investigational digital mental health intervention, features a relational agent delivering cognitive behavioral therapy–based psychoeducation via text-based conversations. Primary outcomes included feasibility (Usage Rating Profile–Intervention Revised, Feasibility Subscale), acceptability (Usage Rating Profile–Intervention Revised, Acceptability Subscale), and satisfaction (Client Satisfaction Questionnaire–8) assessed at the 8-week end of intervention (EOI). The secondary outcome was change in depressive symptoms (Patient Health Questionnaire–8) among those with elevated baseline symptoms. Exploratory outcomes included anxiety (Generalized Anxiety Disorder–7 items), stress (Perceived Stress Scale), perinatal depression (Edinburgh Postnatal Depression Scale), Mother-to-Infant Bonding Scale, and therapeutic alliance (Working Alliance Inventory–Short Revised). This study followed CONSORT (Consolidated Standards of Reporting Trials) guidelines and received Institutional Review Board approval.

Results: Of 267 participants (W-PPMA=144, waitlist=123), mean age was 32.2 (SD 5.1) years; 12.7% (n=34) identified as Hispanic/Latina, 8.6% (n=23) as Black, and 68.5% (n=183) as White. W-PPMA users engaged with the app a median of 9 (IQR 5 - 24) days across 4 active weeks (IQR 2 - 7). At EOI, W-PPMA participants reported high feasibility (Usage Rating Profile–Intervention Revised, Feasibility Subscale median 31, IQR 28 - 34), acceptability (Usage Rating Profile–Intervention Revised, Acceptability Subscale median 30, IQR 28 - 34), and satisfaction (Client Satisfaction Questionnaire–8 median 26, IQR 24 - 29). Among those with baseline depressive symptoms (n=97), Patient Health Questionnaire–8 scores improved modestly in the W-PPMA group compared to waitlist (mean change −0.7, SD 3.4, vs 0.0, SD 4.8; Cohen *d*=−0.16). Exploratory analyses showed a statistically significant between-group difference in Perceived Stress Scale change at EOI (mean difference −1.59, 95% CI −2.4 to −0.73) and a nonsignificant between-group difference in Edinburgh Postnatal Depression Scale change (mean difference −0.51, 95% CI −1.36 to 0.34). Therapeutic alliance (Working Alliance Inventory–Short Revised) was strongest at baseline among Black participants and those from socioeconomically disadvantaged neighborhoods (Area Deprivation Index ≥75). Participants with a high school or General Educational Development reported the highest satisfaction scores, underscoring accessibility across educational backgrounds.

Conclusions: W-PPMA met primary study aims. Preliminary evidence and these findings support W-PPMA, warranting further evaluation in larger trials.

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Trial Registration: ClinicalTrials.gov NCT05662605; https://clinicaltrials.gov/study/NCT05662605

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KEYWORDS

postpartum mental health; postpartum depression; health equity; digital health; mobile apps; relational agent; chatbot; cognitive behavioral therapy; mobile phone

Introduction

Prevalence and Burden of Postpartum Blues and Postpartum Depression

The postpartum period is a time of significant lifestyle, relational, and physical health changes, often accompanied by psychological distress and profound impacts on maternal mood. In this study, we use the term postpartum "psychological distress" to refer to a spectrum ranging from transient mood and anxiety disturbances to full-syndrome postpartum depression (PPD), consistent with the most common manifestations in the early postpartum period. Broader definitions of perinatal mood and anxiety disorders also include posttraumatic stress symptoms [1], which were not assessed in this study. Understandably, many mothers experience various mood and anxiety symptoms and labile emotions after birth, such as mood swings, crying spells, anxiety, irritability, sadness, and feelings of being overwhelmed [2-4]. These symptoms, often referred to as "baby blues," typically begin within the first 2 - 3 days and resolve without intervention within 2 weeks for most individuals [5]. However, recognition and management of persistent postpartum mood and anxiety symptoms is critical, as they are not only distressing to mothers and their families but also represent a risk factor for the development of full-syndrome PPD and anxiety disorders [4,6].

As many as 75% of women report some degree of mood and/or anxiety symptoms after birth [5]. Full-syndrome PPD affects approximately 13% - 20% of postpartum individuals in the United States, with prevalence varying significantly by state and demographic group [4,7]. PPD is associated with adverse outcomes, including increased maternal morbidity and mortality [8], impaired maternal-child interactions [9], diminished parenting behaviors, and cognitive, emotional, and behavioral challenges in child development [10].

Current Treatment

Treatment of peripartum mood and anxiety symptoms typically involves psychotherapy and/or antidepressant therapy. Cognitive behavioral therapy (CBT) and interpersonal psychotherapy (IPT) are recommended as first-line treatments for mild to moderate postpartum mood and anxiety concerns, while antidepressant pharmacotherapy is reserved for more severe cases of PPD [11]. CBT aims to address the reciprocal interactions between thoughts, feelings, and behaviors by challenging negative thought patterns and promoting adaptive behaviors [12]. IPT focuses on alleviating symptoms by improving interpersonal functioning, communication, and role clarification in response to relational challenges [13]. Techniques derived from these psychotherapies are beneficial not only for mothers diagnosed with PPD but may also provide effective mental health and emotional support for nonclinical populations.

Barriers to Mental Health Care Support

Despite the existence of evidence-based treatments for peripartum mood and anxiety, many postpartum individuals do not seek or engage in care, even when recommended by health care providers [14,15]. Stigma surrounding mental health is a significant barrier to help-seeking and treatment usage [16]. Additional barriers include a shortage of qualified therapists, inflexible scheduling, long wait times, childcare challenges, transportation difficulties, and affordability concerns [14]. For pharmacotherapy, concerns about antidepressant transmission through breast milk further limit its use [17]. These barriers are especially pronounced among Black, Hispanic/Latina, and low-income mothers, who face higher risks of PPD and significant systemic inequities in accessing care [18].

Low representation of historically marginalized groups in health research exacerbates disparities, reducing the generalizability of findings and hindering the development of effective interventions [19,20]. Ensuring diverse inclusion in research is critical to addressing health inequities and improving outcomes.

Digital Interventions

Digital mental health interventions (DMHIs) offer promise for postpartum mental health support. In this paper, we focus on fully automated, app-based DMHIs such as Woebot, which deliver psychoeducation and coping strategies without requiring a live clinician. We acknowledge that telemedicine-delivered psychotherapy, such as CBT provided by a therapist via video or phone, has also grown substantially, with recent evidence [21] showing it to be noninferior to in-person care with high satisfaction rates across diverse populations. While this is an important parallel development, our study centers on the potential of automated DMHIs to scale support where clinician-delivered therapy is not available [22]. Such DMHIs provide private, stigma-free support, which is particularly relevant for postpartum mothers navigating the unique demands of early parenthood [23]. Moreover, their scalability enables broader population reach, including individuals who might otherwise receive no care.

To address these challenges, this study leveraged the PowerMom mobile research platform [24], chosen for its ability to facilitate decentralized, bilingual (English and Spanish), and scalable data collection for maternal health. PowerMom's capacity to enable remote participation, inclusivity, and generalizability makes it valuable for engaging underrepresented populations in research.

The intervention evaluated in this study is Woebot for Postpartum Mood and Anxiety (W-PPMA), an investigational

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DMHI that offers a guided self-help program that delivers CBT psychoeducation and self-management techniques through brief text-based conversations with a relational agent named Woebot. Woebot is intended to present to users a friendly, helpful, self-help ally that is explicitly not a human or a therapist. Neither W-PPMA nor Woebot have been evaluated, cleared, or approved by the Food and Drug Administration and are not available for general use. W-PPMA integrates evidence-supported techniques from CBT and IPT, specifically tailored to the postpartum experience. Earlier prototypes of Woebot have demonstrated feasibility, acceptability, and preliminary efficacy in improving anxiety and depression symptoms among young adults [25], postpartum women [26,27], and adults addressing substance use [28,29]. Building on these foundations, W-PPMA aims to offer a specialized approach to address the unique mental health needs of postpartum mothers. While prior work in postpartum populations has been limited to smaller pilot trials, this study extends this evidence by conducting the largest randomized evaluation of Woebot in a postpartum cohort to date, with a deliberate emphasis on recruiting underrepresented racial, ethnic, and socioeconomic groups.

The primary aim of this study is to evaluate the feasibility and acceptability of W-PPMA, using app usage and validated measures, among a diverse group of postpartum women. The secondary aim is to assess the preliminary efficacy of W-PPMA relative to a waitlist control condition in managing symptoms of depression at the 8-week end of intervention (EOI) among participants with elevated baseline depressive symptoms. Exploratory aims include (1) examining potential between-group differences in perceived mother-infant bonding, mood and anxiety symptoms, and perceived stress; (2) evaluating therapeutic bond with Woebot at 1 and 8 weeks; and (3) assessing feasibility, acceptability, perceptions of stigma as a barrier to mental health care, and mood outcomes across key sociodemographic variables (eg, race and ethnicity, age, education, gender, marital status, health insurance, and employment status) at baseline and 8 weeks.

Despite the significant prevalence and burden of postpartum psychological distress, existing interventions remain underused, particularly among historically marginalized groups who face systemic barriers to care. While evidence-based psychotherapies such as CBT and IPT are effective in treating postpartum mood disorders, there is a critical need to explore how these interventions can be feasibly and equitably delivered to diverse populations in nonclinical settings. Digital health tools, such as mobile applications, hold immense promise for addressing these gaps by overcoming logistical and stigma-related barriers. However, few digital interventions have been rigorously studied in postpartum populations. By evaluating the feasibility, acceptability, and preliminary efficacy of W-PPMA in a diverse and bilingual cohort, this study aims to advance understanding of scalable, accessible mental health solutions. Ultimately, this research provides critical insights into closing the postpartum mental health treatment gap with an emphasis on equity and inclusion.

Methods

Ethical Considerations

This study was approved as human participants research by the Institutional Review Board (IRB) of the Scripps Research Translational Institute (IRB-21‐7738). This study was conducted at the Scripps Research Translational Institute. All participants provided informed e-consent before participation. Deidentified data were transferred to the Scripps Research Translational Institute for analysis.

Study Design

This randomized waitlist-controlled trial evaluated the W-PPMA digital health tool. The trial consisted of 3 phases: screening/baseline, treatment, and follow-up. Participants were assessed at screening/baseline, day 3, week 4, week 8 (EOI), week 12, and week 16 (end of study [EOS]). The day 3 assessment was included to capture early usability and engagement signals, as well as to verify baseline stability immediately post randomization. All primary end points were evaluated at week 8 (EOI). A waitlist control design was selected to balance methodological rigor with ethical considerations. This approach allowed all participants eventual access to W-PPMA after the 8-week EOI assessment, thereby minimizing the risk of withholding potentially beneficial support from a vulnerable postpartum population. The design was reviewed and approved by the IRB as consistent with ethical standards for studies involving mental health interventions.

Recruitment Strategy

Pregnant and postpartum participants were recruited through the PowerMom baseline research study (Scripps Research Digital Trials Center), a mobile app-based research initiative hosted on the HIPAA (Health Insurance Portability and Accountability Act)–compliant MyDataHelps (CareEvolution, LLC) clinical research platform. PowerMom enables participants to access prenatal health resources while contributing pregnancy-related data to research. Recruitment for PowerMom was supported by a bilingual, multichannel campaign (eg, email, social media, and in-app nudges) involving PowerMom Consortium [30] partners from health and technology organizations, maternal advocacy groups, and community health centers. Key partners included Microsoft, Google/Fitbit, Philips, March of Dimes, and others, and community-based organizations serving Black and Hispanic/Latina populations. Recruitment campaigns outside of consortium partners also included Ovia Health (Labcorp) platform.

English-speaking PowerMom participants received information about the Woebot substudy through email and in-app notifications. Interested PowerMom participants who were in the postpartum period were directed to the Woebot eligibility screening, which included a disclaimer about the sensitive nature of some questions. Eligible participants provided informed consent for the Woebot substudy, and participation in the Woebot substudy did not affect their involvement in the PowerMom baseline study.

The recruitment period for the Woebot substudy was from February 2023 to January 2024. The initial goal was to recruit

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225 participants in each arm of this study. To promote inclusivity, recruitment aimed to enroll at least 30% of participants from underrepresented racial and ethnic groups and 50% from groups underrepresented in biomedical research (UBRs), as defined by the NIH (National Institutes of Health) All of Us Research Program [31]. UBR criteria included racial/ethnic minorities, low socioeconomic status, rural residency, and other categories. To achieve this distribution, the UBR criteria were built into the enrollment workflow in this study's app. This study's app was configured such that enrollment would be paused for any non-UBR participant until we had reached 225 enrolled and consented participants who self-identify from a UBR race or ethnicity or other UBR category. A study coordinator actively monitored enrollment numbers to ensure recruitment targets were being met.

However, the sponsor nominated to end enrollment early (after n=296 consented) given that the a priori goal of sample diversity (50% UBR) was successfully achieved early and also to advance time to results given the importance and relevance of the hypotheses tested herein. The original sample size target (n=450) was selected to provide approximately 80% power to detect a small-to-moderate effect size (Cohen $d \approx 0.30$) in change in depressive symptoms (Patient Health Questionnaire–8 [PHQ-8]) at $\alpha = .05$. Given early closure of enrollment, the final analytic sample (N=267) was underpowered for efficacy analyses, and these outcomes are presented as exploratory.

Inclusion and Exclusion Criteria

Eligible participants were PowerMom enrollees aged 16 years or older, less than 3 months postpartum, English-literate, smartphone users, and willing to engage with the program and assessments for 16 weeks.

Exclusion criteria included a lifetime diagnosis of psychotic or bipolar disorders, suicidal ideation or attempts within the past 12 months, substance use within the past 12 months, pregnancy loss in the past 18 months, or prior use of Woebot programs.

Procedures

Participation spanned 16 weeks, including an 8-week intervention or waitlist control period, followed by exploratory assessments at 12- and 16-weeks. After completing baseline assessments, participants were randomized 1:1 into the W-PPMA group or the waitlist control group. Neither participants nor staff were blinded to group assignments.

Participants randomized to W-PPMA accessed the app from randomization through 16 weeks (EOS) and were encouraged to use it daily, with a recommended minimum of 5 minutes per day during the treatment phase. Waitlist participants accessed W-PPMA starting at 8 weeks (EOI). Assessments were conducted via the PowerMom app at baseline, day 3, 4-week, 8-week (EOI), 12-week, and 16-week (EOS) time points. Each assessment took 10 - 15 minutes, and participants received reminders via email and PowerMom app push notifications.

Participants were eligible to receive up to US $175 in Amazon e-gift cards as compensation, prorated across completion of scheduled study assessments (eg, baseline, midintervention, EOI, and follow-up surveys). The compensation schedule was designed to acknowledge participant time burden across multiple assessments and to support retention over the 16-week study period while remaining modest to minimize undue inducement; the amount and structure were reviewed and approved by the IRB and were consistent across all participants to ensure fairness and transparency. Gift cards were distributed electronically after the completion of each assessment time point. During enrollment, fraudulent activity was detected, characterized by anomalous enrollment patterns (eg, implausibly rapid e-consent and survey completion times and duplicate IP addresses) and an unusual and rapid spike in enrollment across both the baseline study and the Woebot substudy. A small number of fraudulent accounts received e-gift card links before being identified. To ensure data integrity, all fraudulent enrollments were excluded before randomization, and participants who failed to complete baseline assessments were classified as screen failures and not included in this study. Only verified participants who met all eligibility criteria and completed baseline assessments were randomized. The final analytic sample (N=267) excluded all fraudulent accounts and therefore represents postpartum individuals meeting the intended inclusion criteria.

Intervention Groups

W-PPMA

W-PPMA is an investigational DMHI that offers an 8-week guided self-help program that combines CBT- and IPT-based techniques tailored to provide mental health support to postpartum women. Through a text-based interface, a relational agent named Woebot engages users in conversations and provides users with self-guided psychoeducation and mood and anxiety management strategies. The program includes daily push notifications to reengage users and encourage consistent participation. Neither W-PPMA nor Woebot have been evaluated, cleared, or approved by the Food and Drug Administration and are not available for general use.

Waitlist Control

Waitlist control participants had access to W-PPMA from the 8-week (EOI) through to the 16-week (EOS) period with similar usage recommendations.

Safety Considerations

W-PPMA followed safety recommendations from the American Psychiatric Association [32] and American Medical Association [33]. W-PPMA has a language detection protocol that is based on a natural language processing algorithm designed to detect if a user inputs, via free-response text entry, concerning phrases or words that match an a priori identified and thorough list that may be used in crises. Upon detection of any concerning language, the language detection protocol reminds the participant of the app's limitations of services—which are stated in the study's informed consent, the W-PPMA mobile app's privacy policy and terms of service, as well as the intervention's onboarding screens—and offers a resource list of readily accessible support channels, including emergency contact phone numbers and suicide ideation and domestic violence hotline information.

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Additionally, in the event that a participant endorses having current suicidal ideation or a plan when answering the screening questions, an automatic email would be sent to this study's team. Study personnel would then call 911, notify the operator that it is a psychiatric emergency, and provide a trained emergency response person with the participant's phone number to follow up with them. All participants were informed of these procedures in this study's consent form, which explicitly outlined the protocol for responding to safety concerns, including emergency escalation and study personnel involvement in crises.

Assessments

Baseline assessments collected demographic data, including age, race, ethnicity, gender identity, marital status, education, employment, and insurance status. Neighborhood socioeconomic disadvantage was assessed using the Area Deprivation Index (ADI) from the Neighborhood Atlas, which ranks census block groups nationwide by socioeconomic disadvantage, with higher scores indicating greater disadvantage. Pregnancy history included the number of prior pregnancies, outcomes, and any fetal demise within the exclusionary period. Psychiatric history assessed diagnosis of psychotic disorders, mood disorders, and suicidality within the past 12 months, and substance use during the same period. Current or prior use of psychiatric medications and therapy was also documented.

Primary Outcomes: Feasibility, Acceptability, and Satisfaction Measure

Regarding Usage Rating Profile–Intervention Revised (URP-IR) [34], the 6-item feasibility (Usage Rating Profile–Intervention Revised, Feasibility Subscale [URPI-F]) and 6-item acceptability (Usage Rating Profile–Intervention Revised, Acceptability Subscale [URPI-A]) subscales were used to measure feasibility (eg, "The total time required to do the treatment procedures was manageable") and acceptability (eg, "I liked the procedures used in this treatment"). Responses ranged from 1 ("strongly disagree") to 6 ("strongly agree"), with total scores ranging from 6 to 36 and higher average scores indicating greater feasibility or acceptability. The URP-IR demonstrates strong reliability, internal consistency, and discriminant validity [34].

Regarding Client Satisfaction Questionnaire (CSQ-8) [35], this widely used 8-item measure evaluated participants' satisfaction with W-PPMA on a 4-point scale (eg, "How would you rate the quality of service you received?"). Total scores ranged from 8 to 32, with higher scores indicating greater satisfaction.

Regarding app engagement, engagement with the W-PPMA app was assessed using quantitative metrics, including the number of active days, messages sent per week, and the number of content modules completed.

For interpretability, thresholds were applied to define high feasibility, acceptability, and satisfaction. On the URPI-F and URPI-A subscales (range 6 - 36), scores ≥30 were considered indicative of strong feasibility or acceptability. On the CSQ-8 (range 8 - 32), scores ≥25 were considered indicative of high satisfaction. These thresholds are consistent with prior applications of these validated instruments.

Secondary Outcome: Symptoms of Depression

The PHQ-8 is an 8-item measure evaluating depressive symptom severity over the past 2 weeks [36]. Scores range from 0 to 24, with cut points of 5, 10, 15, and 20 corresponding to mild, moderate, moderately severe, and severe depression, respectively [37,38]. The PHQ-8 is a reliable and valid tool for screening depressive symptoms [39].

Exploratory Outcomes

The Edinburgh Postnatal Depression Scale (EPDS) is a 10-item self-report tool that screens for postnatal depression [40]. For this study, the suicidality item was omitted; therefore, 9 items were administered and the total score ranged from 0 to 27, with higher scores indicating greater depressive symptom severity. The EPDS is widely validated for postpartum populations [41]. Both the PHQ-8 and EPDS were included to capture depressive symptoms: the PHQ-8 is widely validated for general populations and aligned with our primary depression outcome, while the EPDS is specific to perinatal populations and allows comparability with prior postpartum research.

Regarding Generalized Anxiety Disorder (GAD-7), the GAD-7 is a 7-item measure assessing anxiety symptoms over the past 2 weeks [42]. Scores range from 0 to 21, with cut points of 5, 10, and 15 indicating mild, moderate, and severe anxiety, respectively. This measure has demonstrated high reliability and validity [43].

Regarding Perceived Stress Scale–10, this 10-item scale measures perceived stress in the past month [44]. Responses range from 0 ("never") to 4 ("very often") and scores range between 0 and 40, with higher scores indicating greater perceived stress. The Perceived Stress Scale–10 demonstrates strong reliability and validity [45].

Regarding the Mother-to-Infant Bonding Scale (MIBS), the MIBS includes 8 one-word emotional descriptors (eg, "loving" or "resentful") rated on a 4-point scale from 0 ("very much") to 3 ("not at all"). Total scores range from 0 to 24, with lower scores indicating stronger mother-to-infant bonding [46,47].

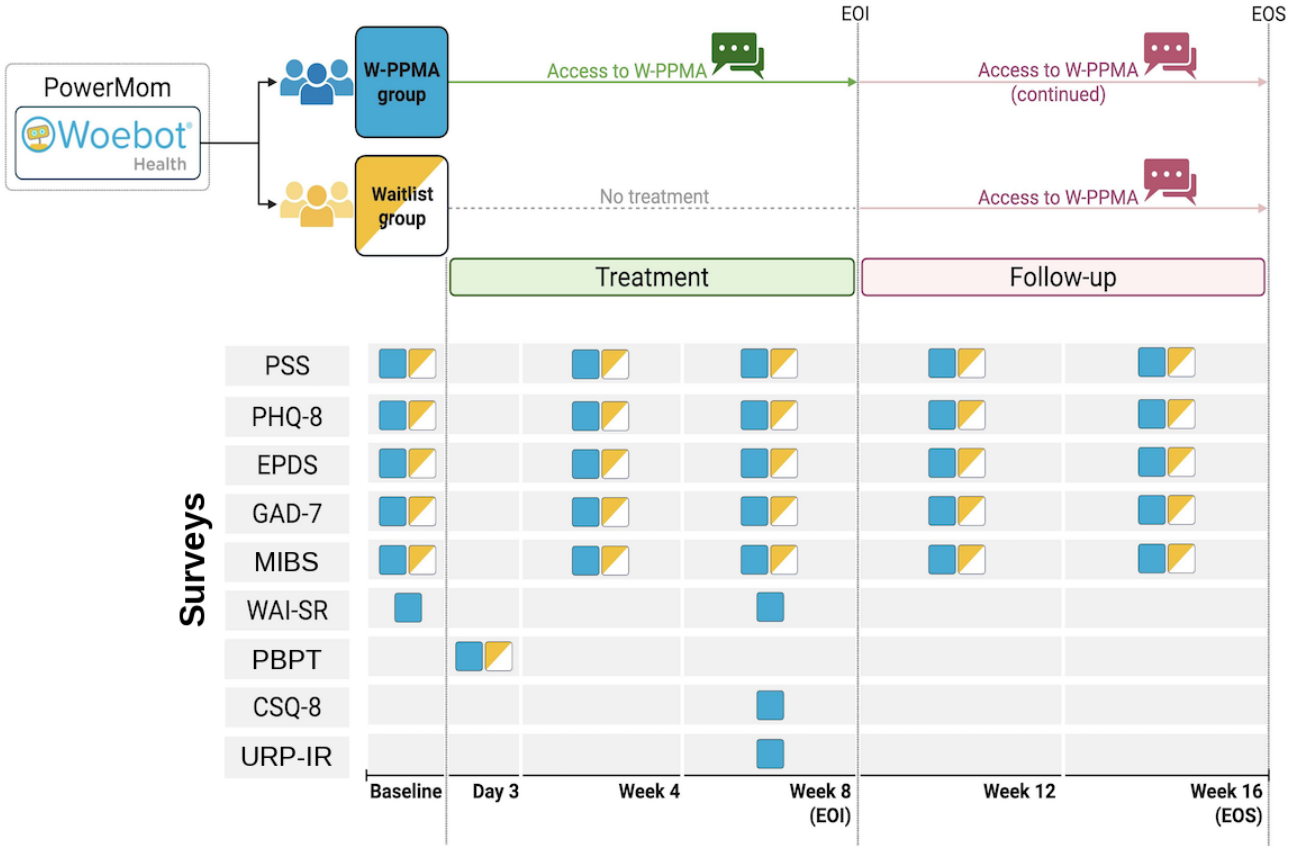
Regarding the Working Alliance Inventory–Short Revised (WAI-SR), the 12-item WAI-SR measures therapeutic alliance using 3 subscales: task agreement, goal agreement, and affective bond [48]. Items were adapted to refer to Woebot as the therapist. Responses range from 1 ("never") to 5 ("always"), with higher scores indicating a stronger therapeutic alliance.

Regarding Perceived Barriers to Psychological Treatment (PBPT), the PBPT [49] identifies potential barriers to engaging in mental health treatment. This study used the 7-item Stigma subscale (eg, "My concern about being judged makes it ____ for me to attend counseling"), with responses ranging from 1 ("not difficult at all") to 5 ("impossible").

Figure 1 presents the schedule of assessments by study group.

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Figure 1. Schedule of assessment. Time point where each outcome measure was administered and whether this was for all participants or only those in the W-PPMA group. Week 8 represents EOI, after which the waitlist control group additionally gained access to the Woebot app. CSQ-8: Client Satisfaction Questionnaire-8 items; EOI: end of intervention; EOS: end of study; EPDS: Edinburgh Postnatal Depression Scale; GAD-7: Generalized Anxiety Disorder Scale; MIBS: Mother-to-Infant Bonding Scale; PBPT: Perceived Barriers to Psychological Treatment, Stigma Subscale; PHQ-8: Patient Health Questionnaire–8; PSS: Perceived Stress Scale; URP-IR: Usage Rating Profile–Intervention Revised; W-PPMA: Woebot for Postpartum Mood and Anxiety; WAI-SR: Working Alliance Inventory–Short Revised.



Statistical Analysis

Primary analyses were conducted using an intention-to-treat strategy whereby participants were analyzed in the treatment group to which they were assigned. Per protocol (PP) sensitivity analyses were performed for the CSQ-8, URPI-A, URPI-F, PHQ-8, GAD-7, EPDS, Perceived Stress Scale (PSS), MIBS, and WAI-SR outcome measures. These sensitivity analyses excluded participants who deviated from the protocol in one or more of these ways: relevant measures not completed in full within the preplanned timing window, withdrew from this study, and, if in the W-PPMA group, did not open the app at least once per week for at least half of the intervention weeks. The latter criterion was based on previous research into app usage patterns.

Sample characteristics, including participant self-reported sociodemographic, psychiatric, and pregnancy history, and prior and concomitant medications and therapy characteristics, were described overall and by intention-to-treat study group.

The primary outcomes of feasibility, acceptability, and satisfaction were described for the W-PPMA study group at the 8-week time point (EOI).

The secondary outcome to assess the preliminary efficacy of W-PPMA relative to a waitlist control condition to manage symptoms of depression was analyzed among the subgroup of participants with PHQ-8 greater than or equal to 5 at baseline (minimal to several symptoms of depression). Mean 8-week change scores were calculated and compared using a 2-sided independent *t* test. Cohen *d* effect size was also calculated. Preplanned sensitivity analyses for this outcome included (1) PP sensitivity analysis as described above, (2) comparing 8-week scores instead of change scores, (3) multiple linear regression to adjust for potential residual confounding by baseline covariates (age, race, psychotherapy at baseline, mental health medication at baseline, previous PPD diagnosis, and previous depression diagnosis), and (4) describing scores by clinical categories. Bonferroni adjustment of *P* values was performed to account for the 4 statistical tests (primary and first 3 sensitivity) run on the PHQ-8 outcome.

The exploratory outcomes for preliminary assessment of mood and efficacy (PSS, EPDS, GAD-7, and MIBS) were summarized at each time point with Cohen *d* to assess group differences. Change scores from baseline to 8 weeks were additionally compared and summarized using the mean difference with 95% CI. Exploratory outcomes of therapeutic bond were summarized at baseline and 8-weeks.

Exploratory stratified analyses were performed to describe outcomes and the measure of perceptions of stigma by strata of age, Hispanic/Latina ethnicity, racial background, marital status, sexual orientation, employment status, education, health insurance, and neighborhood atlas. To maintain a high enough sample size for meaningful grouping, within each stratification

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some response options were grouped or removed. While grouping removes some important between-group differences, we opted to do this to be able to share some information rather than excluding minority groups altogether. Due to variability in circumstances related to being a student, we do not report student strata for employment and education analyses.

Missing Data

For the primary between-group comparison of treatment effect size (secondary outcome PHQ-8), we used multiple imputation to complete any missing PHQ-8 scores to minimize potential bias from missing data. Multiple imputation by chained equations was performed using the miceforest library (version 6.0.3) [50] with the default random forests predictive model. Covariates were the same as for the multiple regression analysis, with missing data in these additionally imputed as needed: study group, age, race, psychotherapy at baseline, mental health medication at baseline, previous PPD diagnosis, and previous depression diagnosis. For single-group and exploratory outcome analyses, where the analytical goals were more descriptive or preliminary, participants who did not complete a measure in full at any given time point were excluded from pertinent analyses. We report the number of participants included at each time point for each measure.

For descriptive analyses, measures were summarized by mean and SD or by median and IQR, whether normally distributed or not, respectively. Analyses were completed in Python (version 3.8).

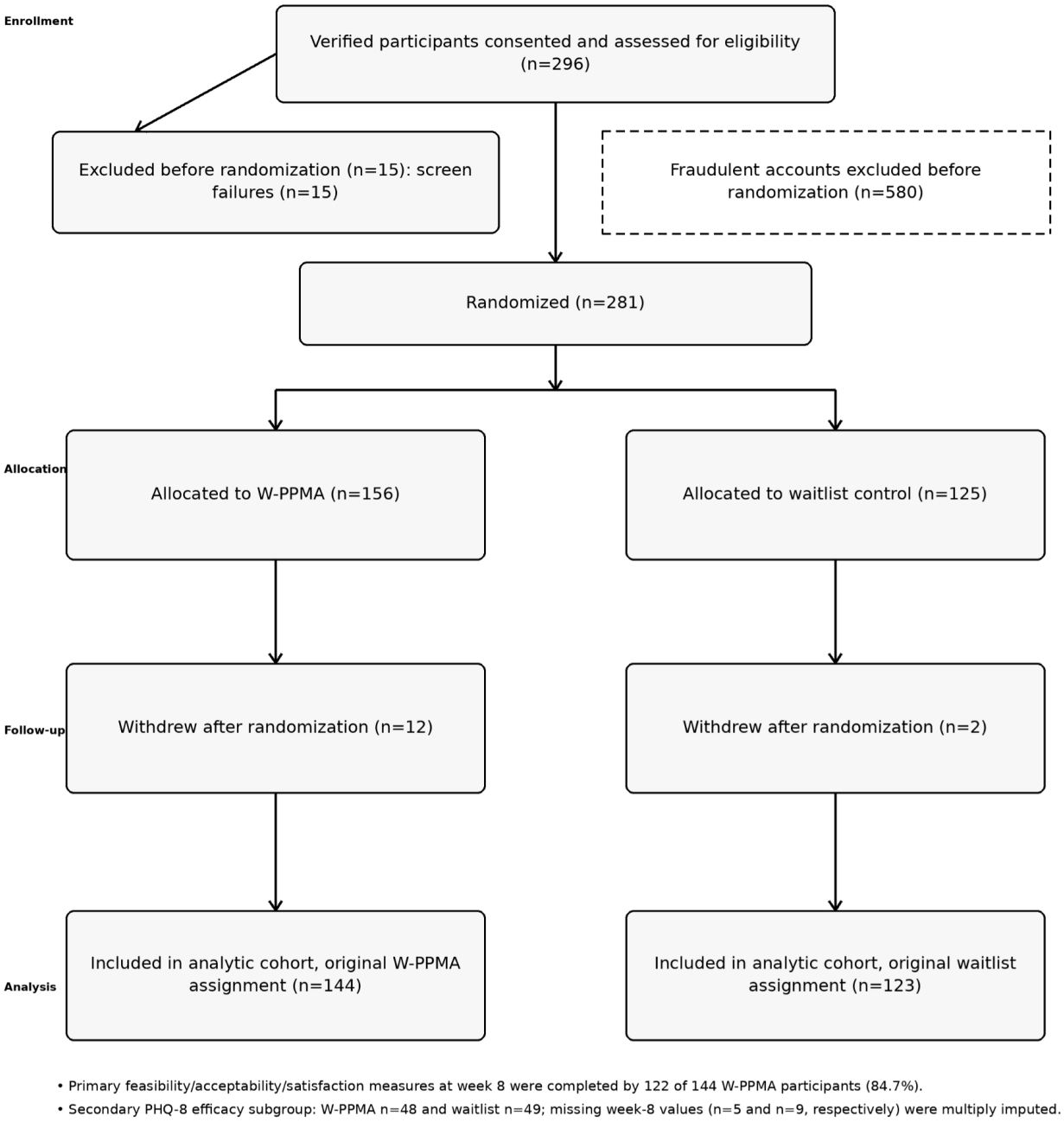
Results

Study Sample

Of 296 participants who consented, 15 (5.1%) were screen failures, and 14 (4.7%; W-PPMA: n=12, waitlist: n=2) withdrew from this study, leaving 267 participants (W-PPMA: n=144, waitlist: n=123) for analyses. There were an additional 580 fraudulent accounts detected and removed; these accounts were identified through study monitoring procedures (eg, anomalous completion times and duplicate IP addresses) and were excluded before randomization and from all analyses (Figure 2). Table 1 shows participant self-reported sociodemographic characteristics overall and by treatment group. Overall, the mean participant age was 32.2 (SD 5.1; range 16.3-48.7)years; all 267 participants identified as women, 34 (12.7%) identified as Hispanic/Latina, and 183 (68.5%) identified as White. After randomization, the W-PPMA and waitlist groups were similar on most characteristics, with notable exceptions that a greater proportion of the W-PPMA group was Hispanic/Latina (23/144, 16%, vs 11/123, 8.9%) and identified with multiple races (24/144, 16.7% vs 11/123, 8.9%) whereas the waitlist group had a higher proportion of White participants (90/123, 73.2%, vs 93/144, 64.6%), participants with a college degree (46/123, 37.4%, vs 39/144, 27.1%), and participants with an ADI ranking of at least 75 (14/123, 11.4% vs 7/144, 4.9%).

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Figure 2. CONSORT (Consolidated Standards of Reporting Trials) flow diagram for participant recruitment.



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Table . Sociodemographic characteristics of participants overall and by assigned treatment group. These self-reported survey data were collected at study baseline[a].

	Overall (N=267)	W-PPMA[b] (n=144)	Waitlist (n=123)
Age category (years), n (%)			
<35	190 (71.2)	103 (71.5)	87 (70.7)
≥35	76 (28.5)	40 (27.8)	36 (29.3)
Missing	1 (0.4)	1 (0.7)	0 (0.0)
Gender, n (%)			
Woman	267 (100.0)	144 (100.0)	123 (100.0)
Sex assigned at birth, n (%)			
Female	266 (99.6)	143 (99.3)	123 (100.0)
Missing	1 (0.4)	1 (0.7)	0 (0.0)
Hispanic/Latina, n (%)			
Yes	34 (12.7)	23 (16.0)	11 (8.9)
No	231 (86.5)	120 (83.3)	111 (90.2)
Missing	2 (0.7)	1 (0.7)	1 (0.8)
Racial background, n (%)			
Asian	8 (3.0)	5 (3.5)	3 (2.4)
Black/African American/African	23 (8.6)	11 (7.6)	12 (9.8)
Hispanic/Latina/Spanish[c]	15 (5.6)	11 (7.6)	4 (3.3)
White	183 (68.5)	93 (64.6)	90 (73.2)
Multiple	35 (13.1)	24 (16.7)	11 (8.9)
Missing	3 (1.1)	0 (0.0)	3 (2.4)
Marital status, n (%)			
Married/partnered/cohabitating	240 (89.9)	127 (88.2)	113 (91.9)
Divorced/separated	4 (1.5)	3 (2.1)	1 (0.8)
Single	22 (8.2)	13 (9.0)	9 (7.3)
Missing	1 (0.4)	1 (0.7)	0 (0.0)
Education, n (%)			
Graduate or postgraduate degree	107 (40.1)	60 (41.7)	47 (38.2)
College degree	85 (31.8)	39 (27.1)	46 (37.4)
Some college or technical school	50 (18.7)	27 (18.8)	23 (18.7)
High school graduate or General Educational Development degree	18 (6.7)	12 (8.3)	6 (4.9)
Some high school (grades 9 - 11)	6 (2.2)	5 (3.5)	1 (0.8)
Student	4 (1.5)	2 (1.4)	2 (1.6)
Missing	1 (0.4)	1 (0.7)	0 (0.0)
Sexual orientation, n (%)			
Straight or heterosexual	230 (86.1)	126 (87.5)	104 (84.6)
Bisexual	23 (8.6)	10 (6.9)	13 (10.6)
Lesbian or gay	3 (1.1)	2 (1.4)	1 (0.8)
Asexual	2 (0.7)	1 (0.7)	1 (0.8)
Pansexual	4 (1.5)	3 (2.1)	1 (0.8)
Demisexual	1 (0.4)	0 (0.0)	1 (0.8)

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	Overall (N=267)	W-PPMA[b] (n=144)	Waitlist (n=123)
Queer	2 (0.7)	0 (0.0)	2 (1.6)
Do not know	1 (0.4)	1 (0.7)	0 (0.0)
Missing	1 (0.4)	1 (0.7)	0 (0.0)
Employment status, n (%)			
Employed, full time	161 (60.3)	83 (57.6)	78 (63.4)
Employed, part time	23 (8.6)	12 (8.3)	11 (8.9)
Primary caretaker at home, not employed outside of the home	57 (21.3)	33 (22.9)	24 (19.5)
Not employed, looking for work	10 (3.7)	6 (4.2)	4 (3.3)
Not employed, not looking for work	9 (3.4)	6 (4.2)	3 (2.4)
On disability, not able to work	2 (0.7)	1 (0.7)	1 (0.8)
Student	4 (1.5)	2 (1.4)	2 (1.6)
Missing	1 (0.4)	1 (0.7)	0 (0.0)
Health insurance, n (%)			
Private insurance	188 (70.4)	101 (70.1)	87 (70.7)
Medicaid, medical assistance, or any kind of government assistance plan for those with low incomes or a disability	56 (21.0)	28 (19.4)	28 (22.8)
TRICARE or other military health care	12 (4.5)	7 (4.9)	5 (4.1)
Veterans Affairs (VA[d]; including those who have ever used or enrolled for VA health care)	1 (0.4)	1 (0.7)	0 (0.0)
Medicare for people 65 years and older, or people with certain disabilities	2 (0.7)	2 (1.4)	0 (0.0)
Do not have health insurance	5 (1.9)	2 (1.4)	3 (2.4)
Do not know	1 (0.4)	1 (0.7)	0 (0.0)
Missing	2 (0.7)	2 (1.4)	0 (0.0)
Level of access to maternity care, n (%)			
Moderate access to care/access to maternity care	245 (91.8)	133 (92.4)	112 (91.1)
Maternity care desert/low access to care	17 (6.4)	8 (5.6)	9 (7.3)
Missing	5 (1.9)	3 (2.1)	2 (1.6)
Neighborhood atlas, n (%)			
ADI_NATRANK[e]>=75	21 (7.9)	7 (4.9)	14 (11.4)
50≤ADI_NATRANK<75	82 (30.7)	42 (29.2)	40 (32.5)
25≤ADI_NATRANK<50	95 (35.6)	55 (38.2)	40 (32.5)
ADI_NATRANK<25	66 (24.7)	38 (26.4)	28 (22.8)

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	Overall (N=267)	W-PPMA[b] (n=144)	Waitlist (n=123)
Missing	3 (1.1)	2 (1.4)	1 (0.8)

[a]The one participant missing age value answered the screening questionnaire to confirm they were aged 16 years or older but did not provide their exact date of birth.

[b]W-PPMA: Woebot for Postpartum Mood and Anxiety.

[c]Indicates participants who self-identified their race as Hispanic/Latina in addition to their ethnicity as Hispanic/Latina.

[d]VA: Veterans Affairs.

[e]ADI_Natrank: Area Deprivation Index–National Rank; derived from the Neighborhood Atlas; higher scores indicate greater neighborhood disadvantage.

Table 2 shows psychiatric and pregnancy history. Overall, 31/267 (11.6%) participants self-reported a previous PPD diagnosis and 113/267 (42.3%) a previous depression diagnosis. At study baseline, 41/267 (15.4%) of participants reported engaging in psychotherapy and 67/267 (25.1%) taking a mental health medication. The number of past pregnancies ranged from 0 to over 5, and regarding participants' most recent pregnancy, 38/267 (14.2%) participants had their child spend time in the neonatal intensive care unit, and 22/267 (8.2%) participants reported receiving a medical and/or genetic disorder diagnosis.

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Table . Participant psychiatric and pregnancy history overall and by study group. These self-reported survey data were collected at this study's baseline.

	Overall (N=267)	W-PPMA[a] (n=144)	Waitlist (n=123)
Psychiatric history, n (%)			
Previous postpartum depression diagnosis			
Yes	31 (11.6)	18 (12.5)	13 (10.6)
No	234 (87.6)	125 (86.8)	109 (88.6)
Prefer not to answer	1 (0.4)	0 (0.0)	1 (0.8)
Missing	1 (0.4)	1 (0.7)	0 (0.0)
Previous depression diagnosis, n (%)			
Yes	113 (42.3)	58 (40.3)	55 (44.7)
No	152 (56.9)	84 (58.3)	68 (55.3)
Prefer not to answer	1 (0.4)	1 (0.7)	0 (0.0)
Missing	1 (0.4)	1 (0.7)	0 (0.0)
Prior and concomitant medications and therapy at baseline, n (%)			
Any treatment at connect study baseline	86 (32.2)	44 (30.6)	42 (34.1)
Psychotherapy			
Yes	41 (15.4)	24 (16.7)	17 (13.8)
No	221 (82.8)	118 (81.9)	103 (83.7)
Not sure	4 (1.5)	1 (0.7)	3 (2.4)
Missing	1 (0.4)	1 (0.7)	0 (0.0)
Mental health medication			
Yes	67 (25.1)	33 (22.9)	34 (27.6)
No	198 (74.2)	109 (75.7)	89 (72.4)
Missing	2 (0.7)	2 (1.4)	0 (0.0)
Connected to or attending activities at connect study baseline	94 (35.2)	51 (35.4)	43 (35.0)
Online support groups for moms	55 (20.6)	31 (21.5)	24 (19.5)
Mommy and me or similar gatherings	26 (9.7)	14 (9.7)	12 (9.8)
Online neighborhood groups (ie, Nextdoor)	15 (5.6)	7 (4.9)	8 (6.5)
Other activity	19 (7.1)	9 (6.2)	10 (8.1)
Missing	1 (0.4)	1 (0.7)	0 (0.0)
Follow-up visits scheduled during the next 8 weeks	251 (94.0)	130 (90.3)	121 (98.4)
OB/GYN[b]	206 (77.2)	105 (72.9)	101 (82.1)
Pediatrician	179 (67.0)	89 (61.8)	90 (73.2)
Primary care doctor	40 (15.0)	22 (15.3)	18 (14.6)
Psychiatrist, therapist, psychologist, or clinical social worker	53 (19.9)	31 (21.5)	22 (17.9)
Other provider	22 (8.2)	9 (6.2)	13 (10.6)
Missing	2 (0.7)	2 (1.4)	0 (0.0)
Pregnancy history, n (%)			
Number of previous pregnancies			

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	Overall (N=267)	W-PPMA[a] (n=144)	Waitlist (n=123)
0	7 (2.6)	4 (2.8)	3 (2.4)
1	116 (43.4)	66 (45.8)	50 (40.7)
2	70 (26.2)	32 (22.2)	38 (30.9)
3	38 (14.2)	21 (14.6)	17 (13.8)
4	17 (6.4)	8 (5.6)	9 (7.3)
5+	17 (6.4)	11 (7.6)	6 (4.9)
Missing	2 (0.7)	2 (1.4)	0 (0.0)
Number of term births			
0	5 (1.9)	3 (2.1)	2 (1.6)
1	142 (53.2)	74 (51.4)	68 (55.3)
2	72 (27.0)	39 (27.1)	33 (26.8)
3	25 (9.4)	14 (9.7)	11 (8.9)
4	9 (3.4)	5 (3.5)	4 (3.3)
5+	5 (1.9)	3 (2.1)	2 (1.6)
Not applicable	7 (2.6)	4 (2.8)	3 (2.4)
Missing	2 (0.7)	2 (1.4)	0 (0.0)
Number of premature births			
0	224 (83.9)	120 (83.3)	104 (84.6)
1	24 (9.0)	12 (8.3)	12 (9.8)
2	9 (3.4)	6 (4.2)	3 (2.4)
3	1 (0.4)	0 (0.0)	1 (0.8)
Not applicable	7 (2.6)	4 (2.8)	3 (2.4)
Missing	2 (0.7)	2 (1.4)	0 (0.0)
Number of miscarriages			
0	208 (77.9)	117 (81.2)	93 (75.6)
1	40 (15.0)	16 (11.1)	24 (19.5)
2	4 (1.5)	2 (1.4)	2 (1.6)
3	4 (1.5)	3 (2.1)	1 (0.8)
5+	2 (0.7)	2 (1.4)	0 (0.0)
Not applicable	7 (2.6)	4 (2.8)	3 (2.4)
Missing	2 (0.7)	2 (1.4)	0 (0.0)
Number of stillbirths			
0	257 (96.2)	137 (95.1)	120 (97.6)
1	1 (0.4)	1 (0.7)	0 (0.0)
Not applicable	7 (2.6)	4 (2.8)	3 (2.4)
Missing	2 (0.7)	2 (1.4)	0 (0.0)
Did your most recently born child spend time in the NICU[c]?			
Yes	38 (14.2)	20 (13.9)	18 (14.6)
No	222 (83.1)	119 (82.6)	103 (83.7)
Prefer not to answer	3 (1.1)	1 (0.7)	2 (1.6)
Missing	4 (1.5)	4 (2.8)	0 (0.0)
Has your most recently born child been diagnosed with any of the following?			

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	Overall (N=267)	W-PPMA[a] (n=144)	Waitlist (n=123)
No	241 (90.3)	132 (91.7)	109 (88.6)
Medical condition (eg, loss, heart condition, other birth defect)	8 (3.0)	5 (3.5)	3 (2.4)
Genetic disorder (eg, Down syndrome)	1 (0.4)	0 (0.0)	1 (0.8)
Medical and genetic conditions	1 (0.4)	0 (0.0)	1 (0.8)
Other	12 (4.5)	3 (2.1)	9 (7.3)
Missing	4 (1.5)	4 (2.8)	0 (0.0)

[a]W-PPMA: Woebot for Postpartum Mood and Anxiety.

[b]OB/gyn: obstetrician/gynecologist.

[c]NICU: neonatal intensive care unit.

Primary Outcomes: Feasibility, Acceptability, and Satisfaction

Table 3 shows app engagement metrics. Across the 8-week intervention, the median number of days that participants used W-PPMA was 9.0 (IQR 5.0-23.8) and 4.0 (IQR 2.0-7.0) active weeks. Participants sent a median of 217 (IQR 89-688) in-app messages and completed 6.0 (IQR 2.3-18.8) stories and 1.5 (IQR 1.0-3.0) tools.

Table . Woebot app engagement metrics**.** These are the primary outcome measures of app engagement among the W-PPMA[a] group for the initial 8-week treatment period. As the W-PPMA user experience is tailored entirely to the user's input, there is no a priori set number of stories and/or tools a user must complete; rather, each conversation with Woebot is adapted to the user in the moment with as-needed offering of stories and/or tools.

Engagement metric	Values, median (IQR)
Active days	9.0 (5.0-23.8)
Active weeks	4.0 (2.0-7.0)
Messages sent by user	217 (89-688)
Stories completed	6.0 (2.3-18.8)
Tools completed	1.5 (1.0-3.0)
Tools rated	1.0 (0.0-2.0)

[a]W-PPMA: Woebot for Postpartum Mood and Anxiety.

Of the intention-to-treat W-PPMA group, 122/144 (84.7%) completed the 8-week (EOI) measures for acceptability, feasibility, and satisfaction. The median score for URPI-F was 31.0 (IQR 28.0-34.0), for URPI-A was 30.0 (IQR 28.0-34.0), and for CSQ-8 was 26.0 (IQR 24.0-29.0). Score distributions are presented in Figure S1 in Multimedia Appendix 1. Slightly higher scores were seen in the PP sensitivity analysis that included 76/144 (52.8%) of the W-PPMA group, with median scores of 32.0 (IQR 29.0-36.0) for URPI-F, 31.5 (IQR 28.0-35.2) for URPI-A, and 27.0 (IQR 24.0-29.2) for CSQ-8.

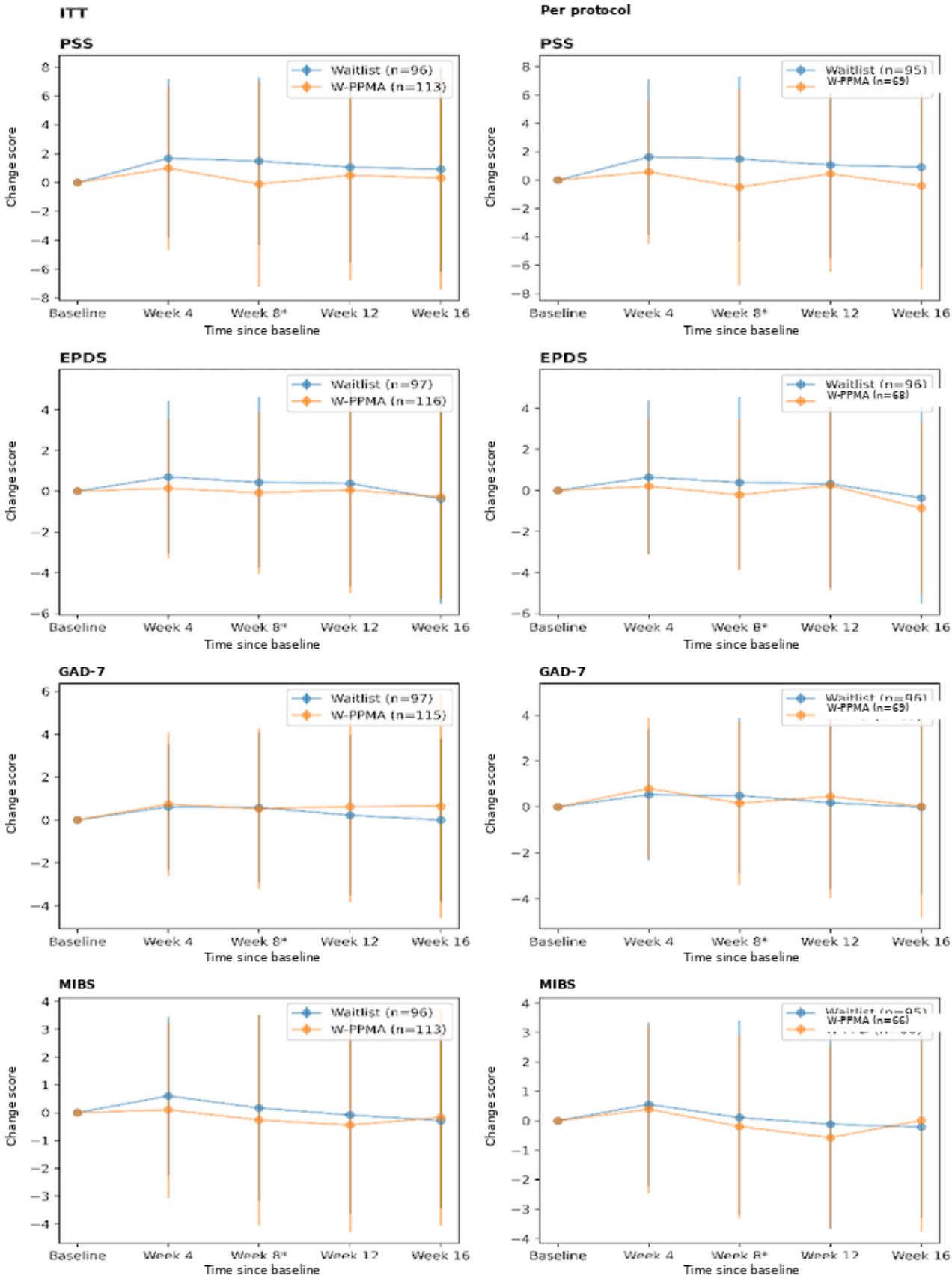
Secondary Outcome: Symptoms of Depression (PHQ-8)

There were 97 participants (n=48 W-PPMA, n=49 waitlist) with a baseline PHQ-8 score of at least 5, the minimal total score of the PHQ-8 indicating the presence of at least mild symptoms of depression. Multiple imputation was used to impute missing 8-week PHQ-8 scores for 14 participants (n=5 W-PPMA, n=9 waitlist). Overall mean change in PHQ-8 from baseline to EOI was −0.3 (SD 4.2), whereby W-PPMA averaged slight improvement (−0.7, SD 3.4) and the waitlist group averaged no change (0.0, SD 4.8). The between-group effect size was small (Cohen *d* −0.16) and not statistically significant after adjustment for multiple testing ($P \geq .99$). The PP sensitivity analysis showed a greater separation of groups (W-PPMA: −1.4, SD 3.5, waitlist: 0.7, SD 3.9, adjusted $P=.13$) with medium effect size (Cohen *d* −0.57). Figure 3 shows the distribution of change scores for the intention-to-treat and PP subgroups.

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Figure 3. Change scores for exploratory mood and preliminary efficacy measures. Mean and SD of change scores at each time point relative to the baseline overall and by treatment group. To support interpretation in the context of the established measures, scores are presented in the original units and should not be directly compared between scales, as a 1-point change represents a different percentage change across scale ranges (PSS: 0 - 40, EPDS: 0 - 27, GAD-7: 0 - 21, MIBS: 0 - 24). The asterisk indicates the 8-week end-of-intervention point after which the waitlist group gained access to the intervention. The number in each legend is the minimum number of participants included across all time points. EPDS: Edinburgh Postnatal Depression Scale; GAD-7: Generalized Anxiety Disorder Scale; ITT: intention-to-treat; MIBS: Mother-to-Infant Bonding Scale; PSS: Perceived Stress Scale; W-PPMA: Woebot for Postpartum Mood and Anxiety.

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Additional planned sensitivity analyses produced similar patterns, but neither analysis was statistically significant: the comparison of week-8 EOI scores had an adjusted *P* value of .38, and the adjusted regression analysis had an adjusted *P* value of .96. Comparison of the 8-week EOI scores alone showed lower average symptoms in the W-PPMA (mean 6.9, SD 3.4) than waitlist (8.4, SD 5.1) group (Cohen *d* −0.48, adjusted *P*=.38). Multiple regression analyses to adjust for potential

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residual confounding by baseline characteristics found access to W-PPMA was associated with a 1-point reduction in PHQ-8 change score as compared to the waitlist control group (95% CI −2.69 to 0.69, adjusted *P*=.96). All regression coefficients are presented in Table S1 in Multimedia Appendix 1. Examining PHQ-8 scores by clinical category showed similar distributions at baseline and descriptively lower severity in the W-PPMA group than in the waitlist group; no P value was reported for this descriptive comparison (Table S2 in Multimedia Appendix 1). Intention-to-treat results indicated that among those with elevated symptoms at baseline, 9/48 (18.8%) W-PPMA and 9/49 (18.4%) waitlist participants improved by at least 4 points. In the PP subgroup, 7 W-PPMA participants and 5 waitlist participants improved by at least 4 points.

Exploratory Outcomes: Postnatal Anxiety (GAD-7), Depression (EPDS), Stress (PSS), MIBS, and Therapeutic Bond (WAI-SR)

Preliminary mood and efficacy measures. Table 4 displays the median (IQR) scores with Cohen *d* between-group effect size for each exploratory outcome at each time point. The PSS and EPDS showed small between-group effect sizes in favor of W-PPMA at 4-, 8-, and 12-week points. By the 16-week EOS point, differences had mostly disappeared, driven by a reduction in waitlist scores, while the W-PPMA scores stayed relatively stable after 8-weeks; the waitlist group had access to the app from 8-weeks to 16-weeks while the W-PPMA group had access for the full 16-weeks. There were very small or no differences between W-PPMA and waitlist groups across all time points for the GAD-7 and MIBS. Participant counts by measure and time point are reported in Table S3 in Multimedia Appendix 1. In the PP sensitivity analyses, differences were not statistically significant but were descriptively larger than in the primary intention-to-treat analysis, with the largest effect observed for the PSS at EOI (Cohen *d*=−0.47; Table S4 in Multimedia Appendix 1). Figure 3 shows the change scores for each measure across this study's period. The mean difference from baseline to EOI was −1.59 (95% CI −2.4 to −0.73) for PSS, −0.51 (95% CI −1.36 to 0.34) for EPDS, −0.05 (95% CI −0.91 to 0.80) for GAD-7, and −0.43 (95% CI −1.28 to 0.42) for MIBS. For all measures except MIBS, the difference was larger in favor of W-PPMA in the PP sensitivity analyses (Table S4 legend in Multimedia Appendix 1)

Therapeutic Bond. The WAI-SR median score was 42.0 (IQR 36.0-51.0) at baseline among the 94/144 (65.3%) W-PPMA participants who completed it, and increased to 48.0 (IQR 41.0-53.0) at EOI among the 113/144 (78.5%) who completed it at the second time measure. PP sensitivity analysis scores were similar (baseline: 43.0, IQR 37.0-51.0, with n=54, week 8: 51.0, IQR 45.0-54.8, with n=70).

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Table . Exploratory measures of mood and efficacy at each study time point. Median (IQR) scores with Cohen *d* measure of effect size between W-PPMA[a] and waitlist groups for exploratory measures of mood and preliminary efficacy at each time point. Negative Cohen *d* represents lower scores in the W-PPMA group. The number of participants who completed each measure and are represented in the calculations is reported in Table S3 in Multimedia Appendix 1.

	Baseline	Week 4	Week 8	Week 12	Week 16
PSS[b] (range 0-40)					
Overall, median (IQR)	13.0 (8.8-20.0)	15.0 (9.0-21.0)	15.0 (8.0-20.0)	14.0 (8.5-20.5)	13.5 (8.0-20.8)
W-PPMA, median (IQR)	13.0 (8.0-19.0)	15.0 (8.0-20.0)	13.0 (8.0-19.5)	13.0 (7.0-20.0)	13.0 (8.0-20.0)
Waitlist, median (IQR)	14.0 (9.0-20.0)	16.0 (10.2-22.8)	16.0 (10.0-22.0)	15.0 (10.0-22.0)	15.0 (8.0-21.0)
Cohen *d*	−0.16	−0.25	−0.33	−0.23	−0.13
EPDS[c] (range 0-27)					
Overall, median (IQR)	5.0 (2.0-9.0)	5.0 (2.0-10.0)	5.0 (2.0-9.0)	5.0 (2.0-10.0)	4.0 (2.0-8.0)
W-PPMA, median (IQR)	5.0 (2.0-8.0)	4.0 (2.0-9.0)	4.0 (2.0-8.0)	4.0 (1.0-9.0)	4.0 (1.0-8.0)
Waitlist, median (IQR)	5.5 (2.0-10.0)	7.0 (3.0-11.0)	6.0 (2.2-10.0)	5.0 (2.0-11.0)	5.0 (2.0-8.0)
Cohen *d*	−0.16	−0.26	−0.22	−0.23	−0.10
GAD-7[d] (range 0-21)					
Overall, median (IQR)	4.0 (2.0-7.0)	5.0 (2.0-8.0)	5.0 (2.0-8.0)	5.0 (1.0-8.0)	4.0 (1.0-7.0)
W-PPMA, median (IQR)	4.0 (2.0-7.0)	5.0 (2.0-8.0)	4.0 (1.0-7.0)	4.0 (1.0-7.8)	4.0 (1.0-7.0)
Waitlist, median (IQR)	5.0 (3.0-7.0)	5.0 (3.0-8.0)	5.0 (2.0-8.0)	5.0 (2.0-8.0)	4.0 (1.0-7.0)
Cohen *d*	−0.18	−0.11	−0.14	−0.10	0.06
MIBS[e] (range 0-24)					
Overall, median (IQR)	3.0 (1.0-5.0)	3.0 (1.0-6.0)	3.0 (1.0-5.0)	2.0 (0.0-6.0)	2.0 (1.0-5.0)
W-PPMA, median (IQR)	3.0 (1.0-5.0)	3.0 (1.0-5.0)	2.5 (1.0-4.0)	2.0 (0.0-5.2)	2.0 (1.0-5.0)
Waitlist, median (IQR)	3.0 (1.0-5.0)	3.0 (1.0-6.0)	3.0 (1.0-6.0)	2.0 (0.0-6.0)	2.0 (0.0-5.0)
Cohen *d*	0.04	−0.14	−0.12	−0.08	0.08

[a]W-PPMA: Woebot for Postpartum Mood and Anxiety.

[b]PSS: Perceived Stress Scale.

[c]EPDS: Edinburgh Postnatal Depression Scale.

[d]GAD-7: Generalized Anxiety Disorder Scale.

[e]MIBS: Mother-to-Infant Bonding Scale.

Exploratory Analyses: Stratified Analyses

Perceptions of Stigma

The overall baseline PBPT-Stigma Subscale score median was 12.0 (IQR 9.0-15.0), similar in W-PPMA (12.0, IQR 9.0-14.0) and waitlist (11.0, IQR 10.0-15.0) groups at baseline. Variation across strata was within 2 points. The highest point estimate was among the racial background strata of Hispanic/Latina (14.0, IQR 13.8-15.2) and those who did not have health insurance (14.0, IQR 11.5-17.5). The lowest point estimates were among those employed part time (10.0, IQR 8.0-13.5) and with military health insurance (10.0, IQR 9.0-11.5; Table S5 in Multimedia Appendix 1).

Usability and Acceptability Measures

The median URPI-F score was similar across strata, with the lowest median scores being 2 points below the overall median among those not employed and with ADI ranking 75 and above,

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and 5 points lower than the overall median among those without health insurance. Two overall strata had median scores 2 points higher, including military health care insurance and those with high school or General Educational Development (GED) education. The URPI-A had a wider range of scores across strata, with a median score 6 points above the overall median among those single, separated, or divorced and 5 points higher among ADI ranking 75 and above; and a median 6 points below the overall median among those without health insurance. The CSQ-8 had the highest median score among those with a high school or GED education and lowest among those without health insurance. All stratified usability and acceptability measure scores, including by study subgroups, are in Table S6 in Multimedia Appendix 1.

Preliminary Mood and Efficacy Measures

The PSS baseline scores were highest among those who reported being Black, not employed, or not having health insurance. The EOI scores were highest among those who reported being Asian, Hispanic/Latina, or not employed (Table S7 in Multimedia Appendix 1). EPDS baseline scores were highest among those who reported being Black and without health insurance, with week 8 scores additionally highest among those who reported being Black or not employed (Table S8 in Multimedia Appendix 1). GAD-7 and MIBS median scores among the entire cohort were within 2 points across all strata (Tables S9 and S10, respectively, in Multimedia Appendix 1). WAI-SR scores were highest among Black participants, and ADI ranking of at least 75 strata at baseline and among those with military health insurance or ADI ranking of at least 75 at week 8 (Table S11 in Multimedia Appendix 1).

Discussion

Principal Results

In this study, we assessed the feasibility, acceptability, and preliminary efficacy of the W-PPMA intervention to provide emotional support among a diverse and bilingual cohort. The results demonstrated high feasibility and acceptability among participants, as evidenced by strong scores on the URP-IR and CSQ-8. The intervention achieved notable engagement, with participants using W-PPMA for a median of 9 (IQR 5 - 24) days and sending a median of 217 (IQR 89-688) messages across the 8-week intervention period.

The primary PHQ-8 outcome showed a small, nonsignificant effect in the intention-to-treat analysis (Cohen d=−0.16; P≥.99). Among exploratory outcomes at EOI, the between-group difference in PSS change favored W-PPMA and had a 95% CI that excluded 0 (mean difference −1.59, 95% CI −2.4 to −0.73), whereas the EPDS difference was not statistically significant (mean difference −0.51, 95% CI −1.36 to 0.34). Participants in the W-PPMA group had a statistically significant improvement in perceived stress relative to the waitlist control group at EOI; the between-group difference in EPDS scores was not statistically significant. PP analyses indicated moderate effect sizes, particularly for perceived stress, highlighting the potential of W-PPMA in reducing postpartum psychological distress. Therapeutic bonding with Woebot was also positively rated, suggesting the relational agent's ability to foster a supportive user experience.

Despite challenges in achieving the full recruitment target in a timely fashion, this study successfully enrolled a diverse cohort of postpartum individuals, ensuring representation of underrepresented racial, ethnic, and socioeconomic groups. Notably, W-PPMA demonstrated strong engagement across these diverse populations, reinforcing its promise as a scalable and inclusive intervention. The findings further support W-PPMA's potential to foster positive therapeutic engagement among groups historically underrepresented in digital health research. For example, working alliance (WAI-SR) scores were highest among Black participants and those residing in the most socioeconomically disadvantaged neighborhoods (ADI ≥75) at baseline. By week 8, Hispanic/Latina participants, those of multiple racial backgrounds, and those in areas with an ADI ranking of at least 75 demonstrated the highest WAI-SR scores, suggesting that W-PPMA effectively engaged these populations over time.

Additionally, participant satisfaction with W-PPMA was notably high among those with a high school or GED, as indicated by the CSQ-8 scores. This underscores W-PPMA's accessibility and acceptability among individuals who may have limited access to traditional mental health services. The intervention's ability to resonate across educational backgrounds, racial and ethnic identities, and socioeconomic strata highlights its potential as an equitable and scalable digital mental health tool.

The small effect estimates and largely nonsignificant differences should also be interpreted in the context of the study's early enrollment closure and resulting limited statistical power. However, the overall findings suggest that digital interventions such as W-PPMA hold promise for reducing postpartum psychological distress, particularly in populations with historically limited access to mental health care.

Comparison With Prior Work

Fitzpatrick et al [25] demonstrated that Woebot reduced anxiety and depression symptoms among young adults, and Prochaska et al [28,29] extended this work to substance use, reporting favorable usability and clinical outcomes. More recently, Suharwardy and Ramachandran [26,27] piloted Woebot in postpartum women, showing feasibility but in smaller, less diverse samples. Compared with these studies, our trial represents the largest randomized evaluation of Woebot in a postpartum cohort to date, and uniquely emphasized recruiting participants from underrepresented racial, ethnic, and socioeconomic groups. While the effect size for depressive symptoms was modest, it is consistent with early evaluations of DMHIs and underscores the importance of feasibility and acceptability outcomes as precursors to broader clinical impact. Our results extend the literature by demonstrating high engagement, satisfaction, and therapeutic alliance in a diverse postpartum population, highlighting W-PPMA's potential to address equity gaps in perinatal mental health care. It is also notable that guided digital interventions and telemedicine-delivered psychotherapy have generally shown stronger efficacy than unguided self-help programs [51,52]. Our modest effect sizes align with this broader pattern, while the

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high feasibility and acceptability of W-PPMA underscore its potential as a scalable, lower-intensity option that complements rather than replaces clinician-delivered care.

Limitations

Although our sample included greater representation of racial and ethnic minority participants than many prior digital psychotherapy and postpartum intervention trials, it nevertheless remained majority White, which may constrain generalizability. This distribution is consistent with national surveillance data showing that most postpartum samples in the United States are majority White [7] and reflects a common challenge across perinatal mental health intervention trials. Selection bias is also possible, as participants were drawn from individuals already enrolled in the PowerMom digital research platform and willing to engage in an app-based trial, which may overrepresent those who are more digitally literate or motivated to participate in research. Our study was initially designed with a larger recruitment target to support efficacy analyses; however, early closure of enrollment resulted in an underpowered sample for detecting small to moderate effect sizes. Accordingly, efficacy findings should be interpreted as exploratory, while the primary study objectives of feasibility, acceptability, and satisfaction remain adequately addressed. Despite efforts to recruit underrepresented racial and ethnic groups, challenges in reaching some populations persisted. Future studies should consider additional strategies to ensure greater representation, such as leveraging community partnerships and multilingual recruitment materials.

Second, while this study demonstrated high engagement, the intervention's duration (8 wk) may have been insufficient to capture the full impact of W-PPMA on all outcomes, particularly for participants with more severe baseline symptoms of depression. Additionally, reliance on self-reported measures introduces the potential for response bias, and app engagement metrics may not fully capture the depth or nuance of participants' interactions with the intervention.

Third, an unexpected challenge was fraudulent attempts to obtain participation incentives (e-gift cards). The relatively high level of participant compensation may have contributed to fraudulent enrollment attempts. The platform's automated system was exploited by 580 fraudulent enrollments, leading to a rapid spike in participation in both the baseline study and the Woebot substudy. These accounts were detected and excluded before randomization, ensuring that the final analytic sample comprised only verified participants who met eligibility criteria. A small number of fraudulent accounts received e-gift card links before detection. We implemented anomaly detection measures, including monitoring the time taken to complete e-consent and baseline surveys and flagging irregular enrollment patterns (eg, duplicate IP addresses). These measures successfully curtailed fraudulent activity. Future studies should incorporate automated fraud detection tools from the outset to prevent disruptions and ensure data integrity.

Fourth, the lack of blinding and the use of a waitlist control group, rather than an active comparator, may have influenced participants' responses. While ethical considerations guided this choice, future research should explore the efficacy of W-PPMA against active comparators to better contextualize its effectiveness.

Finally, attrition and missing data were challenges, particularly among participants with higher baseline depressive symptoms. Although imputation methods and sensitivity analyses were used to address this, results should be interpreted with caution.

Future Directions

Future work should prioritize adequately powered randomized controlled trials with active comparators to rigorously assess clinical efficacy. Longer follow-up periods beyond 16 weeks will be essential to evaluate the durability of intervention effects and their potential role in relapse prevention. In parallel, implementation studies are needed to explore how W-PPMA can be integrated into postpartum care pathways, including obstetric, pediatric, and primary care settings. Real-world deployment of W-PPMA could involve integration within obstetric, pediatric, or primary care settings, where it may serve as a first-line or adjunctive support tool. As the intervention is automated, per-user delivery costs are likely to be substantially lower than clinician-delivered psychotherapy, although formal cost-effectiveness evaluations are needed. Finally, equity considerations remain central. Although our recruitment strategy successfully engaged historically underrepresented populations, additional strategies are needed to address barriers such as technology access, digital literacy, and bilingual delivery. Ensuring equitable reach and sustained engagement will be critical to maximizing the impact of DMHIs such as W-PPMA on postpartum mental health.

Conclusions

This research demonstrates W-PPMA's feasibility, acceptability, and potential as a scalable digital support tool for postpartum mental health in a diverse population. High user engagement and satisfaction underscore the intervention's usability, while exploratory findings suggest benefits for depressive symptoms and perceived stress. Importantly, W-PPMA's accessibility and cultural adaptability highlight its promise in addressing systemic barriers to postpartum mental health care, including stigma, cost, and provider shortages.

Beyond individual outcomes, these results contribute to the growing evidence base for DMHIs, extending prior work by demonstrating engagement and therapeutic alliance in a large, diverse postpartum cohort. Collectively, our findings position W-PPMA as a promising equitable solution to bridge persistent gaps in perinatal mental health support.

Acknowledgments

This study was made possible through the support of the PowerMom research platform and its consortium partners. We extend our gratitude to the community-based organizations that assisted in recruitment efforts, particularly those serving Black and

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Hispanic/Latina populations. We also acknowledge the contributions of this study's participants, whose engagement and feedback have provided invaluable insights. From the Scripps Research team, we thank Shiri Warshawsky for her instrumental role in study operations and monitoring; Felipe Delgado, BS, for his contributions to custom development within MyDataHelps and preliminary data exports; and Giorgio Quer, PhD, and the Scripps Research data science team for setting up the initial coding necessary for this project. From the Woebot team, we would like to thank Stephanie Rapoport, MA, and Emily Durden, PhD, for their early contributions to drafting this study's protocol, Megan Flom, PhD, for quality control of the statistical analysis plan, and Stephanie Eaneff, MSP, for developing the code and extracting app usage data. Lastly, we thank the Institutional Review Board of the Scripps Research Translational Institute for their oversight and guidance in conducting this research.

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Data Availability

The datasets generated and analyzed during the PowerMom study are not publicly available due to privacy and confidentiality restrictions. This study collected sensitive health and demographic data from participants, which are deidentified but remain protected under Institutional Review Board protocols. Researchers who wish to access the data for legitimate academic purposes can submit a formal request to the corresponding author. Requests will be evaluated on a case-by-case basis to ensure compliance with ethical guidelines and data use agreements. The code used for data analysis is available upon request from the corresponding author.

Authors' Contributions

TA and AR were principal investigators for this study and led this paper's writing, review, and revisions. Two statisticians (JW and JK), employees of Scripps Research with no relationship to Woebot, were responsible for the analyses. LA and LB managed project operations, reviewed this paper, and participated in drafting sections. ER and KB-M contributed to study design and provided high-level review and edits of this paper. AW contributed to the initial statistical analysis plan and paper review. GM contributed to statistical analysis and reviewed and edited the manuscript.

Conflicts of Interest

AR, AW, and MA, are employed by Woebot Health. LB is a former employee of Woebot Health.

Multimedia Appendix 1
Outcome distributions, regression coefficients, data-completion counts, sensitivity analyses, and stratified analyses.
[DOCX File, 308 KB - pediatrics_v9i1e74083_app1.docx]

Checklist 1
CONSORT-eHealth Checklist.
[PDF File, 94 KB - pediatrics_v9i1e74083_app2.pdf]

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Abbreviations

ADI: Area Deprivation Index
CBT: cognitive behavioral therapy
CONSORT: Consolidated Standards of Reporting Trials
CSQ-8: Client Satisfaction Questionnaire–8 items
DMHI: digital mental health intervention
EOI: end of intervention
EOS: end of study
EPDS: Edinburgh Postnatal Depression Scale

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GAD-7: Generalized Anxiety Disorder–7 items
GED: General Educational Development
HIPAA: Health Insurance Portability and Accountability Act
IPT: interpersonal psychotherapy
IRB: Institutional Review Board
MIBS: Mother-to-Infant Bonding Scale
NIH: National Institutes of Health
PBPT: Perceived Barriers to Psychological Treatment
PHQ-8: Patient Health Questionnaire–8 items
PP: per protocol
PPD: postpartum depression
PSS: Perceived Stress Scale–10
UBR: underrepresented in biomedical research
URP-IR: Usage Rating Profile–Intervention Revised
URPI-A: Usage Rating Profile–Intervention Revised, Acceptability Subscale
URPI-F: Usage Rating Profile–Intervention Revised, Feasibility Subscale
W-PPMA: Woebot for Postpartum Mood and Anxiety
WAI-SR: Working Alliance Inventory–Short Revised

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The Association Between Prenatal Anxiety and Depression and Autism Spectrum Disorder With Gastrointestinal Symptoms in Children: Case-Control Study

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Abstract

Background: Studies have indicated that maternal anxiety and depression during pregnancy can contribute to neurodevelopmental disorders and gut flora dysbiosis in children. However, it is unclear whether these factors increase the risk of autism spectrum disorder (ASD) with gastrointestinal (GI) symptoms in children.

Objective: This study aimed to analyze the relationship between maternal anxiety and depression during pregnancy and ASD with GI symptoms.

Methods: A total of 470 children with ASD and 486 children with typical development were enrolled in the study. The caregivers of all enrolled children completed questionnaires, including information on maternal mental health and GI symptoms.

Results: The percentage of maternal prenatal anxiety or depression was significantly higher in the ASD group than in the typical development group (P<.001). Children whose mothers experienced anxiety or depression during pregnancy had substantially higher risk of developing ASD than those whose mothers did not experience these conditions (unadjusted odds ratio [OR] 4.274, 95% CI 2.799-6.526; adjusted OR 3.897, 95% CI 2.481-6.119). For children with ASD, those whose mothers had prenatal anxiety or depression had a significantly higher risk of GI symptoms than those whose mothers did not have these conditions (unadjusted OR 1.883, 95% CI 1.209-2.934; adjusted OR 1.943, 95% CI 1.236-3.054).

Conclusions: Mothers who experience anxiety or depression during pregnancy may have a higher likelihood of their children developing ASD with GI symptoms.

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KEYWORDS

autism spectrum disorder; gastrointestinal symptoms; comorbidity; risk factor; prenatal

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that has an early onset and significantly affects children's health. The common core symptoms of ASD are impaired social skills and communication and restricted or repetitive behaviors [1]. The etiology and pathogenesis of ASD are still not well understood. It is currently accepted that both genetic and environmental factors play key roles in the development of ASD [1]. Environmental conditions during early life, such as exposures during maternal pregnancy, may impact the neurodevelopment of children and increase the risk of ASD.

The manifestations of ASD are highly heterogeneous. In addition to the core symptoms, there are often comorbidities such as sleep disorders, attention-deficit/hyperactivity disorder, and gastrointestinal (GI) symptoms [2]. The etiology of ASD is also complex and cannot be explained by a single factor. Thus, certain causes may contribute to both core symptoms and comorbidities of ASD. GI symptoms are a common comorbidity of ASD, and quite a number of studies have shown that the prevalence of GI symptoms in children with ASD is much higher than in children with typical development [3]. As such, some factors may affect both early neurodevelopment and GI function, potentially leading to the development of ASD and GI symptoms.

The prenatal period is crucial for the neurodevelopment of children, and various environmental factors can greatly influence this development [4,5]. One important environmental factor is the mother's mental health status during pregnancy. Due to hormonal changes and other factors, some pregnant women who have no history of mental illness may develop psychological disorders, and thus, there is a relatively high prevalence of anxiety and depression during pregnancy [6,7]. Studies have demonstrated that maternal prenatal anxiety and

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depression can affect the neurodevelopment of children and may be associated with neurodevelopmental disorders such as attention-deficit/hyperactivity disorder and cognitive disorders [8-10]. In addition, some studies have reported associations between maternal prenatal anxiety and depression and ASD in children. For instance, a large cohort study found that prenatal depression was associated with increased ASD-related traits in children [11]. Similarly, a meta-analysis reported an increased risk of ASD in children whose mothers experienced depressive disorders [12]. Another recent systematic review and meta-analysis demonstrated that maternal prenatal mood and anxiety disorders were associated with a significantly increased risk of ASD in children [13]. Pregnancy is also a critical period for the development of the enteric nervous system (ENS), and maternal anxiety and depression during this time have been found to alter the intestinal microbiota of children [14]. We speculate that maternal prenatal anxiety and depression may be linked to ASD and comorbid GI symptoms in children by simultaneously affecting the development of both the central nervous system and the ENS or by influencing children's gut microbiota and thereby affecting the development of both the brain and the gut via the gut-brain axis. Nevertheless, the relationship between prenatal anxiety and depression and GI symptoms in children is unclear, and the relationship between maternal anxiety and depression during pregnancy and ASD with GI symptoms has not been reported. Maternal anxiety and depression during pregnancy are mostly mild to moderate [15], but these symptoms may not be fully recognized and treated, partly because pharmacological interventions during pregnancy require particular caution and nonpharmacological interventions are not always readily available [16]. The purpose of this study was to analyze the relationship between mild and moderate maternal prenatal anxiety or depression and ASD in children, as well as the potential link between these conditions and ASD with GI symptoms.

Methods

Participants

A total of 470 children with ASD aged 2 to 7 years who visited the child psychobehavioral clinic of our hospital from July 2022 to June 2024 were recruited. The child psychobehavioral clinic is a specialized outpatient clinic within an affiliated hospital of a medical college primarily responsible for the diagnosis and treatment of developmental and behavioral disorders. Recruitment was conducted systematically: all children who visited the clinic with suspected or previously diagnosed ASD were screened for eligibility by the attending clinician. Then, a research coordinator contacted eligible families and explained the study purpose, procedures, and confidentiality protections. Families who agreed to participate were then scheduled for a comprehensive evaluation. The diagnosis of ASD was confirmed by 2 developmental-behavioral pediatricians based on the diagnostic criteria defined in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* [17], after a series of structured interviews and in combination with the results of the Childhood Autism Rating Scale (CARS) assessment. The CARS is a widely used standardized assessment scale for ASD symptoms, and individuals with a total CARS score of 30 or higher are considered to have ASD characteristics [18]. The exclusion criteria were history of developmental disabilities other than ASD or neurological disorders (children with ASD and co-occurring developmental disabilities were not excluded), severe physical or sensory impairment, no medical records of maternal mental health during pregnancy, history of maternal prepregnancy mental illness or paternal mental illness, physician-advised antidepressants or use of other medications (eg, antipsychotics, mood stabilizers, or anxiolytics) or substances (eg, alcohol, tobacco, or illicit drugs) during maternal pregnancy, and unwillingness to participate. Of the 522 initially screened children with ASD, 52 (10%) were excluded: 29 (5.6%) due to meeting the exclusion criteria and 23 (4.4%) due to parental refusal, resulting in a final sample size of 470 (90%). There were no missing data for the primary variables in the ASD group.

During the same period, 486 children with typical development were recruited from the child health clinic of the same hospital. They were frequency matched to the ASD group by sex and age. This clinic provides regular monitoring and guidance on the growth and development of children. Recruitment was conducted systematically: researchers approached families of children aged 2 to 7 years who attended the clinic for routine health checkups. After obtaining verbal consent, the researchers screened the children to ensure they met the inclusion criteria. Families who met the criteria were then invited to participate. The exclusion criteria were history of developmental disabilities or neurological disorders, severe physical or sensory impairment, no medical records of maternal mental health during pregnancy, history of maternal prepregnancy mental illness or paternal mental illness, physician-advised antidepressants or use of other medications (eg, antipsychotics, mood stabilizers, or anxiolytics) or substances (eg, alcohol, tobacco, or illicit drugs) during maternal pregnancy, and unwillingness to participate. Of the 532 children with typical development initially screened, 46 (8.6%) were excluded: 17 (3.2%) due to meeting the exclusion criteria and 29 (5.5%) due to parental refusal, resulting in a final sample size of 486 (91.4%). All enrolled participants with typical development completed the assessments, and there were no missing data for core variables in this group.

Ethical Considerations

The study protocol was approved by the ethics committee of the Affiliated Hospital of North Sichuan Medical College (2022ER268-1). Informed consent was obtained from the parents of all participants.

Questionnaires

Caregivers of all enrolled children, both those with ASD and those with typical development, completed questionnaires under the guidance of trained investigators, including questionnaires on general demographic information, maternal mental health during pregnancy, and GI symptoms. Prenatal anxiety or depression was determined based on 2 sources: scores on the Edinburgh Postnatal Depression Scale (cutoff of 10 or higher for depression) [19] and scores on the Self-Rating Anxiety Scale (cutoff of 50 or higher for anxiety) [20,21] completed during pregnancy, as well as medical records indicating clinical diagnoses of anxiety or depression by pregnancy care physicians.

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Only mothers who scored above the cutoff on the relevant scale and had a documented medical diagnosis were classified as having prenatal anxiety or depression. The GI symptom questions related to constipation, diarrhea, abdominal pain, flatulence, and nausea and vomiting were all based on the Questionnaire of Pediatric Gastrointestinal Symptoms–Rome IV (QPGS-IV), a validated tool for diagnosing functional GI disorders in infants and children [22]. The QPGS-IV defines a "GI symptom" as meeting specific frequency and duration thresholds (eg, diarrhea requires ≥4 loose stools per day for at least 1 month). As stool odor is not clearly defined in the QPGS-IV, it was defined as abnormal odor of the stool, such as rotten egg smell in this study [23]. A child was classified as screening positive for GI symptoms if at least 1 of the 6 GI symptoms was positive.

Covariates

The covariates we considered were age, sex, maternal educational level, paternal educational level, age of the mother at conception, mode of delivery, preterm birth, place of residence, and annual household income. Among these, maternal educational level, paternal educational level, mode of delivery, place of residence, and annual household income were significantly different between the ASD and typical development groups. Age, sex, and covariates that were significantly different between the ASD and typical development groups were all included in the logistic regression model.

Statistical Analyses

The data analysis was conducted using the SPSS statistical software (version 25; IBM Corp). Before analysis, the distribution of each dataset was tested for normality using the Kolmogorov-Smirnov goodness-of-fit test. The nonnormally distributed continuous variables were described using medians and IQRs, and differences between groups were assessed using the Mann-Whitney *U* test. Categorical variables were described as frequencies and percentages, and differences between groups were assessed using the chi-square test. Binary logistic regression was used to evaluate the relationship between prenatal anxiety or depression and the risk of ASD in children, as well as the link between prenatal anxiety or depression and the risk of GI symptoms in children with ASD.

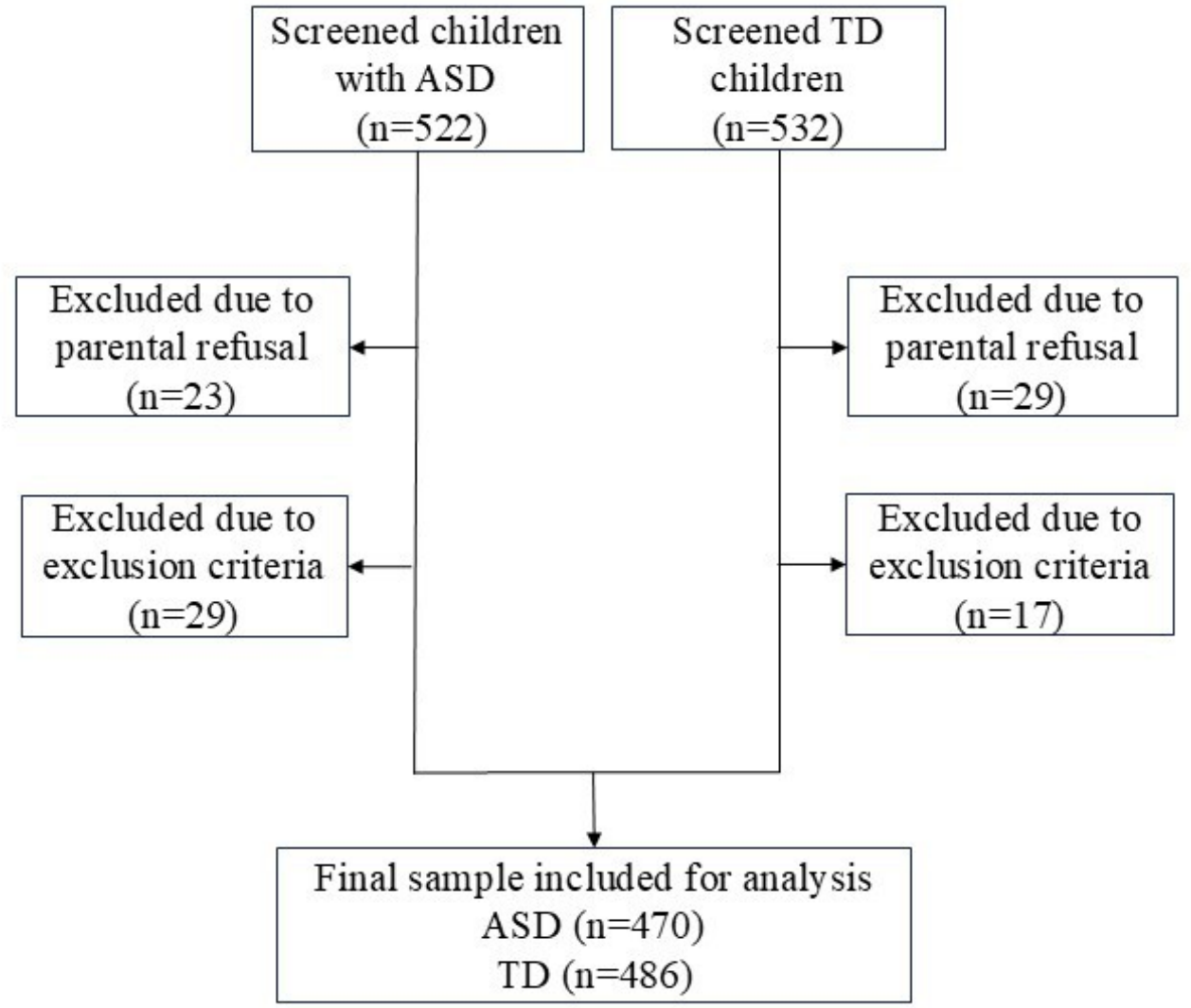
Results

Characteristics of the Participants in the Typical Development and ASD Groups

The present study included 470 children with ASD (388 male and 82 female) and 486 children with typical development (388 male and 98 female; Figure 1). The median age of the ASD group was 4.0 (IQR 3.2-4.9) years, and that of the typical development group was 4.3 (IQR 3.1-5.3) years. There were no significant differences in sex ratio or age distribution between the 2 groups. As shown in Table 1, there were significant differences between the 2 groups in terms of both the maternal and paternal educational levels ($P<.001$), with increased proportions of both mothers and fathers with lower educational levels and decreased proportions of those with higher educational levels in the ASD group compared to the typical development group. There were no significant differences in the age of mothers at conception ($P=.70$) or the proportion of preterm births ($P=.40$) between the 2 groups. However, the proportion of vaginal delivery was significantly lower, and the proportion that lived in urban areas was also significantly lower in the ASD group than in the typical development group ($P<.01$). The annual household income was significantly different between the 2 groups ($P<.001$). In the ASD group, the proportion of those with an income below CN¥ 50,000 (CN¥ 1=US $0.15 as of October 15, 2026) was higher, while that of those with an income above CN¥ 100,000 was significantly lower.

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Figure 1. Flowchart of participant recruitment. ASD: autism spectrum disorder; TD: typical development.



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Table . Characteristics of the participants in the typical development (TD) and autism spectrum disorder (ASD) groups.

Variables	TD (n=486)	ASD (n=470)	*z* or chi-square (*df*)	*P* value
Age (y), median (IQR)	4.3 (3.1-5.3)	4.0 (3.2-4.9)	–1.507[a]	.13
Sex, n (%)			1.2 (1)[b]	.28
Male	388 (79.8)	388 (82.6)		
Female	98 (20.2)	82 (17.4)		
Maternal educational level, n (%)			68.8 (2)[b]	<.001
Primary school or lower	1 (0.2)	11 (2.3)		
Secondary school	109 (22.4)	213 (45.3)		
College or higher	376 (77.4)	246 (52.3)		
Paternal educational level, n (%)			46.3 (2)[b]	<.001
Primary school or lower	1 (0.2)	12 (2.6)		
Secondary school	113 (23.3)	191 (40.6)		
College or higher	372 (76.5)	267 (56.8)		
Age of mother at conception (y), n (%)			0.2 (1)[b]	.70
<35	443 (91.2)	425 (90.4)		
≥35	43 (8.8)	45 (9.6)		
Mode of delivery, n (%)			9.2 (1)[b]	.002
Vaginal	270 (55.6)	215 (45.7)		
Cesarean	216 (44.4)	255 (54.3)		
Preterm birth, n (%)			0.7 (1)[b]	.40
Yes	59 (12.1)	49 (10.4)		
No	427 (87.9)	421 (89.6)		
Place of residence, n (%)			44.2 (1)[b]	<.001
Urban	448 (92.2)	360 (76.6)		
Rural	38 (7.8)	110 (23.4)		
Annual household income (CN¥; CN¥ 1=US $0.15 as of October 15, 2026), n (%)			121.7 (2)[b]	<.001
<50,000	121 (24.9)	236 (50.2)		
50,000-100,000	110 (22.6)	145 (30.9)		
>100,000	255 (52.5)	89 (18.9)		
Prenatal anxiety or depression, n (%)			50.9 (1)[b]	<.001
Yes	31 (6.4)	106 (22.6)		
No	455 (93.6)	364 (77.4)		
GI[c] symptoms, n (%)			56.7 (1)[b]	<.001
Yes	129 (26.5)	236 (50.2)		
No	357 (73.5)	234 (49.8)		

[a]*z* statistic.

[b]chi-square statistic.

[c]GI: gastrointestinal.

In the ASD group, 22.6% (106/470) of the individuals had maternal prenatal anxiety or depression, while only 6.4% (31/486) in the typical development group did. The percentage of maternal prenatal anxiety or depression was significantly higher in the ASD group than in the typical development group (*P*<.001).

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In addition, 50.2% (236/470) of the children in the ASD group had GI symptoms compared with 26.5% (129/486) in the typical development group. The GI symptoms were significantly higher in the ASD group than in the typical development group (*P*<.001).

Associations Between Maternal Prenatal Anxiety or Depression and the Risk of ASD in Children

To examine the potential link between maternal prenatal anxiety or depression and ASD in children, we conducted logistic regression analysis. The results, shown in Table 2, indicate that in univariate logistic regression, prenatal anxiety or depression (odds ratio [OR] 4.274, 95% CI 2.799-6.526), lower maternal educational level (secondary school: OR 2.987, 95% CI 2.255-3.957; primary school or lower: OR 16.813, 95% CI 2.157-131.049), lower paternal educational level (secondary school: OR 2.355, 95% CI 1.779-3.118; primary school or lower: OR 16.719, 95% CI 2.161-129.360), nonvaginal delivery (OR 1.483, 95% CI 1.149-1.913), and nonurban residence (OR 3.560, 95% CI 2.400-5.281) were all associated with an increased risk of ASD, while higher household income (CN¥ 50,000-100,000: OR 0.676, 95% CI 0.485-0.941; >CN¥ 100,000: OR 0.179, 95% CI 0.129-0.248) was linked to a reduced risk of ASD. To assess independent effects, we included all significant variables along with age and sex into a multivariable logistic regression model. The results showed that maternal prenatal anxiety or depression remained a significant risk factor for ASD (adjusted OR 3.897, 95% CI 2.481-6.119). Among the other variables, maternal educational level (secondary school vs college or higher: adjusted OR 1.865, 95% CI 1.232-2.823), delivery mode (adjusted OR 1.387, 95% CI 1.042-1.845), residence (adjusted OR 2.076, 95% CI 1.326-3.252), and household income (>CN¥ 100,000 vs <CN¥ 50,000: adjusted OR 0.252, 95% CI 0.176-0.362) also remained significant but with smaller effect sizes than prenatal anxiety or depression. Paternal educational level was no longer significant (*P*>.05).

Table . Univariate and multivariate logistic regression analysis of factors potentially associated with autism spectrum disorder.

Variables	Univariate		Multivariate	
	OR[a] (95% CI)	*P* value	OR (95% CI)	*P* value
Age (y)	0.926 (0.836-1.027)	.15	0.863 (0.767-0.970)	.01
Sex				
Female	1 (reference)	—[b]	1 (reference)	—
Male	1.195 (0.863-1.655)	.28	1.169 (0.810-1.687)	.41
Maternal educational level				
College or higher	1 (reference)	—	1 (reference)	—
Secondary school	2.987 (2.255-3.957)	<.001	1.865 (1.232-2.823)	.003
Primary school or lower	16.813 (2.157-131.049)	.007	3.921 (0.374-41.073)	.25
Paternal educational level				
College or higher	1 (reference)	—	1 (reference)	—
Secondary school	2.355 (1.779-3.118)	<.001	0.865 (0.569-1.316)	.50
Primary school or lower	16.719 (2.161-129.360)	.007	4.505 (0.437-46.415)	.21
Mode of delivery				
Vaginal	1 (reference)	—	1 (reference)	—
Cesarean	1.483 (1.149-1.913)	.002	1.387 (1.042-1.845)	.02
Place of residence				
Urban	1 (reference)	—	1 (reference)	—
Rural	3.560 (2.400-5.281)	<.001	2.076 (1.326-3.252)	.001
Annual household income (CN¥; CN¥ 1=US $0.15 as of October 15, 2026)				
<50,000	1 (reference)	—	1 (reference)	—
50,000-100,000	0.676 (0.485-0.941)	.02	0.804 (0.565-1.146)	.23
>100,000	0.179 (0.129-0.248)	<.001	0.252 (0.176-0.362)	<.001
Prenatal anxiety or depression				
No	1 (reference)	—	1 (reference)	—
Yes	4.274 (2.799-6.526)	<.001	3.897 (2.481-6.119)	<.001

[a]OR: odds ratio.

[b]Not applicable.

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Comparison of GI Symptoms and Their Association With Maternal Prenatal Anxiety or Depression in Children With ASD

We compared the GI symptoms in children with ASD whose mothers had and did not have prenatal anxiety and depression. As shown in Table 3, a total of 62.3% (66/106) of children with ASD whose mothers had prenatal anxiety or depression exhibited at least one GI symptom, while 46.7% (170/364) of children with ASD whose mothers did not have prenatal anxiety and depression exhibited GI symptoms. Our analysis revealed that children with ASD whose mothers had prenatal anxiety or depression had a significantly higher proportion of GI symptoms than those whose mothers did not have prenatal anxiety and depression (P<.01). Specifically, the rates of constipation and abdominal pain were significantly higher in children with ASD whose mothers had anxiety or depression during pregnancy (P<.01). However, there was no significant difference in the prevalence of diarrhea, nausea and vomiting, flatulence, and stool odor between the 2 groups (P>.05).

Table . Comparison of gastrointestinal (GI) symptoms between children with autism spectrum disorder (ASD) whose mothers had and did not have prenatal anxiety and depression.

Symptoms	ASD without prenatal anxiety or depression (n=364), n (%)	ASD with prenatal anxiety or depression (n=106), n (%)	Chi-square (*df*)	*P* value
Constipation	105 (28.8)	47 (44.3)	9.0 (1)	.003
Diarrhea	25 (6.9)	10 (9.4)	0.8 (1)	.38
Abdominal pain	43 (11.8)	25 (23.6)	9.2 (1)	.002
Nausea or vomit	24 (6.6)	9 (8.5)	0.5 (1)	.50
Flatulence	18 (4.9)	10 (9.4)	3.0 (1)	.09
Stool odor	36 (9.9)	14 (13.2)	1.0 (1)	.33
Total GI symptoms	170 (46.7)	66 (62.3)	8.0 (1)	.005

We further assessed the relationship between maternal prenatal anxiety or depression and the risk of GI symptoms in children with ASD. Our findings, as shown in Table 4, indicate that children with ASD whose mothers experienced anxiety or depression during pregnancy had a significantly higher risk of total GI symptoms than children whose mothers did not have these conditions (OR 1.883, 95% CI 1.209-2.934). This trend remained consistent even after adjusting for age, sex, maternal educational level, paternal educational level, mode of delivery, place of residence, and annual household income (adjusted OR 1.943, 95% CI 1.236-3.054). Specifically, the risk of constipation and abdominal pain was significantly higher in children with ASD whose mothers had prenatal anxiety or depression than in those whose mothers did not have these conditions (OR 1.965, 95% CI 1.259-3.067 and OR 2.304, 95% CI 1.329-3.993, respectively). These results were still evident after adjusting for covariates (adjusted OR 2.083, 95% CI 1.315-3.299 and adjusted OR 2.302, 95% CI 1.305-4.062, respectively). However, there was no significant increase in the risk of diarrhea, nausea and vomiting, flatulence, or stool odor in children with ASD whose mothers had prenatal anxiety or depression compared to those whose mothers did not have these conditions (P>.05).

Table . Association between maternal prenatal anxiety or depression and the risk of gastrointestinal (GI) symptoms in children with autism spectrum disorder (ASD).

GI comorbidities in ASD	Unadjusted		Adjusted[a]	
	OR[b] (95% CI)	*P* value	OR (95% CI)	*P* value
Constipation	1.965 (1.259-3.067)	.003	2.083 (1.315-3.299)	.002
Diarrhea	1.412 (0.656-3.043)	.38	1.530 (0.692-3.385)	.29
Abdominal pain	2.304 (1.329-3.993)	.003	2.302 (1.305-4.062)	.004
Nausea and vomiting	1.314 (0.591-2.921)	.50	1.335 (0.581-3.067)	.50
Flatulence	2.002 (0.895-4.480)	.09	2.154 (0.922-5.031)	.08
Stool odor	1.386 (0.717-2.680)	.33	1.272 (0.646-2.505)	.49
Total GI symptoms	1.883 (1.209-2.934)	.005	1.943 (1.236-3.054)	.004

[a]Adjusted for age, sex, maternal educational level, paternal educational level, mode of delivery, place of residence, and annual household income.

[b]OR: odds ratio.

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Discussion

Principal Findings

The clinical manifestation of ASD is highly heterogeneous, often with comorbidities such as GI symptoms in addition to the core symptoms [24]. Certain causes may lead to developmental abnormalities in both the brain and GI tract, resulting in ASD with GI symptoms. In this study, we investigated the impact of maternal mental health, specifically anxiety or depression during pregnancy, on the likelihood of ASD and GI symptoms in children.

In our study, we found that the prevalence of maternal prenatal anxiety or depression was 6.4% (31/486) in children with typical development and 22.6% (106/470) in children with ASD. This is a relatively high prevalence and is consistent with findings from other studies [9,25]. Our study also revealed a significant difference in the prevalence of maternal prenatal anxiety or depression between children with ASD and children with typical development, suggesting a potential link between prenatal mental health and the development of ASD in children. We used logistic regression models to further examine this association. In the univariate analysis, factors including prenatal anxiety or depression, lower maternal and paternal educational level, nonvaginal delivery, nonurban residence, and lower household income were all significantly associated with increased risk of ASD. To assess the independent effect of prenatal anxiety or depression, we included all these variables along with age and sex in the multivariable logistic regression model. The results showed that maternal prenatal anxiety or depression remained a significant independent risk factor for ASD (adjusted OR 3.897, 95% CI 2.481-6.119). Although some other variables also retained significance, their effect sizes were smaller than that of prenatal anxiety or depression. These findings suggest that maternal prenatal anxiety or depression may independently increase the risk of ASD in children. This is consistent with previous cohort studies linking maternal anxiety or depression before birth to ASD or ASD-related traits [11,26,27] and with systematic reviews and meta-analyses reporting increased ASD risk among children of mothers with affective, depressive, or anxiety disorders [12,13]. Although the precise mechanisms remain to be clarified, both animal and human studies have demonstrated that maternal prenatal anxiety and depression may be associated with neurodevelopmental disorders [28]. As such, addressing and managing maternal prenatal anxiety and depression may be crucial for reducing the prevalence of neurodevelopmental disorders, including certain forms of ASD, in children.

GI symptoms are a common comorbidity in children with ASD [3]. In the present study, we found that 50.2% (236/470) of children with ASD had GI symptoms, which was significantly higher than the proportion of children with typical development with GI symptoms. Additionally, we compared the prevalence of GI symptoms in children with ASD whose mothers had and did not have prenatal anxiety and depression. The results showed that for children with ASD whose mothers had prenatal anxiety or depression, the prevalence of total GI symptoms was 62.3% (66/106), which was significantly higher than that of children with ASD whose mothers did not have prenatal anxiety and depression (170/364, 46.7%). Among the GI symptoms, the prevalence of constipation and abdominal pain was significantly higher in children with ASD whose mothers had prenatal anxiety or depression than in children with ASD whose mothers did not have prenatal anxiety and depression. This suggests a potential link between maternal anxiety and depression during pregnancy and GI symptoms in children with ASD. Furthermore, we used logistic regression models to analyze the relationship between maternal prenatal anxiety or depression and GI symptoms in children with ASD. The results suggested that maternal prenatal anxiety and depression might be risk factors for GI symptoms in children with ASD, with an increased risk of constipation, abdominal pain, and total GI symptoms. This trend remained consistent even after adjusting for potential confounding factors. It has been reported that there is a correlation between maternal depressive symptoms and infant gastroesophageal reflux disease and constipation [29]. However, to our knowledge, no other research has explored the link between maternal anxiety and depression during pregnancy and GI symptoms in children with ASD.

The mechanisms underlying the association between maternal prenatal anxiety and depression and ASD with GI symptoms in children are unknown. Depression and anxiety are highly comorbid with GI abnormalities as well as microbiome dysbiosis [30,31]. In the case of maternal depression during pregnancy, they can also have a significant impact on both the mother's and the child's gut microbiome [32]. A study conducted by Galley et al [14] also supports the idea that maternal prenatal anxiety and depression can affect the gut microbiome of children. Additionally, prenatal stress has been found to affect placental cytokines and neurotrophins [33]. Moreover, an animal study has suggested that maternal microbiome can modulate fetal neurodevelopment [34]. In addition, abnormalities in the development of the brain and ENS can contribute to the development of ASD and GI symptoms [35]. Thus, we speculate that maternal prenatal anxiety and depression may affect the development of children's brains and GI tracts through abnormalities in maternal microbiota as well as abnormalities in placental function, or it may directly affect children's gut microbiota and further influence brain development through the gut-brain axis, which may increase the risk of ASD and GI symptoms in children. However, the specific mechanisms need to be further explored in animal experiments.

Limitations

This study has several limitations. First, it was a cross-sectional study, which does not allow for causal inferences to be made about the relationship between prenatal anxiety and depression and ASD with GI symptoms. In addition, some of the questionnaire data, including general demographic information and certain maternal mental health information, were collected retrospectively at enrollment when the children were aged 2 to 7 years and, thus, may be subject to retrospective recall bias. Second, there is no standardized and validated method for assessing GI symptoms in children with ASD. In this study, GI symptoms were judged based on the caregivers' answers to questions based on the QPGS-IV, and children with ASD usually have communication problems, so there may be bias in

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evaluating GI symptoms. Third, although we adjusted for major confounding factors, our analysis may still have residual unmeasured confounding such as maternal fever, obesity, and diabetes, which were not included in the analysis and could influence the observed associations. Finally, as the ASD group was recruited from a specialized tertiary behavioral clinic while the typical development group was drawn from a routine well-child health clinic, there may be potential selection and referral biases due to differences in referral pathways and clinic attendance.

Conclusions

Our study found that a higher proportion of children with ASD had mothers with prenatal anxiety and depression compared to children with typical development. Children with ASD whose mothers experienced anxiety or depression during pregnancy had significantly higher rates of GI symptoms than children with ASD whose mothers did not experience anxiety and depression during pregnancy. Our logistic regression models suggest that maternal prenatal anxiety and depression may increase the risk of ASD and GI symptoms in children. These findings highlight the importance of mental health during pregnancy and that even mild and moderate anxiety and depression may increase the risk of ASD and GI symptoms in children, so they need to be actively prevented and treated.

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Conflicts of Interest

None declared.

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Abbreviations

ASD: autism spectrum disorder
CARS: Childhood Autism Rating Scale
ENS: enteric nervous system
GI: gastrointestinal
OR: odds ratio
QPGS-IV: Questionnaire of Pediatric Gastrointestinal Symptoms–Rome IV

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Predicting Infant Sleep Patterns From Postpartum Maternal Mental Health Measures: Machine Learning Approach

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Abstract

Background: Postpartum maternal mental health (MMH) symptoms, including depression, anxiety, and childbirth-related post-traumatic stress disorder, are known to influence infant sleep trajectories. While previous research has examined their individual and combined associations, the predictive utility of these MMH symptoms for the early identification of infant sleep problems through machine learning (ML) remains understudied.

Objective: This study aimed to examine whether postpartum MMH measures can predict infant sleep outcomes during the first year of life. The analysis focused on 2 clinically relevant sleep indicators: (1) nocturnal sleep duration and (2) night awakening frequency.

Methods: A total of 409 mother-infant dyads were included in the study. Predictor variables comprised postpartum MMH symptoms assessed between 3 and 12 months postpartum, along with sociodemographic characteristics of mothers and infants. MMH symptoms were measured using 3 validated instruments: the Edinburgh Postnatal Depression Scale, the Hospital Anxiety and Depression Scale, and the City Birth Trauma Scale. Infant sleep outcomes were assessed using the Brief Infant Sleep Questionnaire. Six supervised ML algorithms were evaluated: logistic regression, random forest, support vector classifier, extreme gradient boosting, Light Gradient Boosting Machine, and multilayer perceptron. Post hoc feature importance analyses were conducted to identify the most influential predictors associated with each infant sleep outcome.

Results: All models demonstrated high predictive performance. The best model achieved a precision-recall area under the curve of 0.92, F_1-score of 0.84, and accuracy of 0.88 for predicting short nocturnal sleep duration. For frequent night awakenings, the top precision-recall area under the curve was 0.91, with an F_1-score of 0.78 and accuracy of 0.85. Key predictors included maternal age and total scores from the Edinburgh Postnatal Depression Scale, Hospital Anxiety and Depression–Anxiety subscale, and City Birth Trauma Scale, with individual symptom items offering additional discriminative value.

Conclusions: ML models can accurately predict which infants are at risk for suboptimal sleep based on MMH measures, enabling personalized, responsive, and developmentally informed postpartum care that promotes long-term maternal and infant well-being.

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KEYWORDS

artificial intelligence; sleep; postpartum; mental health; depression; women's health.

Introduction

Infant sleep plays a foundational role in early neurodevelopment, with significant implications for cognitive functioning, emotional regulation, physical growth, and long-term health outcomes [1-3]. During the first year postpartum, infant sleep patterns are highly dynamic and marked by individual variability in both nocturnal sleep duration and the frequency of night awakenings. Insufficient or fragmented sleep during this critical period has been associated with impaired memory consolidation, behavioral dysregulation, and suboptimal emotional development [4,5].

A growing body of research [6-12] has demonstrated that maternal mental health (MMH) symptoms during the postpartum period, including depression [13,14], anxiety [8,15], and childbirth-related post-traumatic stress disorder (CB-PTSD) [16,17], are associated with alterations in infant sleep architecture. However, the underlying mechanisms through which these maternal conditions influence infant sleep remain

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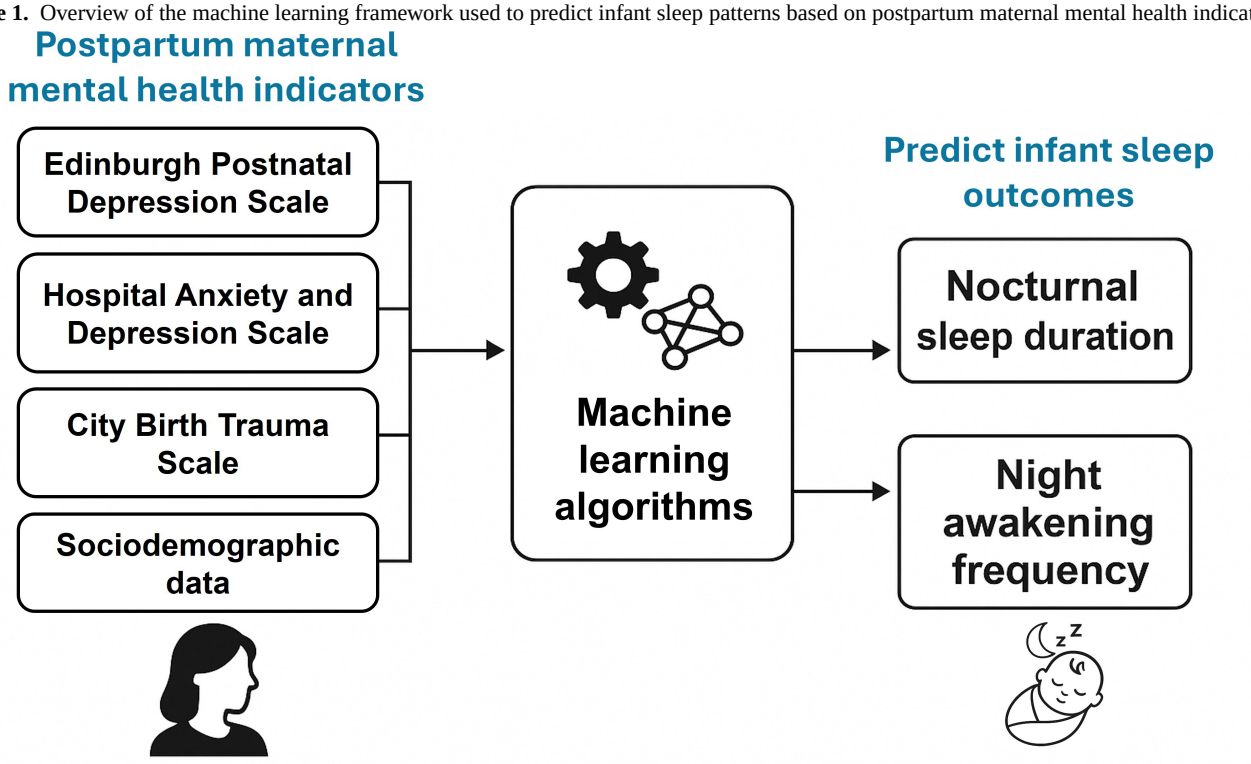
poorly understood [18]. Furthermore, most prior studies have examined these symptoms in isolation or as covariates, without evaluating their collective predictive value using integrative modeling approaches.

In parallel, machine learning (ML) approaches offer a powerful alternative to traditional regression techniques. Beyond simply reproducing associations already established using regression or structural equation models, ML offers added value by flexibly capturing nonlinear relationships and higher-order interactions among MMH symptoms and covariates. In this context, ML models can benchmark a range of algorithms on predictive performance, support individual-level risk stratification, and highlight symptom patterns that are most informative for early identification of infants at risk of sleep disturbance. In turn, this can refine existing theoretical models and guide more targeted, data-driven clinical decision support.

Recent studies have demonstrated the utility of ML in various infant sleep and postpartum mental health applications [19]. For example, Wang et al [20] developed an automated sleep-stage classifier using heart rate and respiratory rate data to predict white matter development in preterm infants. Similarly, Werth et al [21] designed a deep learning–based system for sleep-stage classification in preterm infants using electrocardiogram (ECG) signals. Additionally, the Sleep Well Baby project introduced a real-time sleep-wake state prediction algorithm based on physiological signals, facilitating improved monitoring in neonatal intensive care units [22]. In another study, Chang et al [23] utilized a multimodal wearable device to collect audio, ECG, and motion data, employing transformer-based neural networks to classify infant sleep/wake states with high accuracy. Furthermore, Huang et al [24] applied ML models to classify and identify infant sleep positions. However, existing ML-based studies have mostly focused on characterizing infant sleep problems using demographic, behavioral, or sensor-derived features, without explicitly leveraging MMH symptoms as primary predictors. To date, no study has examined whether postpartum MMH symptoms can be used, in conjunction with ML methods, to predict infant sleep patterns during the first year of life.

The present study addresses this gap by leveraging ML methods to predict infant sleep trajectories across the first year postpartum based on MMH symptoms and sociodemographic characteristics of mothers and infants. Specifically, we aimed to evaluate the performance of six supervised ML models in predicting two clinically relevant sleep outcomes: nocturnal sleep duration and the frequency of night awakenings (Figure 1). In addition, feature importance analyses were conducted to identify key MMH predictors associated with each outcome.

Figure 1. Overview of the machine learning framework used to predict infant sleep patterns based on postpartum maternal mental health indicators.



We hypothesized that postpartum MMH symptom measures, in combination with basic maternal-infant characteristics, would enable supervised ML models to accurately predict infant sleep outcomes. To operationalize this hypothesis, we addressed the following research questions: (1) Can MMH indicators and sociodemographic characteristics accurately predict infant sleep outcomes (ie, nocturnal sleep duration and night awakening frequency) during the first year postpartum using ML models? and (2) Which MMH features are most predictive of infant sleep outcomes across the first year postpartum? By characterizing the predictive utility of MMH symptoms and elucidating the most influential features, this study seeks to inform early screening and intervention strategies to optimize both MMH and infant developmental well-being.

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Methods

Study Population and Data Sources

This study utilized a publicly available dataset [11] comprising 410 mother-infant dyads, collected via an online cross-sectional survey conducted between June and September 2020 at a university hospital in Switzerland. Eligible participants were birth mothers aged 18 years or older with infants between 3 and 12 months of age at the time of data collection and with no reported major neonatal complications.

The dataset included measures of MMH symptoms, infant sleep outcomes, and sociodemographic characteristics of both mothers and infants. A detailed description of the input features used in the analysis is provided in Multimedia Appendix 1. One mother-infant dyad was excluded due to missing information on nocturnal sleep duration, resulting in a final sample of 409 dyads.

Data Elements

MMH Measures

MMH symptoms were assessed using 3 validated self-report instruments: the Edinburgh Postnatal Depression Scale (EPDS), the Hospital Anxiety and Depression Scale-Anxiety subscale (HADS-A), and the City Birth Trauma Scale (CBTS). These measures were selected to comprehensively capture postpartum symptoms of depression, anxiety, and CB-PTSD, respectively.

The EPDS is a 10-item screening tool designed to detect symptoms of postnatal depression in women [25]. It focuses on emotional and cognitive symptoms experienced during the preceding week, excluding somatic complaints that may overlap with normal postpartum changes. Each item is scored on a 4-point Likert scale, and total scores ranging from 0 to 40, with higher scores indicating greater symptom severity.

The HADS-A is the anxiety subscale of the Hospital Anxiety and Depression Scale [26]. It consists of 7 items that assess the frequency and severity of anxiety symptoms experienced during the preceding week. Responses are rated on a 4-point scale, yielding a total score ranging from 0 to 21, where higher scores reflect more severe anxiety symptomatology.

The CBTS is a 29-item instrument [27] specifically developed to assess CB-PTSD symptoms based on the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (*DSM-5*). The scale is divided into 2 subscales: the birth-related symptoms subscale, which assesses intrusion and avoidance symptoms as well as a subset of negative mood items, and the general symptoms subscale, which captures remaining negative cognition and hyperarousal symptoms. The total score for the *DSM-5*–based items ranges from 0 to 60, with higher scores indicating greater severity of CB-PTSD symptoms. Together, these 3 instruments provided a multidimensional assessment of postpartum MMH, enabling the identification of symptom patterns relevant to infant sleep outcomes.

Infant Sleep Measures

Infant sleep was assessed using the Brief Infant Sleep Questionnaire (BISQ), a widely used and validated parent-report instrument designed to evaluate sleep behavior in infants and toddlers [28]. Mothers were asked to report on their infant's sleep patterns over the preceding week, including total nocturnal sleep duration (between 7:00 PM and 7:00 AM), frequency of night awakenings, and method of falling asleep. For the purposes of this study, 2 primary sleep outcomes were derived and categorized as binary variables: nocturnal sleep duration and night awakenings, both of which serve as indicators of infant sleep quality.

Nocturnal sleep duration was classified as either normal (coded as 0) or insufficient (coded as 1). Infants were categorized as having normal nocturnal sleep if their reported sleep duration was ≥9 hours, for all infant age groups. Infants who slept for less than 9 hours per night were classified as having insufficient nocturnal sleep duration. This threshold aligns with prior research and pediatric sleep guidelines that recommend a minimum of 9 hours of nighttime sleep for infants aged 3 to 12 months [29] .

Night awakenings were categorized based on age-specific thresholds. For infants aged 3 to 6 months, normal was defined as ≤3 awakenings per night. For infants aged 6 to 9 and 9 to 12 months, normal was defined as ≤2 awakenings per night. Infants exceeding these thresholds were classified as having frequent night awakenings, consistent with existing sleep research indicating that night waking typically decreases with age as self-regulation improves [30].

Nocturnal sleep duration and night-awakening frequency were modeled as separate primary outcomes because they capture distinct dimensions of infant sleep—quantity (duration) versus continuity (awakenings)—that may have partially different determinants (eg, circadian scheduling/feeding patterns versus arousal regulation) and lead to different clinical actions. Their measurement properties also differ (duration: continuous; awakenings: count/ordinal), warranting distinct modeling approaches and metrics. Analyzing them separately preserves interpretability of feature effects and supports symptom-targeted guidance. Although the 2 domains can co-occur, our predictive focus is outcome-specific.

Data Preprocessing

Preprocessing steps included computing total scores for the maternal mental health instruments (EPDS, HADS-A, and CBTS) according to their manuals and recoding response options for consistency across instruments. For each instrument, both the individual item responses and the derived total scores were retained as candidate predictors, allowing the models to leverage overall symptom burden as well as more fine-grained symptom patterns (eg, specific anxiety, depression, or trauma-related items). Missing values were imputed (numerical features: mean; categorical features: mode). Numerical features were then standardized (z score), and categorical features were one-hot encoded to ensure consistent transformations during model training and evaluation. This procedure yielded a clean, model-ready feature matrix for all classifiers. Because the study's primary aim was to evaluate predictive performance rather than coefficient-level inference, we did not perform formal multicollinearity diagnostics (eg, VIF). Including both total scores and item-level responses intentionally introduces

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some correlation among predictors; however, many of the algorithms employed (eg, tree-based learners and regularized linear models) are designed to handle correlated and partially redundant features by down-weighting or shrinking less informative variables. Potential overfitting from the expanded feature space was further mitigated through cross-validated hyperparameter tuning and evaluation on a held-out test set.

ML Models

Six ML algorithms were employed to predict infant sleep outcomes based on MMH measures and demographic features. These models were selected to represent a diverse range of linear and nonlinear classifiers, including both ensemble and neural network-based approaches.

- Logistic regression: A linear classification algorithm that estimates the probability of a binary outcome based on a weighted combination of input features.
- Random forest: An ensemble learning method that constructs multiple decision trees during training and outputs the class that is the mode of the predictions of the individual trees.
- Support vector classifier: A kernel-based method that identifies the optimal hyperplane separating classes in a high-dimensional feature space.
- extreme gradient boosting (XGBoost): A gradient-boosted decision tree algorithm known for its scalability and performance. It builds an ensemble of weak learners sequentially, optimizing residual errors from prior iterations.
- Light gradient boosting machine (LightGBM): A gradient boosting framework that uses histogram-based learning and leaf-wise tree growth.
- Multilayer perceptron (MLP): A feedforward artificial neural network composed of fully connected layers. It captures complex, nonlinear interactions among features and is trained using backpropagation.

Each questionnaire item and each derived total score was treated as a separate candidate predictor. Modern supervised ML algorithms (eg, tree-based ensembles and regularized models) are generally robust to moderately correlated predictors and can down-weight or ignore redundant features during training, so including both item-level and total-score features does not compromise model learning or model behavior; instead, it allows the algorithm to "decide" whether predictive signal is better captured at the composite-score or item level.

Models Training and Evaluation Strategy

Both outcome variables exhibited class imbalance. For nocturnal sleep duration, 359/409 infants (87.8%) were classified as normal (class 0) and 50/409 (12.2%) as insufficient (class 1). For night awakenings, 346/409 infants (84.6%) were classified as normal (class 0) and 63/409 (15.4%) as elevated (class 1). To address this, we applied 2 strategies. First, we evaluated each model using 4 sampling methods: no sampling, random upsampling, random downsampling, and synthetic minority oversampling technique (SMOTE). This allowed us to assess the impact of different data distributions on model performance. Second, we used evaluation metrics suited for imbalanced data. In addition to accuracy, we computed the precision-recall area under the curve (PR-AUC), which focuses on the minority class and is not influenced by the number of true negatives. We also reported the F_1-score, the harmonic mean of precision and recall, which balances false positives and false negatives. Together, these strategies ensured reliable evaluation of model performance in the context of class imbalance.

All analyses were conducted at the level of the mother-infant dyad. The dataset (N=409 dyads) was randomly split into training (327/409, 80%) and test (82/409, 20%) sets, using stratified sampling to preserve the proportion of infants with nocturnal sleep disturbance and frequent night awakenings in both partitions. All model development (including hyperparameter tuning and internal validation) was performed exclusively on the training set. All analyses were implemented in Python and performed on a high-performance computing node equipped with an NVIDIA A100 GPU (80 GB memory).

To quantify the variability and robustness of model performance, we additionally performed stratified 5-fold cross-validation within the training set for each model-sampling combination. For every fold, we computed PR-AUC, accuracy, and F_1-score and summarized their distribution across folds. Final performance for each model was then evaluated on the held-out test set.

Models Explainability

To characterize which MMH and covariate features contributed most to predictions, we first computed model-based feature importance for the best-performing model for each outcome (as determined by PR-AUC on the held-out test set), using the model's native importance measure. To further enhance interpretability, we then performed a post hoc explainability analysis using Shapley additive explanations (SHAP). For each outcome, we computed SHAP values for all input features. SHAP values quantify the marginal contribution of each feature to the predicted probability of the positive (sleep disturbance) class for individual mother-infant dyads. We summarized global importance by the mean absolute SHAP value across participants and visualized the distribution of feature effects using SHAP summary (beeswarm) plots, as complementary views to the main feature-importance analyses.

Ethical Considerations

This study did not involve the collection or generation of original human subject data. Instead, it utilized publicly available, deidentified data from a licensed source. As such, institutional review board approval and informed consent were not required.

Results

Participant Characteristics

A total of 409 mother-infant dyads were included. Participant characteristics and summary measures are shown in Table 1. The mean maternal age was 30.20 (SD 4.36) years. Nearly half held a university degree (192/409, 46.9%); 388 out of 409 (94.9%) were in a couple relationship. Overall, 51.6% (211/409) of the infants were female and 48.4% (198/409) were male. The mean gestational age at birth was 39.11 (SD 1.90) weeks. At

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assessment, infants were distributed as follows: 147/409 (35.9%) were aged 3 to <6 months, 133/409 (32.5%) aged 6 to <9 months, and 129/409 (31.5%) aged 9 to <12 months. MMH means were 9.06 (SD 6.76) on the EPDS, 7.85 (SD 4.26) on the HADS-A, and 13.15 (SD 10.81) on the CBTS.

Table . Sample characteristics and key measures (N=409).

Domain and variable	Value
Maternal	
Age (y), mean (SD)	30.20 (4.36)
Education, n (%)	
University degree	192 (46.9)
Applied Science/Tech diploma	88 (21.5)
Postsecondary/apprenticeship	103 (25.2)
Completed compulsory school	24 (5.9)
No formal education	2 (0.5)
Marital status, n (%)	
Couple relationship	388 (94.9)
Single	14 (3.4)
Separated/divorced/widowed	7 (1.7)
Pregnancy/birth	
Gestational age at birth (wk), mean (SD)	39.11 (1.90)
Infant	
Sex, n (%)	
Female	211 (51.6)
Male	198 (48.4)
Age group, n (%)	
3 to <6 mo	147 (35.9)
6 to <9 mo	133 (32.5)
9 to <12 mo	129 (31.5)
Maternal mental health, mean (SD)	
EPDS[a] total	9.06 (6.76)
HADS-A[b] total	7.85 (4.26)
CBTS[c] total	13.15 (10.81)

[a]EPDS: Edinburgh Postnatal Depression Scale.

[b]HADS-A: Hospital Anxiety and Depression Scale-Anxiety Subscale.

[c]CBTS: City Birth Trauma Scale.

Prediction of Nocturnal Sleep Duration

Models Performance

Figure 2 presents PR-AUC values for each model across 4 sampling strategies. All configurations achieved PR-AUC values above 0.88, with XGBoost with SMOTE highest (0.931), followed by logistic regression with SMOTE (0.924). Accuracy (Figure 3) showed greater variability, with XGBoost without sampling highest (0.886), followed by random forest without sampling or with upsampling (0.878). F_1-scores (Figure 4) mirrored these trends: XGBoost without sampling achieved the highest F_1 (0.840), followed by random forest (0.821) and support vector classifier/MLP (0.820) with either no sampling or SMOTE.

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Figure 2. Comparison of the precision-recall area under the curve (PR-AUC) across models and sampling methods for outcome nocturnal sleep duration. PR-AUC quantifies how well a model can distinguish positive cases (infants with insufficient nocturnal sleep duration) from negative ones across various thresholds, especially under class imbalance conditions. LightGBM: light gradient boosting machine; MLP: multilayer perceptron; SMOTE: synthetic minority oversampling technique; SVC: support vector classifier; XGBoost: extreme gradient boosting.

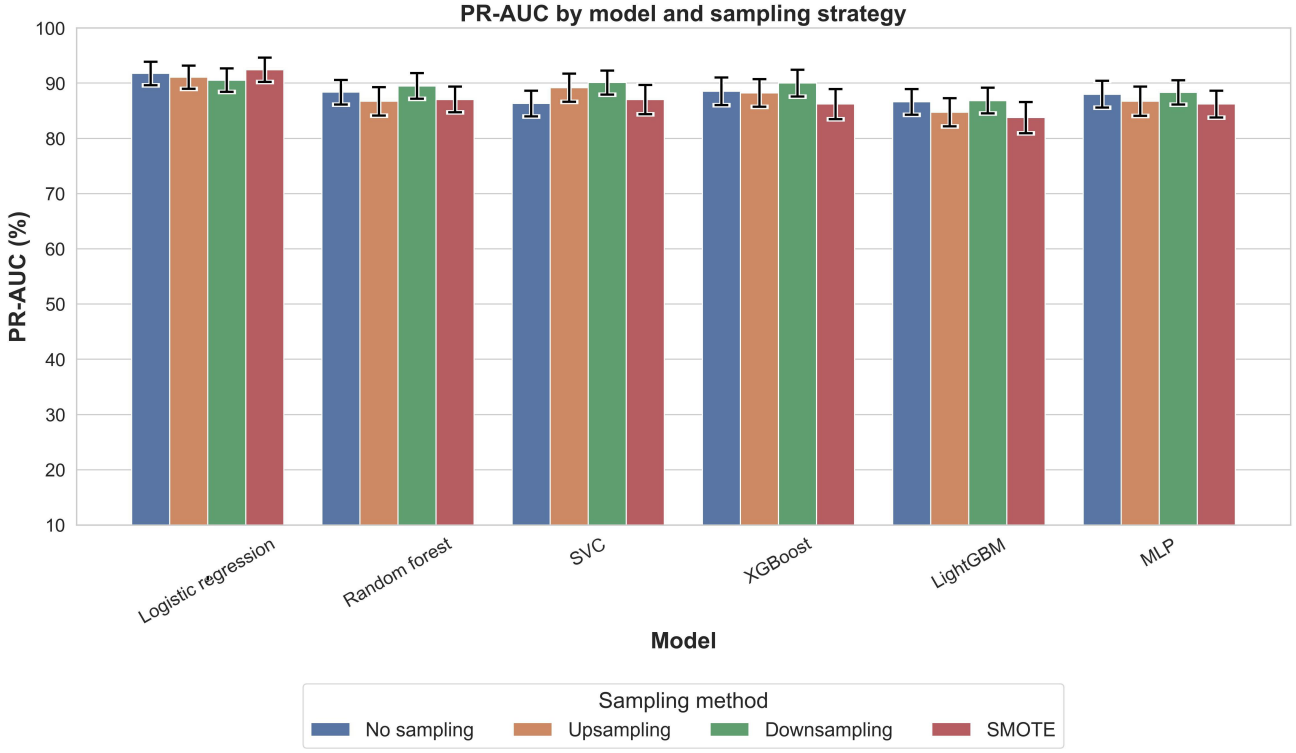
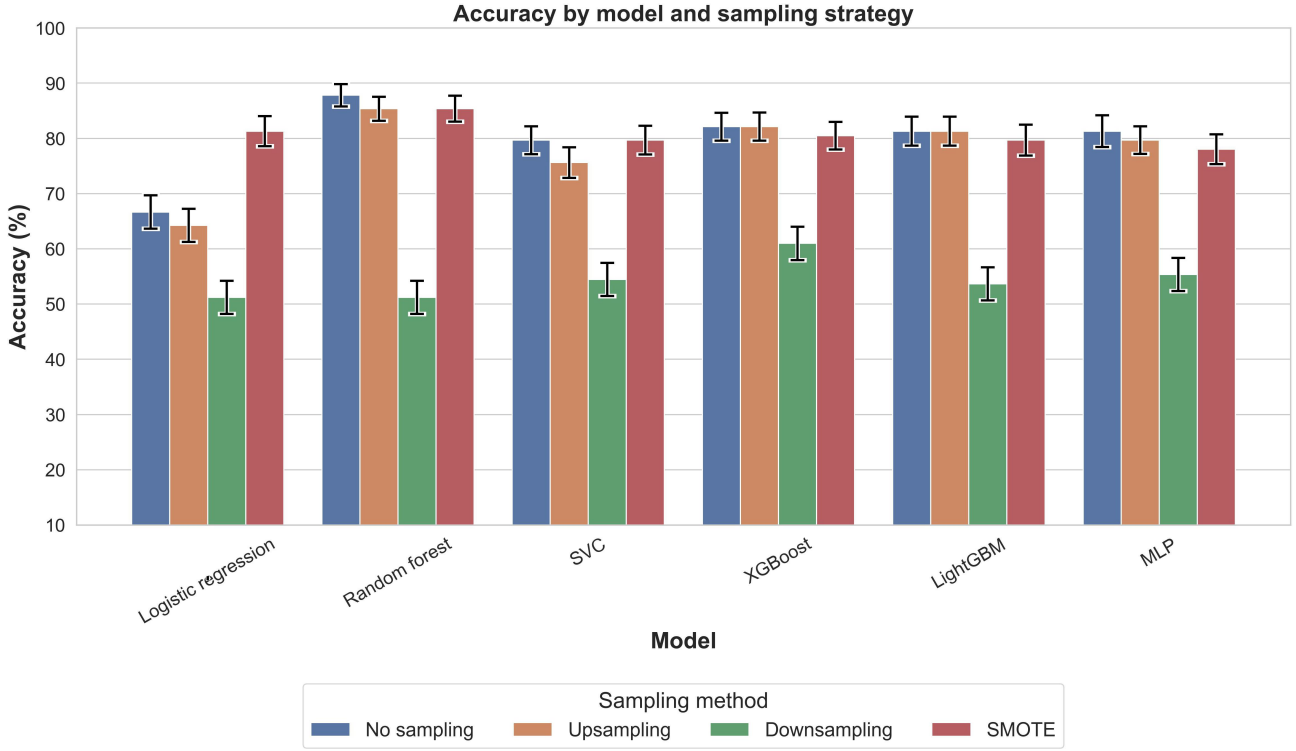
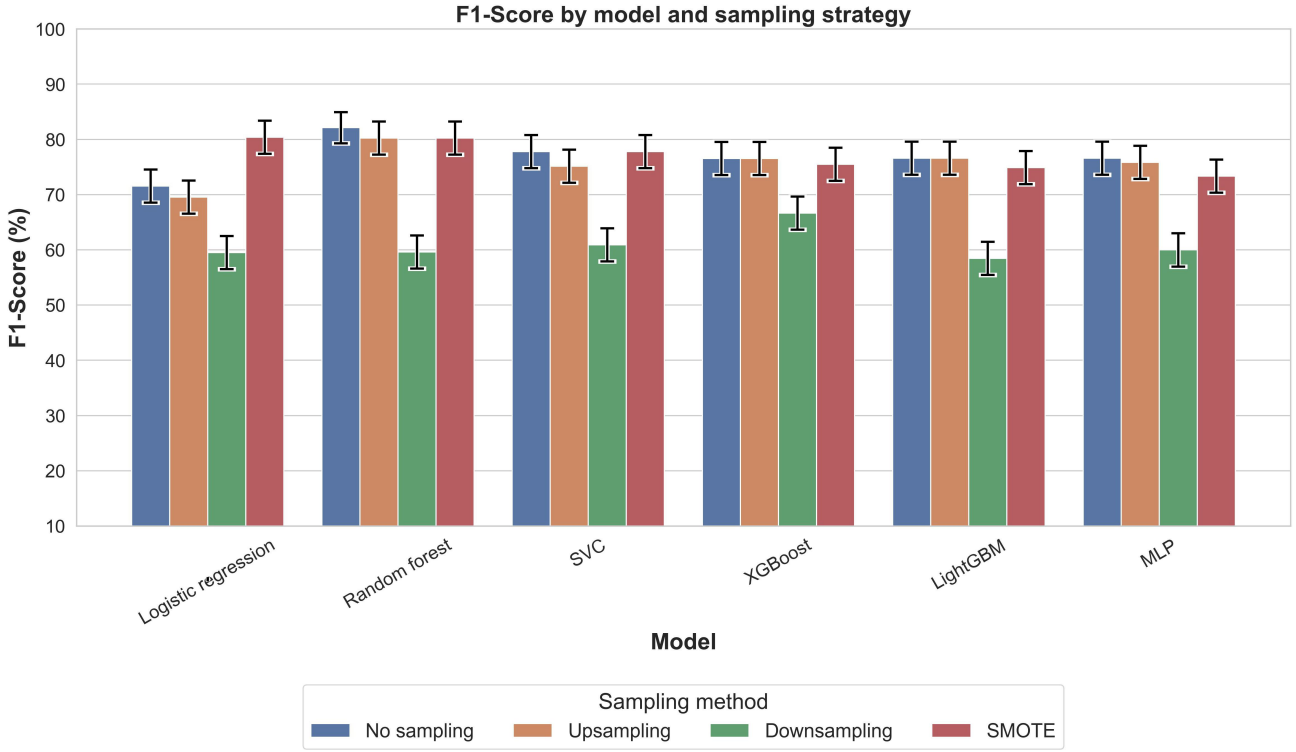


Figure 3. Comparison of accuracy across models and sampling methods for outcome nocturnal sleep duration. Accuracy represents the overall proportion of correct predictions, combining both positive and negative cases, and provides a broad measure of model correctness. LightGBM: light gradient boosting machine; MLP: multilayer perceptron; SMOTE: synthetic minority oversampling technique; SVC: support vector classifier; XGBoost: extreme gradient boosting.



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Figure 4. Comparison of F_1-score across models and sampling methods for outcome nocturnal sleep duration. The F_1-score balances precision and recall, making it a valuable metric for assessing model performance in the context of imbalanced datasets. LightGBM: light gradient boosting machine; MLP: multilayer perceptron; SMOTE: synthetic minority oversampling technique; SVC: support vector classifier; XGBoost: extreme gradient boosting.

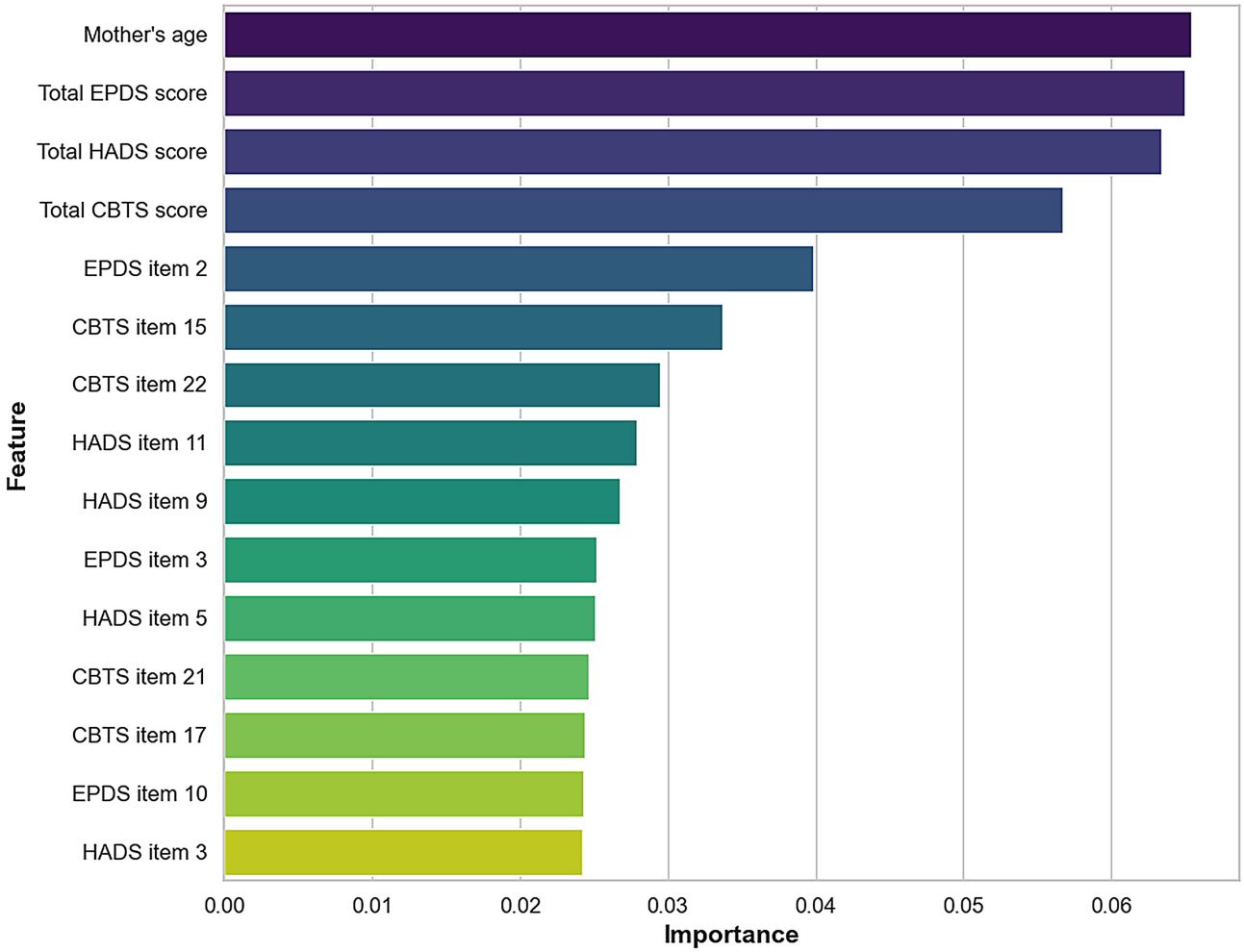


Feature Importance Analysis

Figure 5 shows the most influential predictors of short nocturnal sleep duration: maternal age and total scores on the EPDS, HADS-A, and CBTS. Individual items also contributed meaningfully, particularly EPDS Item 2 (I have looked forward with enjoyment to things) and CBTS Item 15 (Feeling detached from others). To further probe how individual feature values contributed to predictions for the best-performing model, we examined SHAP summary plots for the nocturnal sleep outcome (Multimedia Appendix 1). These global SHAP patterns were broadly consistent with the main feature-importance rankings and illustrate how higher maternal symptom scores tend to shift predictions toward increased risk of nocturnal sleep disturbance.

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Figure 5. Feature importance analysis for outcome nocturnal sleep duration. EPDS: Edinburgh Postnatal Depression Scale; HADS: Hospital Anxiety and Depression Scale; CBTS: City Birth Trauma Scale.



Prediction of Frequent Night Awakenings

Models Performance

Figure 6 reports PR-AUC for predicting night awakenings frequency across models and sampling strategies. All models performed well, typically exceeding 0.83, with logistic regression highest (0.91) and MLP close behind (0.89). Figure 7 shows accuracy, with random forest without sampling highest (0.85) and MLP and XGBoost without sampling at 0.81; downsampling reduced accuracy for all models. F_1-scores (Figure 8) mirrored accuracy, with MLP and XGBoost without sampling at 0.76 and random forest with SMOTE at 0.78. Models trained on downsampled data had the lowest F_1-scores, underscoring the performance cost of sample reduction despite improved class balance.

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Figure 6. Comparison of the precision-recall area under the curve (PR-AUC) across models and sampling methods for outcome night awakenings frequency. LightGBM: light gradient boosting machine; MLP: multilayer perceptron; SMOTE: synthetic minority oversampling technique; SVC: support vector classifier; XGBoost: extreme gradient boosting.

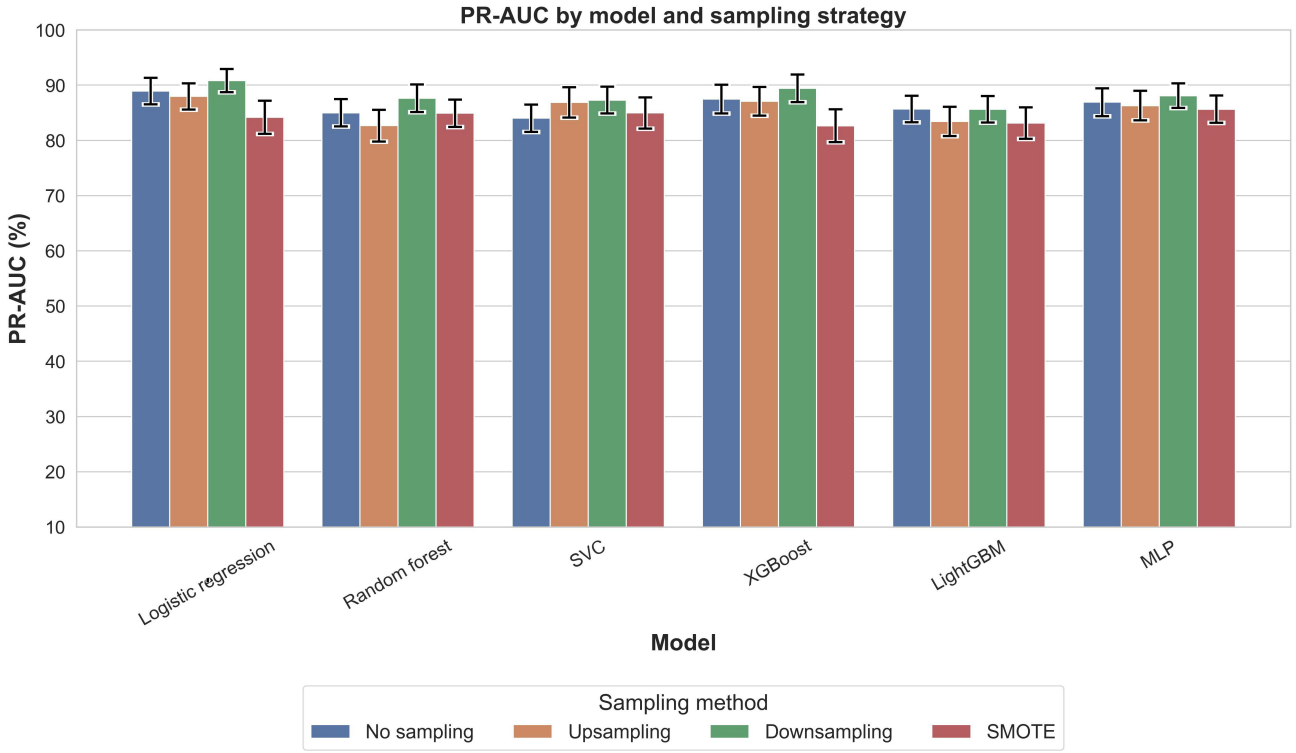
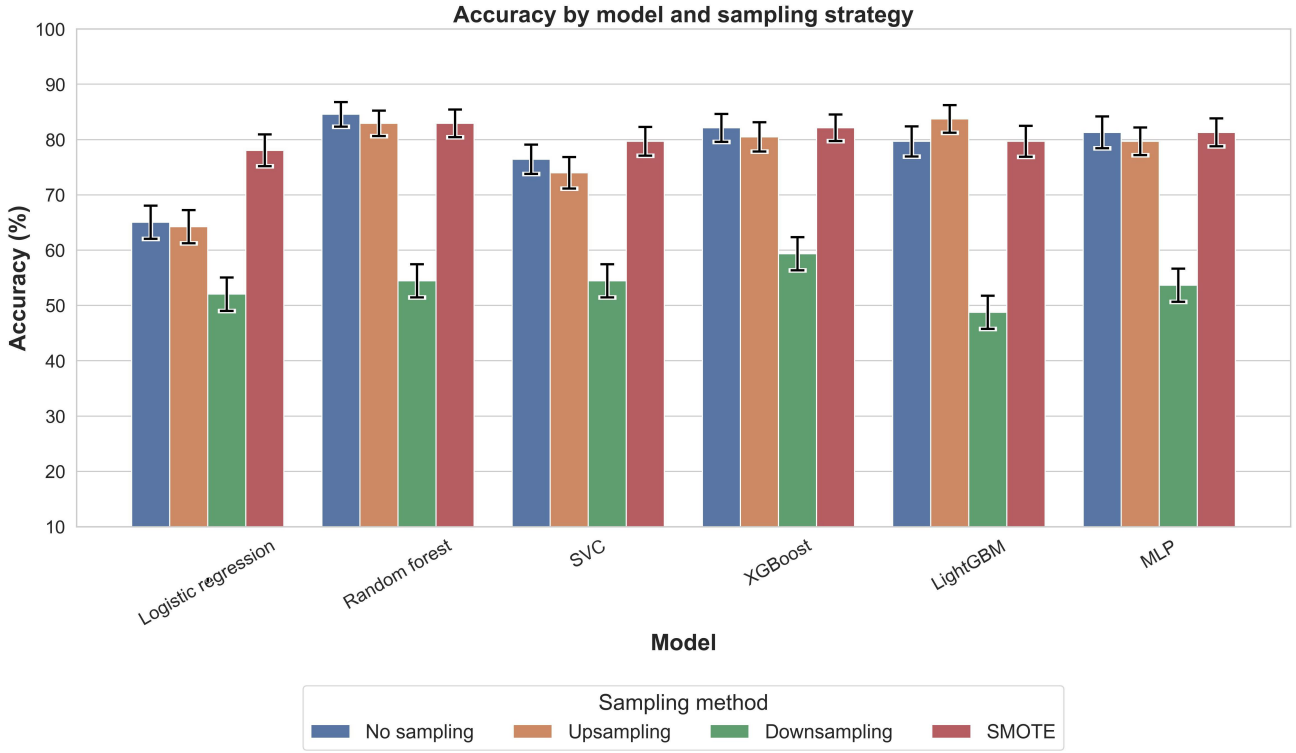
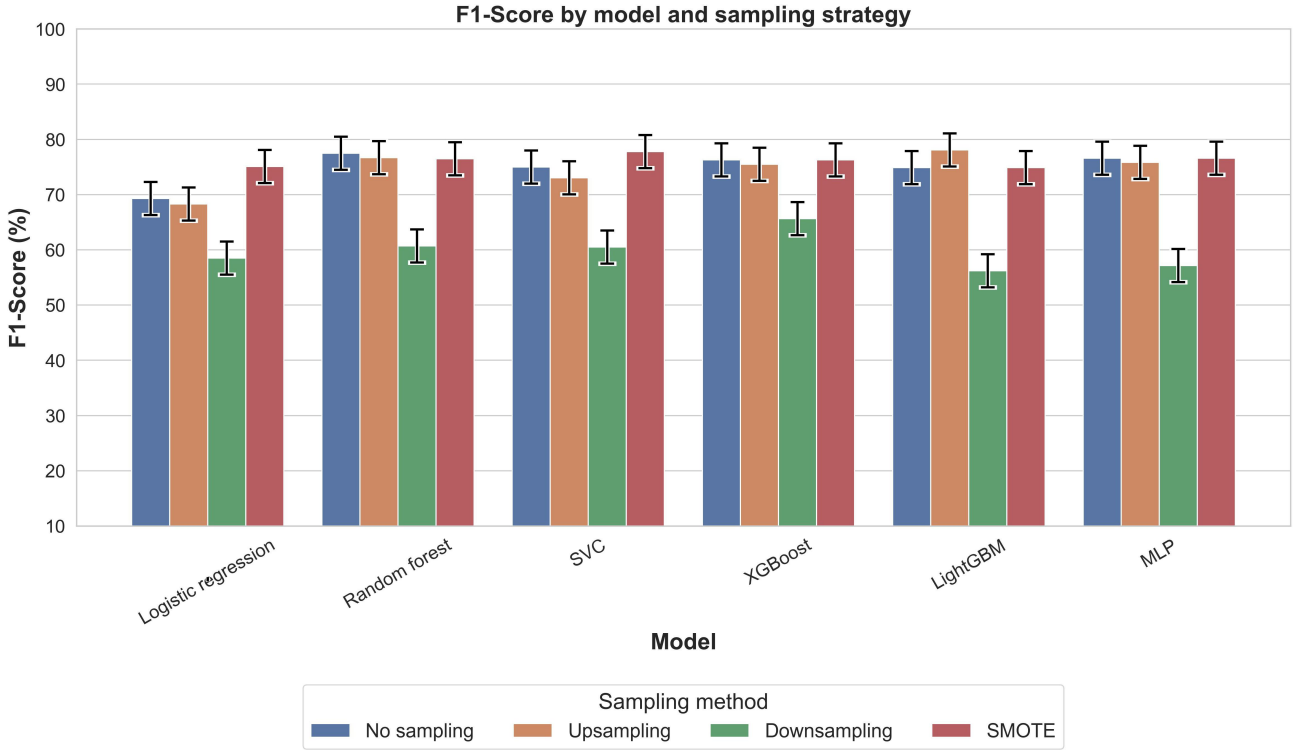


Figure 7. Comparison of accuracy across models and sampling methods for outcome night awakenings frequency. LightGBM: light gradient boosting machine; MLP: multilayer perceptron; SMOTE: synthetic minority oversampling technique; SVC: support vector classifier; XGBoost: extreme gradient boosting.



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Figure 8. Comparison of F_1-score across models and sampling methods for outcome night awakenings frequency. LightGBM: light gradient boosting machine; MLP: multilayer perceptron; SMOTE: synthetic minority oversampling technique; SVC: support vector classifier; XGBoost: extreme gradient boosting.

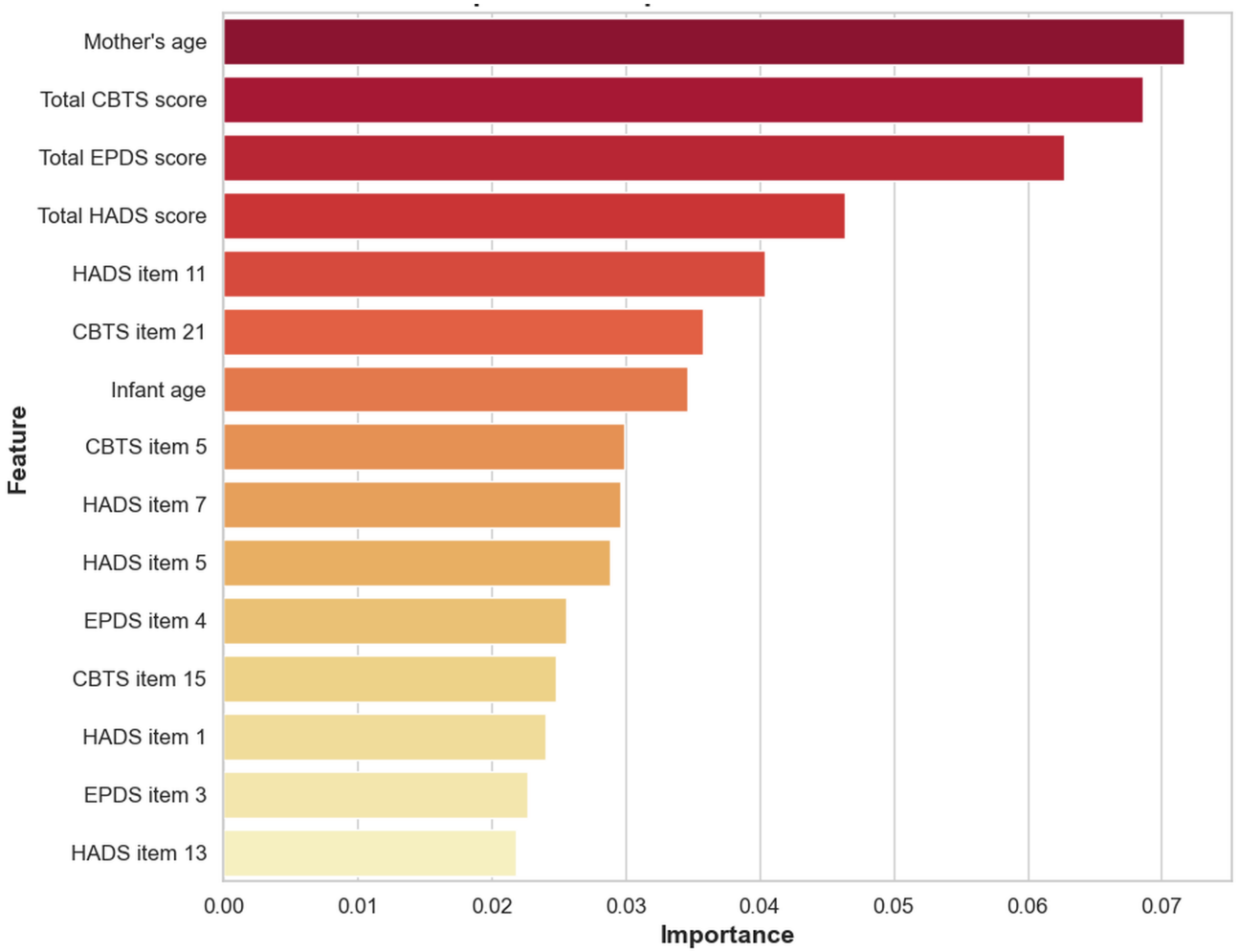


Feature Importance Analysis

Feature importance analysis identified the most influential predictors of elevated night awakening frequency (Figure 9). As with nocturnal sleep duration, maternal age and total EPDS, HADS-A, and CBTS scores were top predictors. Individual items also contributed, notably HADS-A Item 11 (I feel restless and cannot seem to stay still) and CBTS Item 21 (Having difficulty concentrating). Infant age also emerged as a relevant predictor. An analogous SHAP summary plot for night awakenings (Multimedia Appendices 1-3) confirms the prominence of MMH features and illustrates how variations in these scores and sociodemographic factors shift individual predictions toward higher or lower night-awakening risk.

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Figure 9. Feature importance analysis for outcome night awakenings frequency. EPDS: Edinburgh Postnatal Depression Scale; HADS: Hospital Anxiety and Depression Scale.



Discussion

Key Findings

This study evaluated the utility of postpartum MMH measures in predicting infant sleep patterns using an ML approach. Notably, supervised ML models trained on standardized psychological screening instruments (EPDS, HADS-A, and CBTS), combined with basic demographic and maternal variables, demonstrated high predictive accuracy for both outcomes: insufficient nocturnal sleep duration and frequent night awakenings. These findings indicate the feasibility of using MMH symptoms to identify infants at risk for suboptimal sleep patterns. It also confirms the feasibility of integrating ML tools into postpartum care pathways to facilitate early risk identification.

Predictors of Infant Sleep Patterns

Maternal age emerged as a top predictor for both outcomes, potentially reflecting links with parenting experience, physiological resilience, and contextual factors such as social support and caregiving efficacy. Prior work associating younger age with higher postpartum depression and poorer infant sleep [7,31] is consistent with its predictive strength in our models.

Total scores from the EPDS, HADS-A, and CBTS were among the most influential features in both models. Higher total EPDS scores indicate more severe postpartum depressive symptoms, which can impact maternal responsiveness and infant sleep regulation. Elevated anxiety levels (HADS-A) in mothers may lead to increased nighttime interactions, potentially disrupting infant sleep. Additionally, higher CBTS scores reflect greater CB-PTSD symptoms, which can affect maternal-infant bonding and sleep routines. These aggregate scores likely reflect the cumulative burden of postpartum psychological distress, which has been linked in prior research to disruptions in maternal caregiving behavior, nighttime responsiveness, and the emotional climate surrounding infant sleep routines [13,32,33].

Beyond aggregate symptom scores, several individual questionnaire items provided fine-grained insights. For example, EPDS Item 2 (“I have looked forward with enjoyment to things”)—a measure of anhedonia—was highly predictive of short nocturnal sleep duration. Lower scores on this item suggest anhedonia, a core symptom of depression, which may influence maternal engagement in establishing infant sleep routines. Similarly, CBTS Item 15 (“I felt distant or cut off from other people”) was ranked highly predictive of short nocturnal sleep duration, suggesting that maternal emotional withdrawal and social detachment, characteristic of childbirth-related trauma, may negatively impact the ability to establish secure and consistent nighttime routines.

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In the models predicting frequent night awakenings, several additional features emerged as specific to this outcome. These included HADS-A Item 11 (“I feel restless and can’t seem to sit still”) and CBTS Item 21 (“I had difficulty concentrating”), both of which reflect maternal hyperarousal and cognitive dysregulation. These symptoms may manifest in heightened maternal vigilance or difficulty in promoting infant self-soothing, thereby contributing to fragmented infant sleep. Infant age also appeared as a differentiating predictor for this outcome, likely reflecting developmental maturation of sleep consolidation and age-dependent thresholds used in classifying night awakening frequency.

Research and Clinical Implications

From a research perspective, this study illustrates the value of combining symptom-level data with advanced modeling approaches to move beyond correlational frameworks and toward predictive analytics in maternal–infant health. The identification of both composite scores and individual symptom items as key predictors offers a granular understanding of how distinct psychological dimensions—such as anhedonia, emotional detachment, and hyperarousal—may differentially impact infant sleep regulation. These findings advocate for future investigations that examine not only the additive burden of MMH symptoms, but also the specific affective and cognitive pathways through which maternal distress shapes caregiving practices and infant behavioral development. Because MMH and infant sleep outcomes were assessed at the same time point, our models characterize concurrent statistical associations rather than temporal or causal effects. In this context, we use the term “prediction” to denote out-of-sample statistical prediction within the cross-sectional dataset, not longitudinal forecasting. The original analysis of this dataset by Sandoz et al [12] examined the cross-sectional associations between MMH symptom profiles and infant sleep outcomes using traditional statistical methods. In contrast, the present study focuses exclusively on evaluating the predictive performance of supervised ML models that use these MMH measures to classify infant sleep outcomes. Longitudinal studies are particularly needed to clarify the temporal sequence between MMH symptom fluctuations and changes in infant sleep architecture. Moreover, item-level granularity opens avenues for psychometric refinement of postpartum screening instruments, enabling the development of targeted subscales that better predict specific infant outcomes.

Integrating wearable technologies (eg, smartwatches, sleep trackers, biosensors) could passively capture continuous physiological and behavioral data from mothers and infants, reducing reliance on retrospective self-report. When combined with symptom-level psychological data, these rich data streams may improve ML predictive accuracy, enable earlier detection of risk patterns, and support more responsive, personalized interventions.

From a clinical perspective, our findings are best viewed as proof of concept for generating individualized risk scores rather than as a ready-to-deploy screening tool. In practice, such risk scores could be integrated into routine postpartum or well-baby contacts to flag mother-infant dyads who may benefit from closer follow-up (eg, additional monitoring visits or phone check-ins), brief psychoeducation on infant sleep and maternal self-care, targeted support around bedtime routines and soothing strategies, or referral to perinatal mental health services for more structured interventions (such as brief CBT-based programs, parenting support groups, or trauma-focused care where indicated). The exact decision thresholds would need to be codesigned with clinicians and policymakers, balancing sensitivity (minimizing missed high-risk dyads) against specificity and available resources. Our analyses therefore focus on overall discrimination metrics (eg, PR-AUC, F_1) rather than on a single “optimal” cut-off; future work should calibrate and validate context-specific thresholds and decision rules in real-world postpartum care pathways. In addition, findings from this study may inform the design of preventive intervention trials. For instance, trials could test whether tailoring interventions to specific symptom clusters (eg, anhedonia-focused therapies for mothers at risk of short infant sleep duration) yields superior outcomes. Finally, these results highlight the importance of interdisciplinary collaboration—integrating mental health, pediatrics, and data science—to advance personalized, responsive, and developmentally informed postpartum care that promotes long-term maternal and infant well-being.

Limitations and Future Directions

Several limitations should be carefully considered when interpreting the findings of this study.

First, the data relied entirely on maternal self-report questionnaires, which introduces potential response and recall biases. Mothers experiencing psychological distress may perceive or report their infant’s sleep differently, potentially inflating associations between MMH symptoms and infant sleep disturbances due to shared method variance. Furthermore, infant sleep during the first year is influenced by a complex interplay of biological, environmental, and caregiving factors. The exclusive focus on MMH, without integrating other relevant variables such as infant temperament, feeding methods, family routines, or the home sleep environment, limits the comprehensiveness of the predictive models. Future studies should incorporate multimodal, multi-informant data sources, including reports from partners or caregivers and objective sleep measures such as actigraphy or polysomnography, alongside contextual and behavioral variables to more accurately capture the multifactorial nature of infant sleep regulation.

Second, the analysis was limited to 409 mother-infant dyads, all recruited from a single university hospital in Switzerland. This relatively modest sample size and geographically restricted setting may limit the generalizability of the findings to broader, more diverse populations. Sociocultural factors, health care systems, parental practices, and support structures can vary significantly across regions and may influence both MMH and infant sleep patterns. Future studies should validate these predictive models using larger, more heterogeneous samples across multiple countries and health care settings to ensure greater external validity and applicability of the results.

Third, the cross-sectional design limits causal inference. Although we examine associations between MMH symptoms and infant sleep, we cannot determine directionality or

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temporality. MMH may influence infant sleep, but the reverse is also plausible, with persistent sleep disturbances worsening maternal distress. Longitudinal studies are needed to disentangle these bidirectional effects and to capture trajectories of MMH and infant sleep over time.

Conclusions

This study demonstrates the feasibility and utility of applying supervised ML models to postpartum MMH symptom measures, together with basic maternal–infant characteristics, to predict infant sleep outcomes—specifically nocturnal sleep duration and night awakening frequency—during the first year of life. The combination of high-performing models and consistent variable importance patterns suggests that both maternal psychological well-being (eg, depressive, anxiety, and CB-PTSD symptoms) and non–mental-health factors such as maternal and infant age are associated with infant sleep patterns in this sample. By integrating scalable mental health screening tools with predictive analytics, this approach holds promise for early identification of at-risk dyads and for informing targeted, preventive interventions that support both maternal and infant health outcomes.

Data Availability

The data used in this study are publicly available and can be accessed through the Zenodo repository [11]. The code used is available at GitHub [34].

Authors' Contributions

Conceptualization: RA, RT, JS
Data Curation: RA
Methodology: RA, RT
Visualization: RA
Writing – Original Draft: RA
Writing – Review & Editing: RT, RB, MA, AA, JS
All authors read and approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Data Dictionary.
[DOCX File, 23 KB - pediatrics_v9i1e78937_app1.docx]

Multimedia Appendix 2
Shapley additive explanations (SHAP) summary plot for nocturnal sleep disturbance.
[DOCX File, 280 KB - pediatrics_v9i1e78937_app2.docx]

Multimedia Appendix 3
Shapley additive explanations (SHAP) summary plot for night awakening.
[DOCX File, 282 KB - pediatrics_v9i1e78937_app3.docx]

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Abbreviations

BISQ: Brief Infant Sleep Questionnaire
CB-PTSD: childbirth-related post-traumatic stress disorder
CBTS: City Birth Trauma Scale
ECG: electrocardiogram
EPDS: Edinburgh Postnatal Depression Scale
HADS-A: Hospital Anxiety and Depression Scale-Anxiety Subscale
LGBM: light gradient boosting machine
ML: machine learning
MLP: multilayer perceptron
MMH: maternal mental health
PR-AUC: precision-recall area under the curve
SHAP: Shapley additive explanations
SMOTE: synthetic minority oversampling technique
XGBoost: extreme gradient boosting

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Infant Feeding Apps and Digital Parenting in Australia: Qualitative Study

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Abstract

Background: Parents are increasingly using infant feeding apps (IFAs) for information and decision-making related to breastfeeding and other aspects of their baby's care. Few studies have explored how users conceptualize data privacy risks in relation to IFAs and how concerns are balanced with app use.

Objective: This qualitative study forms part of the Infant Feeding App project exploring how IFAs influence parent-child communication in Australian families. A focus of this investigation was to explore mothers' understanding of the terms and conditions associated with the use of IFAs and their data privacy concerns.

Methods: We included first-time parents of children aged 0 to 4 years who were breastfeeding at the time of the first interview and previously or currently used 1 or more IFAs. Twenty-four participants completed the first-round interview; of those, 22 returned for a second-round interview approximately 6 months later, and 7 participated in the focus group discussion. Reflexive thematic analysis was used to analyze the data.

Results: This paper draws primarily on findings from the key category of "Data and/or Privacy Practices." This category was further refined into 2 main themes: lack of awareness or acceptance of the terms and conditions associated with the mobile app and the risk mitigation behaviors mothers took to protect their privacy.

Conclusions: Although mothers were aware of the privacy risks associated with IFAs, they nonetheless continued to engage with them, reflecting the broader growth in digital technology use. This paper has highlighted that privacy, a fundamental human right, is at risk when mothers share personal and child-related data through digital apps. Importantly, mothers' willingness to use these applications despite perceived concerns highlights the tension between perceived utility and potential risks. A call for a move toward privacy by design, transparency in privacy policies, and an approach of nonalienation in the use of data is called for.

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KEYWORDS

data privacy; terms and conditions; digital apps; qualitative research; perspectives; risk perception; breastfeeding; first-time parents; Australia

Introduction

The number of infant feeding apps (IFAs) available to parents is growing, offering information to guide breastfeeding decisions and other aspects of care [1]. These apps typically enable the recording of feeding schedules and intake, sleeping patterns, growth metrics, and developmental milestones. The apps aim to offer timely support for women by enabling remote monitoring and information sharing throughout their pregnancy and the postpartum period [2-4]. IFAs have the potential to support timely access to information and have been reported as easy to use and create access to accurate information [5].

A recent randomized controlled trial in Turkey [5] showed that the use of IFAs influenced mothers' breastfeeding experiences in a positive manner, with users reporting fewer breastfeeding-related difficulties and higher rates of exclusive breastfeeding. IFAs have been used as supportive tools for promoting early initiation and continuation of breastfeeding [6] and exchange of knowledge among parents [7,8]. Other studies suggest that the use of IFAs is perceived by some parents as an

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indicator of "good" parenting practices, or what has been termed "tracking-as-care" [9,10].

In Australia, parents have used IFAs to track their child's activities and to assist them with decision-making [1,11]. IFAs have been described as enhancing parental knowledge acquisition [6] and improving parental confidence [1], yet consensus across the literature on the perceived value of IFAs remains difficult to achieve.

Concerns have been noted in relation to the quality and accuracy of the content and the functionality of IFAs [12,13]. These issues are compounded by the scarcity of empirical evidence on data confidentiality and privacy when using mobile and web apps [14]. The use of IFAs often entails continuous input of personal data, including feeding times, infant weight, sleep cycles, and health behaviors that may raise concerns about the opacity of data privacy policies and the extent to which parents understand or consent to data sharing practices [4]. To deliver their functions, IFAs collect a wide range of data that may include parent-related data and personally identifiable information, such as names, birth dates, email addresses, and location. Mortensen and Lomborg [15] have characterized this issue as the continuous generation of digital traces or "data selfies" through engagement with mobile self-tracking apps (p. 6013).

A further issue is the potential for third parties without the explicit knowledge of the user to access and use data. Lupton and Michael [16] found that people recognized the value that could be derived from their own personal data, as well as from the collective insights generated when their data were integrated into aggregated datasets, benefiting both themselves and others. However, they found that people expressed concerns or suspicion about how their data might be used by others and what ultimately happens to their data. Areas for further investigation in relation to these areas include the balance between sharing personal data, the value to the individual as a result, and data privacy.

Normalizing the datafication of everyday activities, such as sleeping data or feeding times (parent and child data), has been raised as a form of dataveillance [8,11]. The acceptance of apps such as IFAs can be argued to normalize the heightened surveillance of both women's and children's bodies [9]. The creation of a data trace across the lifespan is relatively new, with children becoming digital citizens sometimes before they are even born through pregnancy apps and social media postings [17]. Areas for further exploration include: when does personal dataveillance become too intrusive, and how do we balance the growing digitization of children in relation to the sharing, selling, and commodification of data?

While the use of IFAs may assist in developing innovative interventions to support infant feeding practices, the need to develop a more nuanced understanding of how parents perceive and manage issues of data privacy is needed. Therefore, this paper aimed to explore mothers' understanding of the terms and conditions associated with the use of IFAs and their data privacy concerns.

Methods

Design

This study is part of an ongoing research project, "The parent-child communication implications of IFAs," that aims to better understand the impacts of IFAs on parent-child communication among Australian families. The project broadly problematizes the inclusion of a screen as a novel component within early processes of infant feeding, but also acknowledges the potential benefits IFAs offer, especially to first-time parents. A key aim was to explore the motivations and concerns that support parents' use of IFAs and the reasons why some parents might choose not to use them or might discontinue their use. Of particular relevance to this paper were motivations and concerns around privacy practices and terms and conditions.

The data used in this study were collected using a descriptive qualitative design comprising 2 rounds of interviews followed by focus group sessions. The data reported here are derived from 1 of the 2 focus groups conducted as part of a larger study. For inclusivity and flexibility in recruitment, participants were able to join either session according to their convenience. Data collection was concluded once thematic saturation was reached and when additional sessions were unlikely to yield new insights or generate further data.

Having multiple points of data collection created a degree of semilongitudinal data to capture parents' evolving views, while focus groups have the potential to expand data as participants' views may be supported or challenged by engaging in collective dialogue with others [18]. A semistructured interview guide was developed with questions designed to explore parents' data privacy perspectives in the use of IFAs and in their broader digital parenting (Textbox 1).

Textbox 1. Main questions from the interview guide.

The following were the semistructured interview questions:

1. What factors influence new parents' choice to use or not use infant feeding apps?
2. How do parents use infant feeding apps and what do they see as the benefits and drawbacks?
3. What understandings do parents have regarding the terms and conditions of their app use, and the resulting reuse of data and harnessing of data flows?
4. When, how, and why do parents start or end the use of infant feeding apps as part of their infant feeding practices?

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Participants and Recruitment

A total of 24 English-speaking participants were interviewed in 2024. Although recruitment targeted parents of infants aged 0 to 4 years, the actual age distribution was 1 to 10 months at the time of the first round of interviews. The IFA project collected qualitative data from participants through 2 rounds of semistructured interviews, followed by a series of focus groups. Of the initial 24 participants who took part in a first-round interview, 22 returned for a second-round interview approximately 6 months later, with 7 returning for a focus group. All participants were breastfeeding mothers of children at the time of the first round of interviews. A total of 46 interviews and 2 focus groups were conducted online between mid-2023 and mid-2024. Recruitment took place online via social media, predominantly through Facebook mothers' groups, using the snowball method. Participants received an AUD $50 (US $33) gift card at each data collection point.

Data Collection

The semistructured interviews were conducted online. The interviews were recorded with a digital audio-recording device and transcribed by the same researcher who performed the interviews. The interviews lasted a mean of 45 (SD 15) minutes.

Analysis

Interviews and focus groups were transcribed and deidentified before coding in NVivo software (version 1.7.1; Lumivero). Before coding, the research team read through the interviews several times to become familiar with the transcripts and achieve deep immersion in the data. Subsequently, initial codes were systematically developed inductively and organized into subthemes and overarching thematic categories. Multiple researchers assisted in reviewing and examining the coded material within each theme and assisted in defining and refining the themes through the writing up of this study. Of the 5 final codes, the most relevant to this paper is number 4, "Data and/or Privacy Practices," which was divided into further subcategories and themes.

To ensure rigor, interpretations of the coded data emerged from ongoing iterative discussions between all authors of the paper using reflexive thematic analysis [19]; as such, the authors acknowledge that their differing disciplinary and lifeworld perspectives influence their readings of the data, and that more comprehensive readings are potentially made accessible through interdisciplinary dialogue. This study employed reflexive thematic analysis to systematically elucidate patterns of meaning within parents' narratives. The analytic process was strengthened by deliberate reflexivity, enabling critical examination of researchers' preconceptions and fostering methodological transparency. Furthermore, the integration of surveillance theory as an interpretive framework informed the development of latent codes, thereby enhancing the conceptual depth and analytic rigor of thematic constructs.

In the context of this research, IFAs constituted any smartphone app that assisted parents to support or track their children's feeding routine; overarchingly, this meant breastfeeding mothers; however, as the data are semilongitudinal, some participants were in the process of shifting to solid food. The most common IFAs used by parents were "Huckleberry" and "Solid Starts." Of the 24 participants, 6 either did not regularly use IFAs at the time of the research or had never regularly used IFAs.

Ethical Considerations

Data collection was undertaken by researchers from the Edith Cowan University node of the Australian Research Council Center of Excellence for the Digital Child under the oversight of Chief Investigator Professor Lelia Green. The project received approval from Edith Cowan University's Human Research Ethics Committee (approval number 2022 - 03677-GREEN) and was funded by the Australian Research Council Center of Excellence for the Digital Child (project number CE200100022).

All eligible participants were provided written information about the study, and their consent was obtained before data collection.

Results

Participant Characteristics

A total of 24 English-speaking participants were interviewed in 2024. Participant characteristics are reported in Table 1. Infants ranged in age from 1 month to 10 months at the time of the first interview, with balanced representation across genders and the highest proportion observed at 7 months. The duration of IFA use varied between 6 and 24 weeks at the time of the last interview and/or focus group. The majority of participants were based in Western Australia (n=13), with additional representation from New South Wales (n=4), Queensland (n=4), Victoria (n=2), and the Australian Capital Territory (n=1). Across the sample, patterns of parental engagement with IFAs were diverse. While some participants reported minimal or selective use, others actively engaged with multiple apps. Huckleberry, Solid Starts, and Wonder Weeks were the most frequently used.

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Table . Overview of participant characteristics.

Family number	Mother's pseudonym	Child age[a] (gender)	Interview 1	Interview 2	Focus group
F01	Ariel	6-month-old female twins, has not used IFAs[b] with current infants.	✓	✓	—[c]
F02	Helena	6-month-old female, has not used IFAs with current infant.	✓	✓	—
F03	Cassandra	6-month-old female, uses 1 IFA.	✓	✓	—
F04	Elspeth	1-month-old male, never used IFAs.	✓	✓	✓
F05	Sinead	10-month-old female, previously used one IFA, ceased at 3 months.	✓	✓	—
F06	Felicia	7-month-old female twins, has never used IFAs.	✓	✓	✓
F07	Hyacinth	5-month-old female, uses 2 IFAs, ceased another.	✓	✓	✓
F08	Cynthia	6-month-old male, uses 2 IFAs.	✓	✓	✓
F09	Lauretta	6-month-old male, uses 2 IFAs.	✓	✓	—
F10	Marion	7-month-old female, 1 IFA ceased at 5 months.	✓	✓	—
F11	Yennifer	10-month-old male, has never used IFAs.	✓	✓	—
F12	Lillian	6-month-old female, has never used IFAs.	✓	✓	—
F13	Lucia	5-month-old male, uses 2 IFAs.	✓	✓	✓
F14	Semra	8-month-old female, uses 2 IFAs.	✓	✓	—
F15	Morgana	7-month-old male, uses 1 IFA.	✓	—	—
F16	Lydia	7-month-old female, uses 1 IFA, ceased another at 3 weeks.	✓	✓	—
F17	Whitney	8-month-old female, uses 2 IFAs.	✓	✓	—
F18	Patty	8-month-old female, uses 1 IFA, ceased another at 4 months.	✓	—	—
F19	Bella	6-month-old male has never used IFAs.	✓	✓	✓
F20	Babette	5-month-old female, uses 1 IFA, ceased another at 4 months.	✓	✓	—
F21	Paris	6-month-old male, one IFA ceased at 5 months.	✓	✓	—

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Family number	Mother's pseudonym	Child age[a] (gender)	Interview 1	Interview 2	Focus group
F22	Lisette	6-month-old female, uses 1 IFA, ceased another at 5 months.	✓	✓	—
F23	Kelsie	7-month-old male, uses 1 IFA, trialed one other.	✓	✓	—
F24	Bernadette	5-month-old female, uses 2 IFAs.	✓	✓	✓
Total	24 (mothers)	—	24	22	7

[a]Age of child at time of participating in first interview.

[b]IFAs: infant feeding apps.

[c]Not applicable.

Overview

Across the entire project, 4 initial codes were generated through NVivo software (version 1.7.1). The final initial themes included the following:

1. Choice to adopt IFAs (1.A) or to avoid them (1.B).
2. Use of IFAs for record-keeping (2.A) or as a source of support (2.B).
3. Use of alternatives and other non-IFAs (3.A) or non-app modes of support (3.B).
4. Data privacy, including awareness or acceptance of terms and conditions (4.A), experiences or knowledge of risk-changing events, such as hacking or political issues (4.B), and ambivalence toward privacy (4.C).
5. Breastfeeding beyond the IFA context, which included positive (5.A) and negative aspects (5.B).

This paper specifically focuses on Theme 4: Data Privacy, which was refined through reflexive thematic analysis across 3 iterative cycles. During this process, the 3 initial codes were refined and reorganized into two main themes:

1. Awareness and/or acceptance of terms and conditions (subthemes included "data privacy laxity and normalization" and "benefits outweigh risk").
2. Risk mitigation behaviors.

Theme 1: Awareness and/or Acceptance of Terms and Conditions

Major Study Themes

A major theme that emerged from the mothers' interviews and the focus group was mothers' awareness of the privacy risks associated with IFAs, coupled with a pragmatic acceptance of the terms and conditions governing their use. Two subthemes reflected this. The first included "Data privacy laxity and normalization," where mothers normalized and resignified the routine acceptance of surveillance and minimal engagement with terms and conditions. The second included "Benefits outweigh risks," where the practical utility of these apps outweighed potential risks despite underlying discomfort.

Subtheme 1: Data Privacy Laxity and Normalization

Many participants expressed awareness of data collection and privacy risks associated with IFAs. However, they often described a sense of resignation or acceptance toward these practices, particularly in relation to lengthy and complex terms and conditions. Rather than carefully reviewing such documents, most participants reported clicking "accept" as part of everyday app use, recognizing the trade-off between convenience and privacy. Lydia, for example, shared:

> *I just click accept, you know what I mean? I'm not going to put photos on there [...] my understanding was limited.* [Lydia, 7-month-old daughter, uses one IFA, ceased another at 3 wk]

Other participants also commented:

> *I don't normally think about data collection and privacy and stuff in apps; it's just so common, it's supposed to be so much more helpful in our lives […] I don't have time to sit there and read a 20-page long terms and conditions on your data collection processes.* [Bernadette, 5-month-old daughter uses two IFAs]

> *.....I can't say I've read the terms and conditions of every app that you use because who does? I go in with the assumption that nothing's private cause a lot of them.* [Helena, 6-month-old female, uses one IFA, ceased another at 6 wk]

One participant stated:

> *I assume that it's all aggregated data for sale.* [Helena, 6-month-old daughter, uses one IFA, ceased another at 6 wk]

For some mothers, the nature of the data input reduced their concerns in relation to privacy:

> *I don't feel as though I'm providing data that's too personalised, that's a threat I suppose to have on there. It's just times.* [Bernadette, 5-month-old daughter uses two IFAs]

Lucia shared a similar view, expressing little concern over data related to feeding or diaper changes:

> *I don't really think about the data in relation to the baby stuff. [...] How many times I'm getting my boob out or changing nappies, I don't really care if anyone knows.* [Lucia, 5-month-old son, uses two IFAs]

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Many mothers described feeling resigned to the ubiquity of data collection across digital platforms, recognizing that similar practices occur on widely used services like Facebook and Google.

> *[...] we're so used to it (refers to data used for marketing) [...] once you search for one thing they feed you 10 other things related to it and I still use Facebook, I still use Google and everything so I probably would still use it but I would feel a little bit strange or uncomfortable with it, I guess.* [Cassandra, 6-month-old daughter, uses one IFA]

Hyacinth echoed these views, emphasizing that data collection through IFAs does not worry her because data are being collected from phones in general. She explained:

> *[...] I don't really care that much either. I think with data collection our data's being collected anywhere. Any time we pick up our phone, our data's being collected from somewhere, and I guess that kind of data that I'm entering into the app [...] I don't really see how they can use that in any – they can use it however they want; it's not really affecting anyone.* [Hyacinth, 5-month-old daughter, uses two IFAs, ceased another]

Interestingly, the wider policy environment shaped how some participants thought about privacy issues and helped normalize data sharing. This was highlighted in Babette's comment, which contrasted data privacy laws between the EU and Australia.

> *I really hate the EU data privacy laws...you have to repeat your information all the time because of data protection...that's one of the reasons why I decided to move back to Australia.* [Babette, 5-month-old female, uses one IFA, ceased another]

As several participants explained, this behavior reflected not ignorance but a pragmatic response to the demands of parenting and perceived inevitability of data sharing in digital environments. Mothers normalized data sharing, and strict rules were sometimes seen as frustrating rather than protective, reinforcing that surveillance of data was perceived as a normal part of everyday digital life.

Subtheme 2: Benefits Outweigh Risks

Participants spoke about their willingness to forgo privacy concerns in exchange for higher levels of perceived convenience. Some participants differentiated between digital apps, tolerating IFAs while expressing greater concerns about other platforms like Facebook and Instagram.

The majority of mothers described focusing more on the app's utility than on the potential data privacy violations. The utility of IFAs in health care contexts and everyday parenting often outweighed privacy concerns. Patty highlighted their value, stating:

> *When I would go to the child health nurse checkup, I would have all the data and there ready to go. I knew what my trends were, what the averages were.* [Patty, 8-month-old female, uses one IFA, ceased another]

The same participant reframed targeted advertising as supportive:

> *Being suggested a product, I think that's helpful for mum.* [Patty, 8-month-old female, uses one IFA, ceased another]

Cassandra expressed that despite knowing that her data were being collected, she would continue to use an app as well:

> *I've been reading a lot about the privacy of data in those apps which I also used when I was trying and pregnant...Obviously it's not such a concern that it's stopping me using it 'cause I'm still using it and putting in heaps and heaps and heaps of data.* [Cassandra, 6-month-old female, uses one IFA (INT1)]

Bernadette's comments provide further insight. In the early stages of using an IFA, she wasn't focused on privacy concerns as her primary goal was to reduce the mental load of caregiving:

> *In the beginning it probably wasn't something that I was thinking of; I was looking for something to take a mental load off.* [Bernadette, 5-month-old daughter uses two IFAs]

However, after experiencing a data breach that compromised her online accounts, she now views data privacy differently, though it wasn't a priority when she first started using the app.

Another mother added how common it is to overlook privacy considerations, reflecting on the convenience that IFAs provide and on prioritizing their baby's needs:

> *Yeah. I don't know if it would have stopped me from using it or not, but I don't think it would have stopped me from using it.* [Paris, 6-month-old son one IFA ceased at 5 months]

Elspeth and Felicia have never used an IFA but shared a similar experience, explaining that during the intense period of feeding, privacy was not a major concern and was not a consideration regarding whether to use an IFA or not. Although they did not use an IFA, they relied on other online resources. She said:

> *I haven't really thought about it collecting information so that probably hasn't been a primary concern for me.* [Elspeth, 1-month-old son, never used IFAs]

> *I wasn't thinking about privacy and data collection [...] I was thinking about what my baby needed from me at that time.* [Elspeth, 1-month-old male, never used IFAs (FG)]

> *I don't think I even thought about any concern about data privacy as something; again, I just think about what my baby needs.* [Felicia, 7-month-old female twins, has never used IFAs (FG)]

In retrospect, Elspeth was not sure her awareness of privacy concerns would have changed her behavior, noting that she uses other subscription services without much concern for data collection.

> *...It's such a complex world that's changing so much that I don't fully understand it enough. So, I don't*

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> *know how worried I am about it at this point, I suppose.* [Elspeth, 1-month-old male, never used IFAs (FG)]

Others, like Semra, who used 2 IFAs, rationalize that if their data are used for improving services or targeted marketing, they would still use the app if the benefits outweigh the risks.

> *I think they use it to sell me something [...] that's fine if they found something that was helpful for me.* [Semra, 8-month-old daughter, uses two IFAs]

Overall, while some awareness of privacy risks related to IFAs exists, most mothers do not engage deeply with the terms and conditions. Concerns about data privacy, while present, are often outweighed by the perceived utility of the IFAs, leading mothers to continue using them despite reservations. As Bernadette illustrates, the focus remains on immediate caregiving needs, and the complexity of digital privacy in today's world makes it difficult for parents to fully assess or act on these concerns and rarely deter IFA use.

Another mother added that data sharing that led to greater good through research may justify data collection or their personal information being tracked:

> *...] if they took all that data and used it for research purposes then I'd be fine with it because it's not like it's identified data, it's all deidentified, really, they don't have anything.* [Semra, 8-month-old daughter, uses two IFAs]

This suggests that while some participants also demonstrated varying levels of concern over privacy issues among different digital apps, IFAs were perceived as being less invasive compared with other apps.

Collectively, both themes illustrate a tension between risk awareness and acceptance, underscoring how perceived utility often outweighs concerns about surveillance and data trails. While it is true that many users of smart and digital apps commonly skip reading terms and conditions, our findings extend understanding where mothers' quotations revealed how parents specifically interpret and negotiate such practices in the context of infant-feeding apps, as shown in the next section. For example, participants discussed privacy concerns and risk management in relation to their children's health, which reframes a general behavior into a context-specific act. Thus, while the behavior itself may be widespread, its meaning and implications in the domain of infant care are unique to this group.

Theme 2: Risk Mitigation Behaviors

Under this theme, mothers reflected on the measures they employed to mitigate their concerns around data privacy. This included various measures, such as selective disclosure when participants withheld or altered personal details, or avoiding child images or using shortened names.

Some mothers adopted privacy-conscious behaviors such as using pseudonyms or incomplete personal information (eg, incorrect birth dates) to reduce their exposure.

> *[...], I tend to not put anything majorly personal on these apps so I don't have my real name – I have my name but my shortened name so just Patty and [Joey] like I don't put very big identification things on there for that reason probably.* [Patty, 8-month-old daughter, uses one IFA, ceased another at 4 mo]

Similarly, Lucia emphasized her ability to control disclosure, stating:

> *We're pretty careful with any forms we fill out for the hospital... say don't add to my health record and things 'cause it just feels a bit creepy'.* [Lucia, 5-month-old male, uses two IFAs]

Several other mothers, such as Helena, Lauretta, and Semra, shared actions that reflected privacy-conscious behavior and increasing awareness of data vulnerabilities and concern over potential surveillance of their data:

> *[....], they won't let you use it unless you put in the name and the date of birth and that kind of thing, I just make it up, I use something different cause I'm like that doesn't matter. If they're going to give age-based recommendations then I'll change it by two days or something like they just don't need that info.* [Helena, 6-month-old daughter, uses one IFA, ceased another at 6 wk]

> *[....], I'm also probably mindful when I am putting things online that I don't put anything that's too disclosing about where I live or anything like that so they're not going to be getting any data that I wouldn't care if anyone knew.* [Lauretta, 6-month-old son, uses two IFAs]

Another participant echoed:

> *I probably didn't really care too much for Huckleberry and Solid Starts, things that I don't even put too much of my personal information in so it's not linked to my Facebook or any of my applications and I can choose whether I put in her real name, her fake name, a photo.* [Semra, 8-month-old daughter, uses two IFAs]

Overall, mothers' awareness of privacy risks generally did not strongly influence their behavior, and many admit they haven't given much thought to the potential risks. As Morgana noted, her concerns about data privacy increased after a Facebook hack, leading her to reduce her online activity:

> *I've pulled back on sharing a lot of information [...] I've deleted a couple of apps and signed out of them because of it.* [Morgana, a 7-month-old male, uses one IFA (INT1)]

Our findings suggest a dynamic interplay between awareness of surveillance, leading to selective disclosure and deidentification. It shows that mothers acknowledged vulnerabilities and privacy concerns, yet they actively negotiated their engagement and adopted everyday privacy practices that allowed continued use with unease.

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Discussion

Principal Findings

In this study, we explored mothers' understanding of the terms and conditions associated with IFAs and their data privacy concerns. The first emerging theme was awareness and acceptance of terms and conditions. Our findings show that participants demonstrated awareness that engaging with IFAs involved data collection and potential privacy risk. Despite this, many described accepting terms and conditions without reading these in detail, often citing limited time or the perceived inevitability of such practices. For some, this acceptance was framed as a trust in implied digital security, while others expressed resignation, noting that data collection is now an unavoidable aspect of online activity. A few participants articulated the belief that "everyone's data are up for sale," reflecting a broader recognition that privacy compromises are inherent in the use of digital devices and apps.

Building on these insights, it is important to note that control over data remains a fundamental right. The Australian Competition and Consumer Commission's report [20] emphasized reforms to ensure consumers are informed and protected in how their data are used (p. 3). Privacy is negotiated through balanced disclosure with protection [21], but information shared through IFAs may persist, be widely distributed, and be repurposed in unintended ways [22-25]. Our findings show that while some participants acknowledged the potential of their data to be distributed or reused, most participants expressed acceptance of such practices as an unavoidable aspect of digital engagement. In Australia, the Privacy Act sets out 13 Australian Privacy Principles based on a notice and consent model, which places responsibility on individuals to manage their own personal information and to interpret complex privacy policies [26]. For many participants, reviewing such policies was unrealistic due to time constraints or trust in implied protections, a finding consistent with prior research [27]. These findings underscore the limits of privacy self-management and reinforce calls for a mandated "privacy by design" approach, embedding protections into platform development from the outset [28].

Digital privacy is critical for all users of platforms that collect personal data and is widely regarded as essential for protecting consumers from unwanted access and misuse [29].

Privacy carries a positive value, while invasion of privacy is seen as a violation of a protected interest. In this way, participants in this study reflected the broader social narrative that privacy should be protected in digital space [30]. This is consistent with the right to privacy in the digital age that was affirmed by the United Nations General Assembly and the Human Rights Council [31], requiring that any interference meet the principles of legality and proportionality, while noting that emerging technologies, such as artificial intelligence, can affect this right [32].

Despite these protections, many remain resigned to threats from big data, cloud computing, and profiling [33]. Participants in the study accepted that app-collected data could be commodified, expecting it might be used or sold. This raises complex questions about when online data are classified as public or private, whether their reuse constitutes intervention without consent, and how individuals' privacy can be safeguarded [34].

The second emerging theme was risk-mitigation behaviors, where participants described exercising a degree of control over the data they shared by adopting strategies to mitigate perceived risks. These included using pseudonyms rather than real names and obfuscating identifiers such as date of birth. Participants also constructed personal boundaries around what information they considered acceptable to disclose. For example, not sharing visual images was important to one mother, while another noted that the type of information shared, such as the number of feeds or nappy changes, did not feel too personal to share more widely.

Overall, participants perceived the benefits of engaging with IFAs as outweighing the potential risks. Many described a willingness to forgo privacy concerns in exchange for higher levels of perceived convenience. The majority of mothers described focusing more on the mobile app's utility than on the potential data privacy violations. Trust in the security of digital systems and a belief in having some control over the information shared contributed to this sense of acceptance. These findings highlight the complex interplay between utility and privacy trade-offs and are discussed in relation to current debates on data privacy in online environments.

Some participants in this study believed they could protect their privacy by altering key identifiers, such as date of birth. This highlights which types of information about themselves were considered more sensitive than behavioral data like feeding or changing routines. Obscuring personal information is not new and is practiced offline as well [35], with individuals deciding how much to reveal in different contexts.

Online, people sometimes create "Amateur Artists" [36] to protect their privacy. These disguises can range from complete reinvention [37] to small changes, like those seen in this study, where mothers adjusted details but still felt their data reflected real experiences while giving them some protection. Not everyone supports this practice. Zuckerberg argues that having more than one identity shows a lack of integrity and that people should present a single, authentic self online [38,39]. Similarly, Google's Eric Schmidt claimed that "Innocent people have nothing to hide" [40], suggesting privacy concerns are unnecessary.

Our finding is that self-disclosure is complex, with different views on what counts as personal and sensitive information. Literature highlights dimensions such as the depth and value of what is shared [41]; for example, demographic details may be seen as less sensitive than private photos or emotions. However, individuals may share private data unknowingly due to limited risk awareness [42,43], lack of knowledge about ways to protect data [44], or not being aware of how data are distributed postsubmission [45].

Consent remains central to the use of digital data; reliable collection depends on mutual respect and trust between parties [30]. IFAs that require login, membership, or subscription create

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a sense of "perceived privacy," yet most participants in this study did not expect their data to be shared beyond the app and may not have realized this was possible [46]. Consistent with earlier reports, concerns relating to the security of their data have led some users to stop or delete IFAs [47,48], but research on the link between privacy and security in mobile apps remains limited [49,50]. Evidence shows that privacy risks reduce trust in app security, while clear policies can strengthen it. In the health context, privacy can only be assured where individuals control their information and prevent unnecessary disclosure [51,52]. Digital safety is increasingly recognized as essential, particularly for children and young people [53]. Building digital safety requires self-efficacy, knowledge, and skills related to managing risks. Awareness of digital safety can assist parents in adopting strategies to safeguard themselves and their families [53].

The findings of this study were limited by the restricted demographic data collected and the sample profile. This study was limited to English-speaking Australians, breastfeeding mothers recruited mainly via Facebook, which may limit diversity and generalizability. This recruitment strategy may have introduced selection bias and limited the diversity of perspectives, particularly among culturally and linguistically diverse parents or those with lower levels of digital literacy. Consequently, the findings should be interpreted within the context of the participant profile and may not fully reflect the experiences of caregivers from different backgrounds.

Another limitation is the absence of information on socioeconomic and educational data, which further constrains contextual interpretation. These factors may have influenced perspectives on digital privacy and engagement with IFAs, and their absence restricts the ability to fully contextualize findings. However, the study was designed to focus on parents' experiences and perceptions of IFA use rather than to compare outcomes across demographic groups. While this approach provided valuable insights into usage patterns and parental perspectives, future studies would benefit from including broader demographic variables to capture how diverse backgrounds may shape digital practices and privacy concerns. Use of mixed methods and longitudinal approaches can enrich data by combining both qualitative and quantitative insights into privacy literacy and behaviors.

Conclusions

Parents of young children carry dual responsibilities as advocates and primary caregivers [54], and many now rely on digital apps, such as IFAs, to track and manage health behaviors. Breastfeeding as a socially and emotionally charged practice has become increasingly mediated through digital tools, reflecting the demand for accessible, time-sensitive information [55,56]. While such technologies present opportunities for increased access to education and health promotion [57], they also introduce risks that require careful negotiation [53]. Our study shows that mothers' engagement with IFAs is shaped by 2 key dynamics: awareness and acceptance of terms and conditions and risk-mitigation behaviors. This paper has highlighted the varying levels of awareness among mothers of how data about themselves and their child can be used and their expectations of how personal information will be kept confidential and secure through their engagement with a breastfeeding mobile app. The findings highlight the need for action toward privacy by design, transparency in privacy policies, and nonalienation in relation to the use of data. The use of IFAs reveals a paradox: mothers acknowledge the inevitability of data collection, yet actively resist through boundary-setting and risk-mitigation. Embedding privacy by design and fostering genuine trust in IFAs is essential to protect both parental and child well-being

Our findings highlight the importance of transparent privacy policies and respect for contextual integrity and user-centered safeguards that enhance digital safety, protect against hidden risks, and ensure accountability in data use.

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Conflicts of Interest

None declared.

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Abbreviations

FG: focus group
IFA: infant feeding app

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The Technologically Mediated Motherhood Constellation: Smartphone and AI as Novel Actors in Maternal Psychic Organization

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Abstract

The Daniel Stern concept of the motherhood constellation describes a distinctive psychic organization that emerges in the transition to motherhood, structured by 3 relational discourses and 4 thematic concerns: safeguarding infant life and growth, establishing primary relatedness, securing a matrix of support, and reorganizing maternal identity. Formulated in the mid-1990s, this framework preceded the pervasive integration of smartphones, social media, and artificial intelligence (AI) into everyday life. Contemporary mothers now care for infants in environments saturated by online information, connectivity, and AI-mediated support, raising questions about how these factors participate in and reshape the Stern architecture. This theoretical paper argues that smartphones and AI function not as neutral tools but as systemic actors within the motherhood constellation. Drawing on the Stern model, attachment theory, mentalization research, ecological perspectives, sociotechnical theory, and empirical work on technoference, maternal smartphone use, digital parenting, online maternal communities, and AI-based mental health interventions, we conceptualize digital technologies as entities whose affordances co-structure maternal psychic life. Available findings indicate that they simultaneously expand access to information and support, introduce interactional disruptions, and create new, partially algorithmic matrices of support, with effects moderated by patterns of use, maternal reflective functioning, child characteristics, platform design, and socio-structural conditions. We propose a technologically mediated motherhood constellation, in which smartphones and AI enter all 3 discourses (mother–own-mother, mother–self-as-mother, and mother-infant) and all 4 themes. Rather than asking whether technology is "good" or "bad" for motherhood, we outline a spectrum from technology-enhanced to technology-disrupted constellations and derive implications for clinical practice, research, technology design, and social policy.

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KEYWORDS

technoference; digital motherhood; artificial intelligence in mental health; relational third; Daniel Stern

Introduction

In *The Motherhood Constellation*, Stern [1] describes a specific configuration of psychic life that comes to the foreground during pregnancy and early motherhood, organizing the mother's experience around the infant and reshaping her relations to the past, present, and imagined futures. This constellation is structured by concerns about the infant's life and growth, the establishment of a primary emotional relationship, the securing of a sufficiently reliable matrix of support, and the integration of "mother" into the woman's broader identity. These thematic concerns are enacted within 3 interlocking discourses: the mother's dialogue with her own mother and the internalized maternal figure; her ongoing dialogue with herself-as-mother; and the dynamic, moment-to-moment interactional discourse with the infant [1].

Stern's [2] account is inseparable from his earlier work on infant experience and affect attunement, which conceptualizes infant-caregiver intersubjectivity as being built from microregulations of gaze, vocalization, touch, and rhythm. The motherhood constellation is therefore not an intrapsychic structure operating in isolation, but a relational organization coconstructed with the infant, the family, and the broader sociocultural environment. The matrix of support is not merely instrumental; it enters the mother's internal world as anticipated and remembered responses that scaffold her sense of being carried while she carries the child [1].

When Stern developed this model in the mid-1990s, everyday communication and support networks were still largely analog. Information about pregnancy and infant care was obtained from health professionals, printed manuals, and intergenerational transmission. Social support was anchored in copresent kin and

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local communities. Since then, smartphone penetration has reached very high levels in high-income countries, and the early months of motherhood have become densely interwoven with digital media. Qualitative work by Lupton [3] shows that women routinely use websites, apps, blogs, forums, and social media as central resources during pregnancy and early motherhood, describing them as essential for managing anxiety, isolation, and informational uncertainty. Mothers report consulting online sources multiple times per day for questions about sleep, feeding, crying, and health, often before contacting professionals or relatives [4].

Parallel to this informational shift, a rapidly growing body of literature on "technoference" has documented that parental digital technology use can intrude into parent-child interactions in ways that reduce sensitivity and responsiveness, and is associated with child behavior problems [5]. The longitudinal work by McDaniel and Radesky [5] indicates bidirectional associations between parent technology use, parenting stress, and child behavior. Experimental adaptation of the still-face paradigm to smartphone use suggests that even brief episodes of maternal device engagement can elicit infant responses resembling those seen in classic still-face conditions, including increased negative affect and efforts to reengage the caregiver [6].

However, the same period has seen digital media emerge as vital support infrastructures. Online parenting communities provide emotional validation, practical advice, and a sense of belonging, especially for parents who feel isolated [4,7]. Empirically, participation in supportive online communities has been associated with reduced depressive symptoms and increased parenting self-efficacy in some studies [7]. Conversational agents such as Woebot, although not designed specifically for mothers, have shown promising effects in reducing depressive and anxious symptoms in young adults and perinatal populations, suggesting that artificial intelligence (AI)-mediated interaction can play a meaningful role in mental health support [8].

These apparently contradictory findings highlight the inadequacy of simple "screen time" or "digital good versus digital bad" frameworks. If the motherhood constellation is a context-sensitive organization of psychic life, then the introduction of smartphones, social platforms, and AI systems into maternal environments constitutes a structural perturbation. Technologies now enter all 3 discourses of the constellation as quasi-others that speak, respond, withhold, and curate. This study addresses three questions: how smartphones and AI function as actors within Stern's framework; through what mechanisms they influence maternal-infant coregulation, reflective functioning, and support matrices; and under which conditions they support or compromise the adaptive functions of the motherhood constellation.

We argue that digital technologies neither simply enhance nor straightforwardly disrupt motherhood. Instead, they participate in a technologically mediated motherhood constellation whose emergent properties depend on patterns of use, design features, maternal and infant characteristics, and socio-structural factors. This holistic framing aims to provide more than a mere theoretical update; it serves a crucial pragmatic purpose for both research and clinical practice. By identifying smartphones and AI as active "systemic actors" rather than neutral tools, we offer clinicians a more nuanced vocabulary to assess digital "technoference" not as a simple behavioral habit, but as a structural shift in maternal psychic organization. This perspective allows for the development of targeted interventions that address how digital interactions may either bolster maternal self-efficacy or, conversely, fragment the primary relatedness essential for infant development. Ultimately, the "technologically mediated motherhood constellation" provides a roadmap for navigating the complexities of modern parenting in an era where the "support matrix" is increasingly digital.

Theoretical Framework

Core Concepts of the Motherhood Constellation

The Stern motherhood constellation refers to a temporally bounded but developmentally consequential psychic organization that becomes dominant during pregnancy and the first years of the child's life [1]. Its thematic focus on life and growth—ensuring that the infant survives and thrives—is accompanied by an equally intense concern with establishing a primary relationship that feels emotionally alive and mutually responsive. Simultaneously, the mother must secure a supporting matrix that can carry her in the new role and reorganize her identity so that "mother" becomes integrated rather than dissociated or alien. These concerns permeate perception, fantasy, and action.

The 3 discourses through which these themes are elaborated are central. In the discourse of the mother with her own mother, transgenerational narratives, identifications, and conflicts are revisited and renegotiated. In the discourse of the mother with herself-as-mother, she evaluates, justifies, and sometimes critiques her caregiving self, using cultural and familial ideals as standards. In the discourse of the mother with the infant, she engages in concrete, embodied interaction whose microregulation feeds back into the other 2 discourses [1]. This triadic architecture makes the constellation inherently relational and context-embedded. The Stern framework was derived from a synthesis of longitudinal infant observations and extensive clinical interviews with parents in psychotherapy, rather than controlled laboratory experimentation. This approach allowed him to capture the subjective, phenomenological "internal world" of the parent during this transition. However, since its publication, the theory has been subject to various revisions. Critics have pointed out its traditional focus on the nuclear family, which may not fully represent the diversity of modern parenting structures (eg, single, same-sex, or adoptive parents). Furthermore, while Stern emphasized the "support matrix" as a physical and relational network, contemporary scholars argue that his model can at times overidealize maternal attunement, potentially neglecting the socioeconomic and structural stressors that modern parents face [9].

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Dyadic Regulation, Attachment, and Reflective Functioning

Work on dyadic regulation and attachment clarifies why disruptions in maternal attention may have outsized developmental consequences. The mutual regulation model developed by Tronick and Beeghly [10] conceptualizes infant–caregiver interaction as a process in which both partners attempt to coordinate states, inevitably failing at times but ideally repairing mismatches. Successful repair, rather than perfect synchrony, supports the infant's sense of efficacy and trust. Ainsworth's concept of maternal sensitivity—the capacity to perceive, interpret, and respond appropriately to infant signals—emerged as a robust predictor of attachment security in her classic Baltimore studies [11]. The attachment theory by Bowlby [12] cast these patterns in a developmental perspective, emphasizing how early experiences of caregiver availability are internalized as working models of self and other.

Mentalization theory adds a further layer by highlighting the importance of the caregiver's capacity to see the child as a psychological agent. Fonagy and Target [13] introduced parental reflective functioning as a construct that captures how parents understand and talk about their child's mind and their own. Later work has shown that higher reflective functioning is associated with more sensitive caregiving and more secure attachment, even under stress [14]. Reflective functioning also shapes how parents use and interpret external advice and support.

Digital technologies intersect with these mechanisms in several ways. Smartphones compete with infant cues for attentional resources, often via deliberately salient notification systems [5,15]. They provide alternative routes for affect regulation, including distraction and remote social contact, which may either support or displace dyadic coregulation. They offer additional "voices"—online communities, influencers, and AI systems—that comment on maternal practices and infant states, thereby entering into the discourse of the mother with herself-as-mother and with her own mother. Understanding maternal-technology relations, therefore, requires situating them within this regulatory and reflective architecture. For instance, AI-driven chatbots, such as Woebot, are increasingly used by women during the perinatal period to monitor mood symptoms and obtain immediate cognitive-behavioral support [8]. These tools effectively act as digital "auxiliary" supports within the maternal psychic space, providing a 24/7 interactive presence that complements the traditional matrix of support, yet also introduces new dynamics of technological mediation in the mother-infant bond.

Technology as a Systemic Actor: Ecological and Sociotechnical Perspectives

To conceptualize smartphones and AI as actors in the motherhood constellation, we draw on ecological systems theory and actor–network theory. Bronfenbrenner's [16] ecological model describes development as being shaped by nested systems, ranging from the immediate microsystem of face-to-face interactions to the macrosystem of culture and institutions [17]. Digital platforms complicate this stratification. A smartphone is present in the microsystem—literally on the sofa where the mother and infant interact—yet it is also an exosystemic conduit for work demands, news, and distant relationships, as well as a macrosystemic embodiment of economic and cultural logics.

Actor–network theory, particularly Latour's [15] work, emphasizes that nonhuman entities such as technologies participate in networks of action through their material properties and designed affordances. Smartphones prompt checking through push notifications, haptic feedback, and interface designs optimized for engagement. Social media platforms algorithmically curate content, promoting certain narratives of "good motherhood" while occluding others. AI systems generate text that appears conversationally responsive and emotionally attuned, even when it is based on statistical patterning rather than genuine understanding. These features shape human behavior without determining it.

In this paper, smartphones and AI are treated as systemic actors whose affordances, constraints, and algorithmic architectures coconstitute the motherhood constellation. They do so by capturing and fragmenting attention, structuring access to information, shaping perceived norms through algorithmic curation, and providing new forms of quasi-relational responsiveness. The question is not whether mothers "use" technology but how these actors participate in and modify the 3 discourses and 4 themes of the Stern framework.

Technoference as a Mechanism of Disruption

The construct of "technoference," developed by McDaniel and Radesky [5], captures everyday intrusions of digital devices into family interactions. In their longitudinal study of parents of young children, higher levels of perceived technoference—defined as technology-based interruptions during parent–child activities—were associated with more externalizing and internalizing problems in children, with parenting stress mediating part of this association [5]. This work extends earlier cross-sectional findings linking problematic parent technology use to less responsive parenting and more child behavior problems.

Experimental studies adapt the still-face paradigm to smartphones. Myruski et al [6] asked mothers to interact naturally with their infants, then to engage with their phones for a short period, and then to reengage. Infants exhibited increased negative affect, decreased gaze toward their mothers, and elevated attempts to reestablish interaction during the phone phase, followed by incomplete recovery in the reunion phase [6]. Systematic reviews, including those by Kildare and Middlemiss [18] and by Braune-Krickau et al [19], synthesize accumulating evidence that parental mobile device use is associated with reduced responsiveness, increased child bids for attention, and more conflict around device management [8].

From a motherhood constellation perspective, technoference can be conceptualized as a recurrent perturbation of the discourse between a mother and her infant. The smartphone becomes a third presence in the dyadic field, sometimes silent, sometimes loudly calling the mother away. Its interruptions are not neutral; they are structured by work demands, social expectations of constant availability, and persuasive design

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features. These microruptures in mutual regulation do not necessarily produce pathology, but they may accumulate in ways that shape an infant's expectations of caregiver availability and a mother's self-representations as "distracted" or "failing."

Technology as an Actor in the Parenthood Constellation: Empirical Evidence

This section revisits the 4 thematic concerns by Stern—life growth, primary relating, matrix of support, and identity reorganization—in light of empirical work on digital media, smartphones, and AI in maternal contexts.

Life Growth and Digital Information Seeking

Within the life-growth theme, perhaps the most visible transformation concerns how mothers access and evaluate knowledge about infant health and development. Lupton's [3] focus-group study with Australian mothers documented that digital media were experienced as central, sometimes indispensable, sources of information during pregnancy and early motherhood. Participants described using websites, apps, blogs, forums, and social media to understand bodily changes, interpret infant behavior, and manage anxiety, often multiple times per day [4]. They valued immediacy, anonymity, and the ability to triangulate among different sources.

An earlier work by Madge and O'Connor [7] on "parenting gone wired" similarly depicted the internet as a vital site of empowerment for new mothers, providing alternative information channels and virtual companionship during isolated periods. Mothers reported that online forums and email lists were often more responsive and less judgmental than offline supports, especially when discussing taboo topics such as regret, sexual difficulties, or ambivalence.

At the same time, research has identified an information-abundance paradox. High-frequency online searching about health has been associated with heightened health anxiety and "cyberchondria," as described by Starcevic and Berle [20]. In maternal samples, intensive online information seeking has been linked to increased worry, decision paralysis, and diminished confidence when digital sources offer contradictory or alarmist content [21]. Algorithmic curation can amplify such effects by preferentially surfacing engaging, emotionally charged posts, including extreme narratives about risk and harm [22].

Conversational AI complicates the life-growth landscape further. The randomized controlled trial of the Woebot chatbot by Fitzpatrick et al [8] demonstrated that young adults with depressive symptoms who interacted with the AI for 2 weeks showed significantly greater reductions in depression scores than controls, illustrating the feasibility of fully automated conversational cognitive-behavioral therapy. Although not perinatal-specific, such work has inspired perinatal chatbots that offer psychoeducation, symptom monitoring, and problem-solving strategies to pregnant and postpartum women. Early evaluations suggest high acceptability, with mothers valuing 24/7 availability, nonjudgmental tone, and rapid feedback when they fear something is wrong but feel reluctant to "bother" professionals [23].

From a motherhood constellation perspective, these digital and AI systems enter the life-growth discourse as additional "experts" and "consultants." They coexist with pediatricians, midwives, grandmothers, friends, and manuals, but their temporal characteristics—constant availability, instant response—and discursive style—concise, often prescriptive, sometimes algorithmically optimized for engagement—make them uniquely salient. Some mothers report feeling reassured when digital advice confirms their intuition; others feel increasingly dependent on constant checking, with uncertainty escalating rather than diminishing.

The transgenerational discourse is also affected. Ethnographic and interview studies suggest that mothers use online information both to challenge and to supplement family advice. Some describe the internet as a way to "fact-check" their own mothers and forge more autonomous caregiving identities, while others report that turning first to digital sources has weakened intergenerational conversations, especially when relationships are conflictual or geographically distant [7,24]. Transgenerational knowledge thus becomes one voice among many in a crowded informational field.

Primary Relating and Interactional Quality

The primary related theme focuses on the establishment of an emotionally attuned, mutually regulated relationship between a mother and her infant. Within this domain, technoference research directly implicates smartphones as actors in the dyadic field. McDaniel and Radesky's [5] concept of technoference highlights that seemingly minor, everyday technology interruptions during shared family activities are associated with more problematic child behavior. Their longitudinal work showed bidirectional links: parental technology use predicted later child externalizing behavior, and child behavior predicted later increases in technoference, partly via parenting stress [5].

The adaptation of the still-face paradigm to mobile devices by Myruski et al [6] provided an experimental analog. When mothers were instructed to attend to their phones for a brief period during interaction, infants responded with increased negative affect, protests, and attempts to regain attention, and they showed incomplete recovery after the mothers put the phones away [6]. The authors interpret these findings as evidence that device-induced caregiver unavailability may be experienced by infants as a kind of "digital still face."

Systematic reviews by Kildare and Middlemiss [18], as well as by Braune-Krickau et al [19], converge on the conclusion that parental device use is associated with reduced sensitivity, less verbal and nonverbal engagement, and more conflict around attention and devices [8,19]. A broader review of parental smartphone use and parent-child interactions describes how enhanced connectivity can distract parents from supervising and engaging with children, leading children to engage in risky or disruptive behaviors to recapture attention [8,25].

At the same time, mothers often experience smartphones as essential tools for their own emotional survival. Qualitative studies highlight that many women use phones during feeding,

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rocking, or contact naps to alleviate boredom, maintain their adult identity, seek support, or distract themselves from intrusive worries [4]. Some report that brief digital "time-outs" make it easier to regulate their own affect and return to the infant with more patience. This suggests that digital tools may support maternal regulation in ways that indirectly benefit the dyad, especially when offline support is sparse.

A more concerning pattern arises when screens are routinely used to regulate infant distress. Radesky et al [26] have described how parents increasingly rely on mobile devices to calm upset children, particularly in public settings or during family stress. Longitudinal work suggests that high reliance on screens for emotion regulation may be associated with slower development of self-regulatory skills and more behavioral difficulties, though causality is difficult to establish [26]. In the terms described by Stern, digital devices may come to occupy positions in the coregulatory system that would otherwise be filled by the caregiver's face, voice, and body.

A more optimistic strand of research documents how digital media can enhance primary relationships when used intentionally. Video calling enables ongoing contact between infants and distant relatives; infants quickly learn to respond to familiar faces on screen, and such interactions can sustain relationships that might otherwise deteriorate [27]. Apps explicitly designed to support sensitive parenting—for example, by prompting parents to observe and respond to infants' cues or by suggesting developmentally appropriate play—have shown preliminary promise in increasing parental confidence and observed sensitivity in small trials [23]. In these designs, digital tools are explicitly oriented toward supporting, rather than competing with, mutual regulation.

Matrix of Support in Digital Contexts

The Stern matrix of support encompasses the interpersonal and institutional resources that sustain the mother in her caregiving role [1]. Digital technologies have become deeply woven into this matrix. The study by Madge and O'Connor [7] on online mothering forums demonstrates that the internet functions as an "intimate public" in which mothers share experiences, seek advice, and normalize distress. Participants describe online communities as accessible, flexible, and less judgmental than offline spaces, particularly for sensitive topics.

Lupton's research similarly shows that mothers value online groups and social media for the sense of being "in it together," especially when facing sleep deprivation, loneliness, and contradictory professional advice [3]. These digital communities provide not only informational support but also emotional and identity-related support, with mothers describing experiences of recognition and validation when others articulate similar struggles.

Quantitative research on online peer support for perinatal mental health suggests that participation in moderated, supportive communities can be associated with reduced depressive symptoms and an enhanced sense of competence, though effect sizes are modest and heterogeneity is high [7]. However, passive browsing without interaction appears to be more strongly associated with social comparison and distress [28].

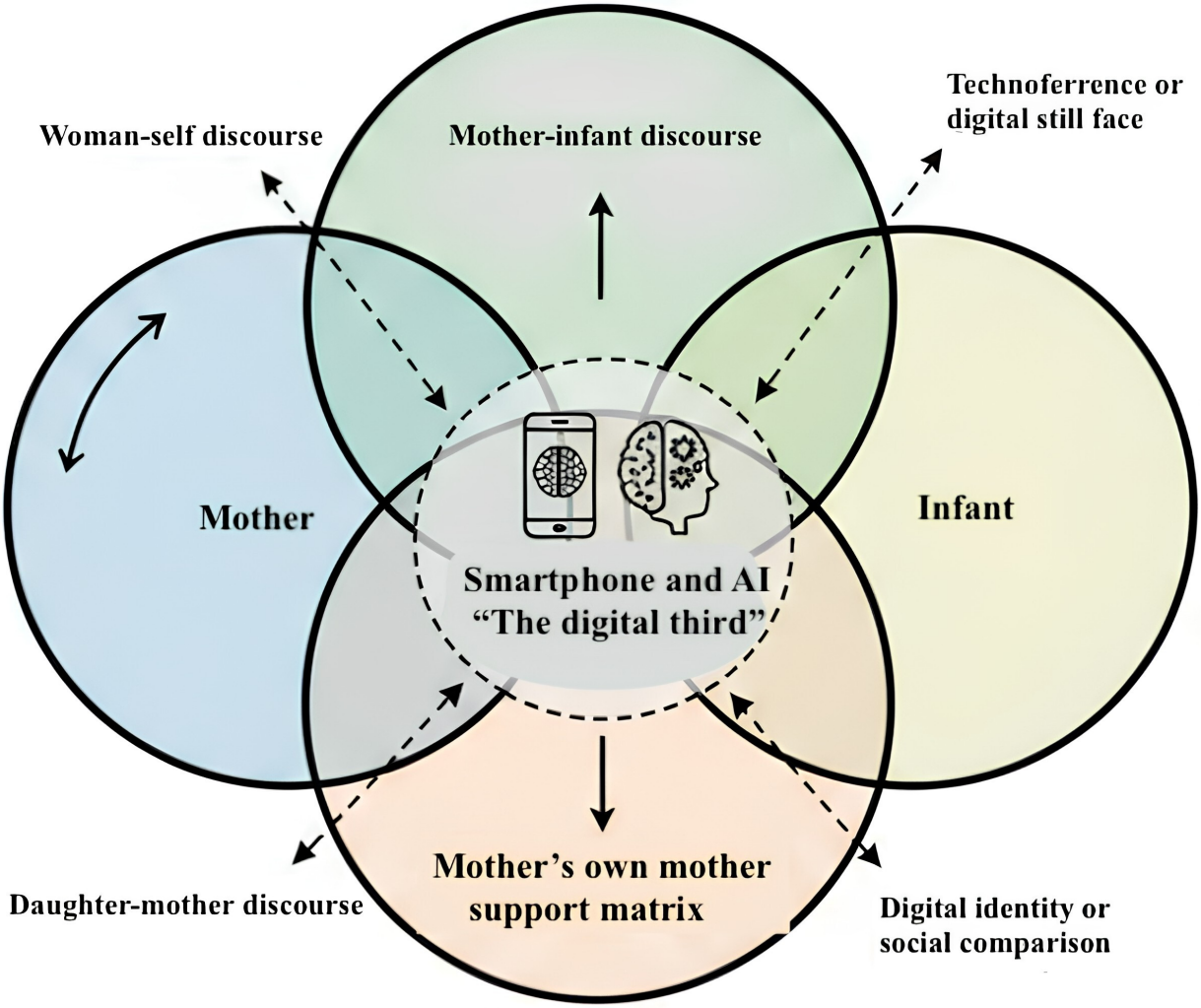
Here, the digital support paradox becomes evident. The same platforms that offer connection also expose mothers to highly curated representations of motherhood. Research on social media and body image has shown that exposure to idealized online images is associated with increased appearance dissatisfaction via social comparison processes [29]. Similar mechanisms likely operate in maternal domains. Studies of "sharenting" and maternal social media use report that mothers often feel pressure to present an image of "good mothering" on platforms like Facebook and Instagram, even when this feels discordant with their lived experience [30,31]. Such pressures can intensify guilt, shame, and self-criticism, especially among mothers who are already vulnerable to depression or anxiety.

The Algorithmic Matrix of Support: A Structural Reconfiguration

In the original framework by Stern, the "matrix of support" is not merely a logistical network but a psychic envelope—akin to Winnicott's "holding environment" [32]—that shields the mother, allowing her to safely undergo the regression necessary to identify with her infant. We contend that the integration of smartphones and AI induces a structural reconfiguration of this matrix, evolving it from an exclusively human-centric system into a hybrid, algorithmic matrix (Figure 1). In this mediated constellation, technology acts as a digital transformational object that reshapes the maternal experience through several complex mechanisms.

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Figure 1. The technologically mediated motherhood constellation framework. AI: artificial intelligence.



The first mechanism concerns the externalization of reflective functioning, as the use of virtual assistants and data-tracking apps shifts the process of meaning-making from an internal, intersubjective space to an external, objective one (as illustrated in the central node of Figure 1). While Stern described a mother learning to interpret her infant's cues through intuitive attunement, contemporary mothers often mediate this interpretation through algorithmic outputs. This suggests a risk of dementalization, where numerical data may supersede affective synchrony, transforming the matrix from an emotional container into a technical service provider.

Furthermore, the emergence of the so-called "digital third" causes a disruption of generational linearity, where the support matrix traditionally operated along a mother–own-mother axis, facilitating the transmission of transgenerational wisdom. The contemporary mother frequently experiences tension between the embodied, lived knowledge of her own mother and the optimized knowledge provided by algorithms. This conflict can weaken the daughter-mother discourse, resulting in a support matrix that is highly efficient in information delivery but potentially impoverished in terms of narcissistic support and relational warmth.

Finally, unlike the human matrix, AI is devoid of its own needs and never sleeps, creating an illusion of infinite availability. This hyperavailability induces a distortion in maternal psychic time, potentially bypassing the necessary frustrations and waiting periods that foster resilience. There is a concrete risk that algorithmic support functions as a psychic prosthesis which, while providing immediate anxiety relief, may interfere with the gradual consolidation of an autonomous maternal identity (Figure 1).

AI systems have begun to occupy positions within the support matrix as quasi-relational resources. Mothers using perinatal chatbots report feeling "heard" and "accompanied" during solitary night-time feeds, framing the AI as a safe, always-available listener for worries they might hesitate to share with others [23]. More broadly, work on digital mental health interventions suggests that users can develop attachment-like feelings toward AI "therapists," experiencing them as supportive companions [33]. In contexts of limited human support, AI may become a primary interlocutor, raising questions about substitution versus supplementation of human relationships.

Digital support is unequally distributed. Research on digital inequalities shows that low-income and marginalized families often have less reliable internet access, lower-quality devices, and fewer digital literacy resources, which limits their ability to benefit from online communities and health information [34]. Within mainstream parenting spaces, mothers of color and other

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marginalized groups report experiencing racism, classism, and judgment, which leads some to withdraw or create alternative, more inclusive subcommunities [35]. Thus, while digital platforms can expand the matrix of support, they can also reproduce and intensify existing inequities.

Identity Reorganization in the Age of Sharenting and Metrics

The identity reorganization theme concerns the integration of the maternal role into the self. Digital practices such as sharenting and online self-presentation are now central to this process. Blum-Ross and Livingstone's [30] analysis of "sharenting" describes how parents share stories and images of their children as part of crafting a digital self that is deeply relational and family-centered. A study by Kumar and Schoenebeck [31] of new mothers on Facebook similarly showed that posting baby photos functions as a "modern day baby book," a way of enacting and receiving validation for "good mothering."

These practices can support identity consolidation by providing external recognition and by enabling parents to narrate their experiences. They also create opportunities to challenge restrictive norms by sharing "honest" accounts of difficulty and ambivalence. Yet, they also generate tensions. Some parents experience a gap between the polished maternal persona they feel expected to perform online and the messy, ambivalent reality of their daily lives, leading to feelings of inauthenticity and self-doubt [31]. For others, metrics such as likes, comments, and shares become subtle but powerful validators of maternal adequacy.

Algorithmic curation shapes which maternal identities are most visible. Analyses of influencer culture suggest that high-visibility maternal personas often embody intensive parenting ideals, combining constant child-centeredness with aestheticized domesticity and entrepreneurial self-branding [36]. For parents who do not fit these templates—because of class, race, disability, family structure, or parenting style—digital landscapes can amplify a sense of being "out of place." Conversely, some parents find in niche online communities, models of motherhood that align more closely with their values, such as queer parenting networks, disability parenting accounts, or antiracist parenting spaces, thereby expanding the repertoire of possible parental selves.

In the terms described by Stern, the discourse of the mother with herself-as-mother is now partially externalized into digital traces that are archived, searchable, and represented via "memories" and recommendation systems. The maternal self becomes a datafied object, visible to others and to future versions of the self. This raises new questions about how the continuity of identity is negotiated when one's earlier maternal posts resurface years later, sometimes in altered relational contexts.

Toward a Technologically Mediated Motherhood Constellation

The empirical material reviewed above suggests that the Stern motherhood constellation remains a valuable organizing framework but requires systematic updating for digital contexts. Rather than proposing an entirely new model, we suggest that smartphones and AI are best conceptualized as additional actors within the existing architecture, giving rise to a technologically mediated motherhood constellation.

A central question in this reconfiguration concerns the place of the father and the broader paternal function. In the Stern original formulation, the father appears primarily as part of the supporting matrix rather than as a central organizer of the constellation [1]. By contrast, psychoanalytic and developmental work since Winnicott [32,37] has conceptualized the paternal function as a crucial "third" that interrupts the mother–infant dyad, limits omnipotence, and introduces the child into a shared reality structured by difference, law, and time. Winnicott's [32,37] account of the transition from subjective omnipotence to objective reality hinges on the infant's progressive discovery that the mother is not fully under their control, and that there are other relationships and demands that claim her attention, a process that is often mediated by the father or paternal figures. Later authors have elaborated on this notion of thirdness: Ogden's [38] "analytic third" describes a jointly created psychic field that is neither reducible to 1 partner nor the other; Britton's [39] work on the parental couple emphasizes that recognizing the parents' relationship to one another is a developmental achievement that requires relinquishing fantasies of exclusive possession and accepting the limits imposed by an already-existing adult couple. Feldman's [40] research on triadic synchrony similarly suggests that coordinated patterns of interaction among mother, father, and infant are associated with better socioemotional outcomes, with each caregiver contributing distinct but complementary regulatory inputs. Epidemiological work on paternal perinatal depression underscores that fathers' psychological functioning is not peripheral; rates of paternal depression in the perinatal period are substantial, and paternal symptoms are correlated with maternal depression and child outcomes [41,42]. Within a technologically mediated constellation, the position of this human third is increasingly shared with, and sometimes displaced by, digital actors. In many families, the everyday triad becomes mother-infant-smartphone, with the device occupying the position of the salient "other" that draws maternal attention away. Crucially, however, the device does not perform the structuring functions of the paternal third. It rarely introduces meaningful, tolerable frustration; instead, it offers a fantasy of limitlessness—endless information, on-demand soothing, perpetual availability—that may collude with omnipotent wishes in both mother and child. Rather than anchoring the dyad in a wider symbolic order, technology frequently presents itself as an extension of individual will and desire. The risk is that digital actors simulate thirdness by inserting themselves into the relational field without providing the kind of containing, law-bearing, reality-introducing presence that human others can offer. When fathers are physically or psychologically present

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and engaged, they can mediate and modulate digital influences, participating in the coconstruction of rules and boundaries around technology use. When they are absent, overwhelmed, or themselves absorbed in digital environments, the mother-infant dyad may be left to negotiate an asymmetrical relationship with powerful technological actors without the support of a robust human third [40-42]. The technologically mediated motherhood constellation must therefore be conceptualized not only as mother–infant–technology, but as embedded in a wider field that includes, or fails to include, paternal and other third functions.

Within this reconfigured constellation, the discourse between a mother and her own mother is increasingly conducted via digital channels. Messaging apps, video calls, and family group chats enable frequent, sometimes intense contact despite geographic distance. Grandmothers can "be present" at feeding, bathing, or milestones via live video, contributing advice and commentary in real time. At the same time, their authority is subtly relativized as mothers can instantly consult alternative digital sources. The grandmother's voice becomes one among many, strengthened by digital connection yet challenged by online communities and AI-generated expertise.

The discourse of the mother with herself-as-mother is deeply permeated by algorithmic input. Reflection on one's adequacy, values, and desires is no longer carried out solely in inner dialogue or in the consulting room, but in interaction with feeds that display other mothers, with notifications that solicit engagement, and with AI systems that provide interpretations and reassurance. The internal critic may be amplified by exposure to idealized images; the internally may be supported by online solidarity and by digital tools that normalize difficulty. For some mothers, conversing with AI systems may function as a form of guided self-reflection; for others, it may externalize and potentially displace their own reflective capacities.

The discourse between mother and infant is altered both directly by technoference and indirectly by the ways digital actors modulate maternal mood, knowledge, and expectations. The smartphone is often physically present in the triad of mother-infant-device; its potential to interrupt is built into its design. Yet, digital tools can also decrease maternal anxiety by providing quick access to trustworthy information or by connecting mothers to supportive communities, thereby freeing attentional and emotional resources for the infant. The same device that disrupts attunement in one context may enable it in another.

These dynamics suggest that the impact of technology on the motherhood constellation is neither uniformly beneficial nor uniformly detrimental. It is better conceptualized as distributed along a spectrum. At one pole lies a technology-enhanced constellation, in which digital actors expand the support matrix, provide reliable information, reduce isolation, and are used in ways that respect and protect the primacy of the mother–infant relationship. In the middle lies a technology-neutral constellation, in which digital tools are present but do not significantly alter core relational processes. At the other pole lies a technology-disrupted constellation, characterized by compulsive use, pervasive technoference, overreliance on digital regulation for both the mother and the infant, and heightened self-criticism driven by social comparison.

Movement along this spectrum is not fixed; mothers may oscillate between more and less adaptive patterns across days, developmental stages, and life events. Crucially, positioning on this spectrum is not solely an individual choice; it is shaped by structural factors such as work demands, availability of offline support, economic pressures, and the business models of platform providers. Recognizing the technologically mediated constellation as a systemic phenomenon rather than an individual failing is essential for ethical responses.

Clinical and Research Implications

Clinical Assessment and Intervention

For clinicians working in perinatal mental health and parent-infant psychotherapy, digital technologies have become integral to the ecology of caregiving. Assessment should, therefore, routinely include exploration of maternal technology use. Rather than quantifying "screen time," the focus should be on patterns, meanings, and contexts: when and why mothers reach for their phones, how they feel before and after digital engagement, what functions different apps serve, and how they experience the impact of technology on their relationship with the infant [43].

Video-based interventions offer a promising route. When mothers and clinicians watch recordings of everyday interactions together, moments of technoference can be observed and reflected upon: a notification that pulls attention away from the infant, a momentary shift in the infant's affect as gaze is withdrawn, or a tension between the perceived urgency of a message and the infant's bid for contact. These microevents can serve as starting points for exploring underlying needs, such as the mother's desire for adult contact, fear of missing work communications, or use of digital distraction to manage anxiety or boredom.

Interventions should avoid moralizing or prescribing blanket digital abstinence. Given that many mothers use digital tools to access support they might otherwise lack, pathologizing technology use risks compounding guilt. Instead, clinicians can collaborate with mothers to develop realistic "micro-boundaries"—for example, device-free feeding routines where possible; silencing nonurgent notifications during certain caregiving windows; or setting aside dedicated times for online support that do not compete with infant cues. Psychoeducation about infants' needs for contingent responsiveness, the mechanisms of technoference, and the paradoxes of online information can support more intentional use [44].

It is equally important to address the broader support matrix. When digital tools compensate for structural deficits—such as the absence of partner support, lack of paid leave, or limited access to professional care—interventions should validate these realities rather than individualize blame. Clinicians can help mothers identify and mobilize additional offline supports where feasible, and advocate at service and policy levels for conditions that reduce forced overreliance on digital actors [45].

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Research Priorities

Several research priorities emerge from this conceptualization. First, longitudinal studies are needed to examine how early maternal technology patterns relate to longer-term outcomes in attachment, child regulation, and maternal mental health, with attention to bidirectional processes. Most existing work is cross-sectional or short-term experimental; developmental trajectories remain under-specified.

Second, intervention research should move beyond screen-time reduction to test programs aimed at reshaping mothers' relationships with digital tools. Mentalization-based interventions that include explicit reflection on technology use, design-informed interventions that leverage apps to scaffold attunement rather than distraction, and community-based interventions that build hybrid online-offline support networks are all promising candidates.

Third, AI-specific research is urgently required. We know little about how mothers use general-purpose chatbots for parenting, how they experience AI-mediated support, and what meanings they attribute to these interactions. Mixed-methods studies could explore whether AI support functions as a gateway to human help-seeking or as a substitute for it, and how it influences the discourses of the constellation.

Fourth, moderator research should systematically examine how reflective functioning, attachment history, psychopathology, socioeconomic status, culture, and child temperament shape the impact of digital engagement. Cross-cultural comparative work is essential, as motherhood norms and digital infrastructures differ markedly across societies. Finally, collaboration with human-computer interaction and design researchers is needed to develop and evaluate "benevolent" technologies intentionally designed to support maternal-infant relationships rather than merely to maximize engagement.

Policy and Design Considerations

Recognizing smartphones and AI as actors in the motherhood constellation has implications for technology design and policy. At the platform level, features that limit intrusive notifications during likely caregiving times, prioritize credible health information, discourage infinite scrolling, and offer clear controls over data collection could meaningfully reduce technoference and anxiety without relying solely on individual self-control [28,46]. Parenting apps and perinatal chatbots should be developed in partnership with clinicians, researchers, and diverse groups of mothers, with explicit attention to safety, equity, cultural relevance, and pathways to human support when needed.

At the policy level, it is crucial to resist framing digital interventions as substitutes for structural support. No chatbot can compensate for the absence of paid parental leave, accessible childcare, or comprehensive perinatal mental health services. Overreliance on technological fixes risks shifting responsibility for coping with structurally generated stress onto individual mothers, exacerbating inequalities. Policies that strengthen the offline matrix of support—economic security, family-friendly work conditions, and equitable health care access—are foundational for any healthy technologically mediated constellation.

Ethical guidelines for AI in health care should be applied rigorously to perinatal applications. These include transparency about AI limitations, clear labeling of AI-generated content, robust data protection, and mechanisms for human oversight and escalation. Given the vulnerability of many mothers during the perinatal period, the commercial exploitation of anxieties through targeted advertising or persuasive design warrants particular scrutiny.

Limitations and Conclusions

This theoretical synthesis is subject to several limitations. The technological landscape is changing rapidly; platforms and AI capabilities evolve faster than empirical research can track. Some of the specific configurations described here may soon be supplanted by new forms of digital engagement. The empirical literature is heavily skewed toward Western, educated, urban samples; the technologically mediated constellation may look quite different in contexts with different kinship structures, caregiving norms, and digital infrastructures. Many studies rely on self-reported technology use and parenting behavior, which are prone to bias; more work using passive sensing, observational methods, and multiinformant designs is needed. Causal inference remains challenging; children's behavior influences parental technology use, and maternal mental health both shapes and is shaped by digital engagement.

Moreover, "technology" is not a single entity. Aggregating across platforms, devices, and uses risks obscuring critical differences between, for example, doom-scrolling news during night feeds, participating in a moderated peer-support group, and using a clinically designed app. Future research and theory should differentiate clearly among these modalities and attend to their specific relational affordances.

Despite these limitations, the Stern motherhood constellation remains a powerful lens for understanding early motherhood in digital societies. Conceptualizing smartphones and AI as systemic actors within this constellation clarifies how they participate in the 3 discourses and 4 themes that organize maternal experience. Digital actors expand access to information and support, create new spaces for connection and identity work, and provide tools for emotion regulation. They also fragment attention, introduce new forms of technoference, amplify social comparison, and can displace or distort intergenerational and local sources of knowledge.

The question is not whether mothers should use technology—for most, this is neither realistic nor desirable—but how digital actors can be integrated in ways that support, rather than undermine, life growth, primary relating, the matrix of support, and identity reorganization. This requires interventions at multiple levels: supporting mothers' reflective and intentional use; designing technologies that respect, rather than exploit, the vulnerabilities of the perinatal period; and addressing structural conditions that currently force many mothers to rely on digital scaffolding in the absence of adequate offline support.

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The technologically mediated motherhood constellation is already a reality. The task for clinicians, researchers, designers, and policymakers is to understand its dynamics and shape environments in which digital actors become allies, rather than adversaries, of the maternal and infant needs at its core.

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During the preparation of this paper, the authors used ChatGPT 5.0 to enhance linguistic clarity, readability, rectify grammatical errors, and refine academic expressions in non-native English sections of the manuscript. The artificial intelligence–generated suggestions were meticulously reviewed, modified, and validated by the authors to ensure adherence to scholarly standards. The authors confirm that no artificial intelligence–generated interpretations, conclusions, or data analyses were incorporated into the final content, and they assume full responsibility for the accuracy and originality of the research.

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Conflicts of Interest

None declared.

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Abbreviations

AI: artificial intelligence

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An Electronic Health Record–Based Intervention to Facilitate Primary Care Referrals to the Special Supplemental Nutrition Program for Women, Infants, and Children: Retrospective Cohort Study

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Abstract

Background: Despite the benefits of the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), many eligible children remain unenrolled.

Objective: This study evaluated responses to an electronic health record (EHR)–embedded federal nutrition program (FNP) participation screening and WIC referral tool implemented within 8 clinics during well-child visits for children younger than 5 years of age.

Methods: Structured EHR data from July 2020 to October 2023 were extracted to summarize screening, referral acceptance, WIC enrollment outcomes, and patient demographics. Multivariable logistic regression was used to examine patient-level predictors of WIC nonenrollment at the first screening, referral acceptance, and enrollment among those accepting a referral, with analyses stratified by clinic type.

Results: Among 5385 children, 51.8% (n=2785) were newborn-aged, 36.6% (n=1969) were Hispanic, and 87.8% (n=4726) were Medicaid-insured. The mean age at the initial screening was 10.7 (SD 14.2) months. Among screened patients (n=3606), 34% (n=1235) were not enrolled in WIC at the first screening. Medicaid coverage, an academic clinic setting, non-Hispanic Black or Hispanic race, and ethnicity were associated with lower odds of WIC nonenrollment. Among those not enrolled with a documented response to referral (n=819), 59% (n=488) accepted the referral. Acceptance was higher among non-Hispanic Black and Hispanic patients, newborn-aged patients, those with Medicaid coverage, and those seen in academic clinics. Among referral acceptors with follow-up (n=438), 61% (n=265) were enrolled at the last screening, with higher odds among newborn-aged patients and those in academic clinics.

Conclusions: An EHR-based automated intervention can facilitate screening and referral to WIC. WIC participation at the first screening, referral acceptance, and enrollment after referral varied by sociodemographic characteristics, suggesting opportunities to improve equitable access through health care system–based approaches.

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KEYWORDS

WIC; food insecurity; electronic health records; referrals; pediatrics

Introduction

The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) is a federal nutrition program (FNP) that provides access to nutritious foods, nutrition education, lactation support, and health care referrals for eligible low-income pregnant and lactating individuals, as well as infants and children under 5 years of age. Participation in WIC is

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associated with numerous health benefits, including improvements in dietary quality and reductions in the risk of prematurity, low birth weight, childhood obesity, and food insecurity [1,2], all of which disproportionately affect racial and ethnic minority populations due to longstanding structural racism [3,4]. Despite these health benefits of WIC participation, many eligible infants and children remain unenrolled.

In 2023, the most recent year in which data are available, only 56% of the eligible 11.8 million women, infants, and children participated in WIC, resulting in benefit underutilization and missed opportunities for improvements in health outcomes [5]. Since 2011, when it peaked at 63%, WIC participation has been declining [6]. Well-documented barriers to participation in WIC include lack of knowledge about WIC or eligibility status, lack of time or transportation to attend in-person visits, cultural and language barriers, negative experiences with WIC clinics, challenges in redeeming benefits, and stigma, among other barriers [7-9]. WIC program flexibilities implemented during the COVID-19 pandemic, such as remote benefit issuance, eased some of the administrative burden of participation and resulted in modest increases in participation [10]. To further expand outreach, increase enrollment in WIC, and ultimately improve health outcomes, cross-sector strategies are necessary [11].

Primary care clinics are uniquely positioned to counsel patients about WIC, facilitate WIC referrals, and encourage enrollment during standard discussions about nutrition at well visits. Providing referrals to WIC in primary care settings represents an evidence-based intervention for reducing food insecurity [12-14]. Several national organizations, including the American Academy of Pediatrics and the Food Research & Action Center, recommend that pediatricians refer patients to WIC [15-17]. Several studies have evaluated care coordination between the health care system and WIC to improve outcomes, such as responsive parenting, and have found that, while few have impacted weight outcomes, integrated services were acceptable among participants [18-21]. However, few have implemented and evaluated WIC participation screening and direct referrals to WIC from the health care system [22-24]. This study evaluated responses to an electronic health record (EHR)–embedded FNP participation screening and WIC referral tool, including screening results, referral acceptance, and WIC enrollment, and examined patient-level correlates and differences by clinic type.

Methods

Study Design and Setting

This retrospective cohort study was part of a mixed methods investigation in which our team expanded an innovative EHR-based FNP participation screening and referral tool. The tool assessed both WIC and the Supplemental Nutrition Assistance Program (SNAP) enrollment and provided WIC referrals at 8 primary care clinics, including 1 academic pediatric clinic, 5 private pediatric clinics, and 2 family medicine clinics, between July 2020 and October 2023. The study took place within Atrium Health Wake Forest Baptist, a large health care system serving a racially and ethnically diverse patient population in the western portion of North Carolina, which uses a fully integrated EHR system (Epic). See McCall et al [24] for a detailed description of the patient demographics of each of these health care clinics. The Wake Forest University School of Medicine Institutional Review Board approved this study.

Electronic Screening and Referrals

Beginning in July 2020, an EHR-embedded tool was implemented during well-child visits at the point of care in one academic clinic, which was a quality improvement project that tested various Plan-Do-Study-Act cycles [22]. Given the success of this project, the tool was expanded in 2021 to 7 other nonacademic clinics, which is the focus of the current study. For the 7 nonacademic clinics, the attending physicians and advanced practice providers exclusively provided care, with patient rooming and screening generally performed by medical assistants (MAs) and other support staff. Within these 7 clinics, considering rooming workflows and the preferences of providers, who did not prefer to have screening embedded in the note template or to perform screening themselves, an automated alert prompted MAs to screen caregivers for FNP participation during the rooming process and to assess family interest in a referral to WIC if not already participating. Given that Medicaid eligibility conferred WIC eligibility, the alert was programmed only to appear for visits with children below 5 years of age who had Medicaid or were uninsured or lived in Forsyth County, North Carolina, the location of our WIC partner. In addition, the alert appeared for those who had not been screened in the prior 6 months and thus did not appear at every visit. The FNP screening question asked: “Does your child currently participate in the WIC or SNAP programs? SNAP is also known as Food Stamps.” Self-reported participation response options of FNP were as follows: WIC only, SNAP only, both WIC/SNAP, neither WIC/SNAP, unsure, or did not ask. For participants who answered the initial FNP screening with the response options of “SNAP only,” “neither,” or “unsure,” an additional automated alert prompted the MA to assess caregiver interest in WIC referral with the following question: “WIC is a free program through the health department that provides food and nutrition support for children from birth through 4 years old. Can we give your information to WIC so they can contact you about enrolling?” Response options were: “Yes, family approves referral for WIC contact” or “No, family does not approve referral for WIC contact.” Prior to activation of the new screening tool within the EHR, research staff visited all clinics in person and conducted hands-on training sessions with clinic staff on how to effectively screen and refer using the tool, as well as how to counsel families. A laminated 1-page job aid was also provided with multiple copies at nursing workstations in each clinic. The job aid included contact information for research team members so that clinic staff or clinic managers could reach out with questions or concerns. Additionally, after the tool was live in the EHR, research staff members followed up regularly through email for 6 months with clinical practice managers to actively ask about any questions or difficulties that staff had encountered with screening.

At the single academic pediatric clinic in our sample, most of the clinical care is provided by residents and advanced practice providers, and the clinical workflows do not typically involve

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MAs performing screening duties. At this clinic, WIC screening was operationalized differently to increase screening and referral uptake, with providers (physicians, usually residents) being prompted to screen for FNP participation via an EHR-embedded tool within the well-child visit note template, which has been previously described [22,24]. At the academic clinic, FNP screening was prompted at every well-child visit for children under 5 years because the clinic serves almost exclusively FNP-eligible patients. The same training for the nonacademic clinic was also provided for the academic clinic. In addition, at the start of every new resident block (eg, every 4 wk), providers were given an orientation at morning report, which included how to effectively screen and refer to WIC using the EHR.

For consenting families at all 8 clinics, automated referrals were sent directly to WIC staff via an EHR in-basket message to begin enrollment, as previously described [6,23]. For the study period, structured data were extracted from the pediatric patient's EHR for screening and referral results as well as demographics, including age, race, ethnicity, insurance type, preferred language for health care use, sex, and clinic in which screening occurred. Race, ethnicity, and preferred language for health care use were extracted from self-reported fields within the EHR. Due to missing demographic data, 112 records were excluded for the first screening instance and 94 for the last screening instance.

Study Demographics

Extracted demographics, as noted above, included child age and sex because WIC participation rates vary by age [6], and male sex has been associated with longer WIC participation duration [25]. For age, we categorized pediatric patients as being newborn-aged (≤3 months old) or not (>3 months old), given that the age distribution of the sample was highly concentrated in early infancy and pediatric visit frequency is particularly high during the newborn phase. Race and ethnicity were included because the percentage of the eligible population participating in WIC varies by race and ethnicity, with non-Hispanic Black and Hispanic WIC-eligible individuals more likely to participate in WIC than non-Hispanic White individuals [6]. For analytic purposes, the race and ethnicity categories were Hispanic, non-Hispanic Black, and non-Hispanic White. We included other races and ethnicities in a combined category that included Asian, American Indian/Alaska Native, and Native Hawaiian/Pacific Islander, but we did not interpret them in our results, given small clinic populations of each of these races and ethnicities. Insurance type was categorized as Medicaid or non-Medicaid; non–Medicaid insured patients included those who were uninsured or had commercial or other third-party insurance types. The language preference of the caregiver for health care use, categorized as English, Spanish, or "other," was included because it may be associated with barriers to participation [9,26]. Given the small number of pediatric patients with a primary language other than Spanish or English, we did not interpret the results of the "other" category. Clinic sites were grouped according to the method by which screening took place, such that the 7 clinics using MAs to screen via the automated alert were considered as one category, while one pediatric academic clinic using providers to screen via the note template was considered as a separate category.

Outcomes and Data Analysis

The primary outcomes were (1) likelihood of WIC nonenrollment at the first screening, (2) likelihood of accepting a referral, and (3) likelihood of enrolling in WIC among those accepting a referral. We characterized the initial FNP screening and WIC referral status using the response categories listed above. Among participants for whom the FNP screening was prompted at more than one visit during the study period, we also characterized those who transitioned from reporting no WIC participation (eg, initial screening results of SNAP only, neither WIC/SNAP) to subsequently reporting WIC participation at the final screen as becoming enrolled in WIC. Because follow-up intervals between well-child visits vary, and to allow sufficient time for WIC referrals to potentially result in enrollment, outcomes were defined using the last documented screening encounter during the study period rather than a fixed follow-up window.

Descriptive statistics were used to summarize demographic characteristics and screening and referral responses. Because this study aimed to evaluate and optimize a novel clinical screening and referral process, we used multivariable logistic regression to assess associations with screening and referral outcomes. All models adjusted for child age, sex, race and ethnicity, preferred language, insurance type, year of screening, and clinic type. In analyses of subsequent WIC enrollment at the last screening encounter, we additionally adjusted for days between the first and last screening visits as an adjustment covariate to account for variation in follow-up time and opportunity for enrollment after referral. Because the primary outcome defined WIC enrollment as a receipt of WIC alone or in combination with SNAP, SNAP participation could not be modeled as a separate, mutually exclusive covariate. Models additionally adjusted for the year of the screening encounter to account for temporal trends during the study period. Because the academic clinic implemented screening earlier than the nonacademic clinics and some individual years contained sparse cells for certain outcomes, screening year was categorized into 2 periods (2020‐2021 and 2022‐2023) for regression analyses. We first fit models including clinic type as an independent variable and then conducted stratified analyses by fitting the models separately among patients from academic and nonacademic clinics. In stratified models with sparse cells, when a categorical predictor level had zero outcome events (complete separation), that level was omitted from the model, and comparisons were estimated among remaining levels with observed events. Results are reported as odds ratios (ORs) with 95% CIs. Robust SEs were used to account for potential heteroskedasticity. The results were considered statistically significant at a 2-tailed $P<.05$. Data cleaning and analysis were completed using SAS version 9.4 (SAS Institute, Inc) and Stata version 18.5 (StataCorp).

Ethical Considerations

The Wake Forest University School of Medicine Institutional Review Board approved this study (IRB00078127). As this was a retrospective cohort, EHR-based study, participants' informed consent was waived, and compensation was not provided.

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Results

There were 5497 unique records in which the FNP screening prompt appeared at ≥1 visit. Of these, 5385 (98%) records had complete data for all demographic measures of interest and were included in analyses. The mean age of the pediatric patient at the initial screening was 10.7 (SD 14.2; range: 0.03 - 59.2) months, and 51.8% (n=2785) were newborn-aged. Just over half of patients were male (n=2780, 51.6%), 36.6% (n=1969) were Hispanic, 76.4% (n=4113) preferred English for health care use, and 87.8% (n=4726) had Medicaid insurance (Table 1). Few (n=129, 2.4%) reported participation in SNAP only, while 44% (n=2369) were already enrolled in WIC or both WIC and SNAP. Because WIC screening was embedded within the provider note template in the academic clinic, we were unable to determine when screening was prompted but not completed in that setting; therefore, screening completion could only be reliably quantified for the nonacademic clinics, where an automated alert allowed explicit documentation of completed or dismissed screening. Within the nonacademic clinics, 1108 (38%) records completed the screening for WIC participation. Among all patients who were screened (n=3606), 66% (n=2371) reported participation in WIC or both WIC and SNAP at the first screening encounter, while 34% (n=1235) reported no participation in FNP or were unsure. Figure 1 details sample sizes at each step.

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Table . Patient characteristics by Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) enrollment status at the first screening encounter, 2020 - 2023 (N=5385).

Demographic characteristic	All patients (N=5385), n (%)	Academic clinic (n=2498)		Nonacademic clinics (n=2887)		
		WIC/WIC and SNAP[a] (n=1857), n (%)	Not participating in WIC (n=641), n (%)	WIC/WIC and SNAP (n=514), n (%)	Not participating in WIC (n=594), n (%)	Not screened (n=1779), n (%)
Sex						
Female	2605 (48.4)	886 (47.7)	313 (48.8)	252 (49.0)	306 (51.5)	848 (47.7)
Male	2780 (51.6)	971 (52.3)	328 (51.2)	262 (51.0)	288 (48.5)	931 (52.3)
Race and ethnicity						
Non-Hispanic White	1171 (21.8)	149 (8.0)	73 (11.4)	115 (22.4)	256 (43.1)	578 (32.5)
Non-Hispanic Black	1788 (33.2)	554 (29.8)	119 (18.6)	254 (49.4)	190 (32.0)	671 (37.7)
Hispanic	1969 (36.6)	1052 (56.7)	377 (58.8)	101 (19.7)	89 (15.0)	350 (19.7)
Non-Hispanic Other[b]	457 (8.5)	102 (5.5)	72 (11.2)	44 (8.6)	59 (9.9)	180 (10.1)
Newborn (<3 mo)						
Yes	2785 (51.8)	1306 (70.3)	426 (66.5)	194 (37.7)	250 (42.0)	609 (34.2)
No	2600 (48.3)	551 (29.7)	215 (33.5)	320 (62.3)	344 (57.9)	1170 (65.8)
Preferred language						
English	4113 (76.4)	1094 (58.9)	351 (54.8)	467 (90.9)	564 (95.0)	1637 (92.0)
Spanish	1208 (22.4)	738 (39.7)	269 (42.0)	45 (8.8)	28 (4.7)	128 (7.2)
Other	64 (1.2)	25 (1.4)	21 (3.3)	2 (0.4)	2 (0.3)	14 (0.8)
Insurance						
Medicaid	4726 (87.8)	1814 (97.7)	573 (89.4)	494 (96.1)	433 (72.9)	1412 (79.4)
Non-Medicaid	659 (12.2)	43 (2.3)	68 (10.6)	20 (3.9)	161 (27.1)	367 (20.6)
Year at the first screening						
2020 - 2021	2497 (46.4)	1140 (61.4)	366 (57.1)	326 (63.4)	222 (37.4)	443 (24.9)
2022 - 2023	2888 (53.6)	717 (38.6)	275 (42.9)	188 (36.6)	372 (62.6)	1336 (75.1)
SNAP-only participation[c]						
Yes	129 (2.4)	—[d]	68 (10.6)	—	61 (10.3)	—
No	5256 (97.6)	—	573 (89.4)	—	533 (89.7)	—

[a]SNAP: Supplemental Nutrition Assistance Program.

[b]Other race and ethnicity categories included Asian, American Indian/Alaska Native, and Native Hawaiian/Pacific Islander.

[c]SNAP-only participation is shown. Participants receiving both WIC and SNAP are included in the WIC participation category used for study outcomes and are therefore not represented in this row.

[d]Not applicable.

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Figure 1. Flow of the analytic sample across Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) screening, referral, and enrollment outcomes. WIC enrolled at the last screening at the time of data extraction. FNP: federal nutrition program.

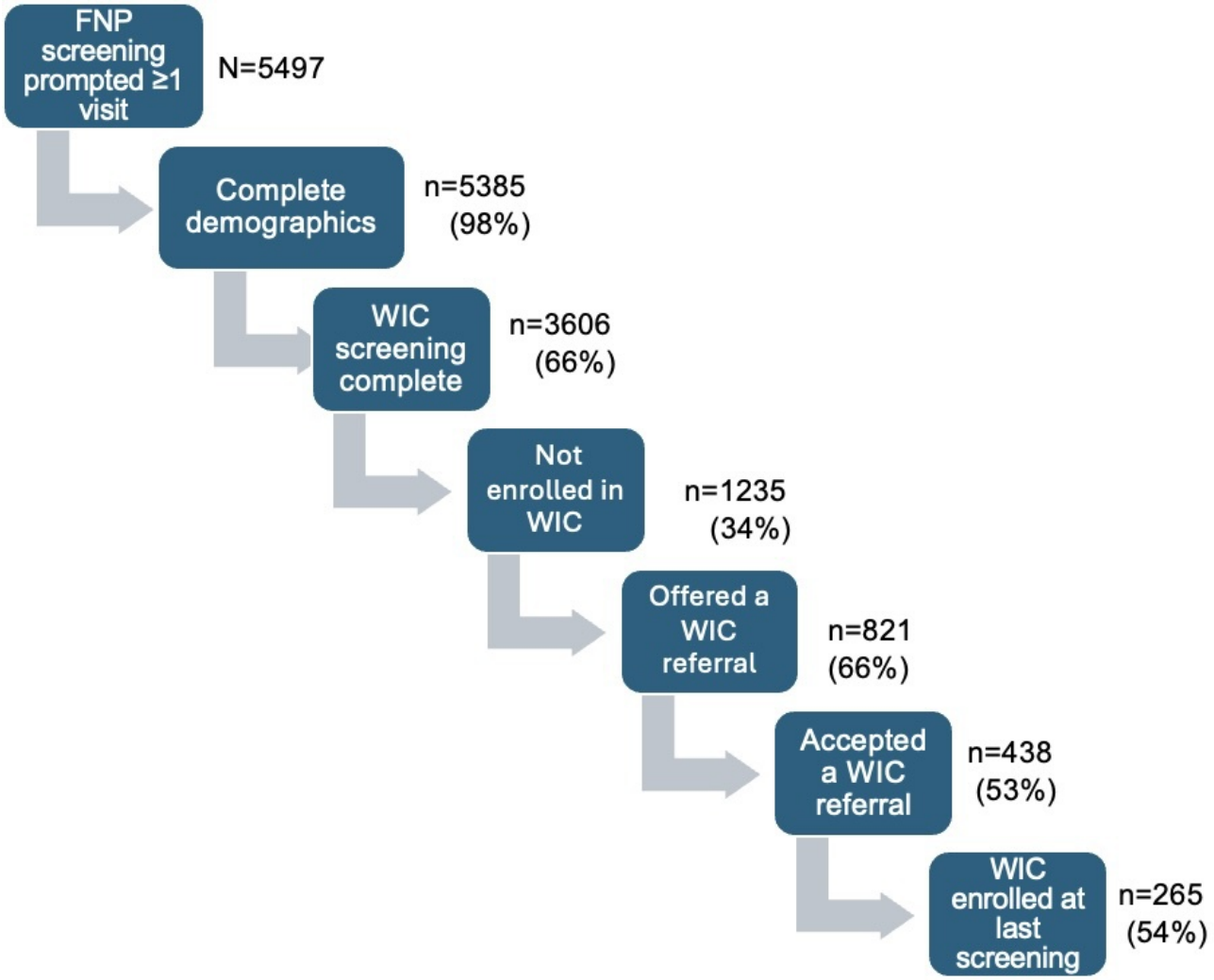


Table 2 presents factors associated with WIC nonenrollment at the first screening encounter; ORs less than 1 indicate lower odds of nonenrollment (ie, greater likelihood of being enrolled in WIC). In the overall model, Medicaid coverage was strongly associated with lower odds of nonenrollment compared with non-Medicaid insurance, and patients attending academic clinics had lower odds of nonenrollment than those seen at nonacademic clinics. Compared with non-Hispanic White patients, non-Hispanic Black and Hispanic patients were also less likely to be unenrolled. Newborn-aged patients had modestly lower odds of nonenrollment relative to older children. In contrast, the odds of WIC nonenrollment increased over time, with higher odds observed in 2022 to 2023 compared with 2020 to 2021. Sex and preferred language were not significantly associated with nonenrollment. Stratified analyses by clinic type demonstrated generally similar patterns, with some attenuation of associations in subgroup models.

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Table . Multivariable logistic regression of the odds of Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) nonenrollment at the first screening encounter, overall and stratified by clinic type (N=3606)[a].

Characteristic	Overall (N=3606), OR[b] (95% CI)	Academic clinic (n=2498), OR (95% CI)	Nonacademic clinics (n=1108), OR (95% CI)
Sex (Ref: female)			
Male	0.96 (0.83-1.11)	0.99 (0.82-1.19)	0.89 (0.69-1.16)
Race and ethnicity (Ref: Non-Hispanic White)			
Non-Hispanic Black	0.45 (0.36-0.78)[c]	0.50 (0.35-0.70)[c]	0.43 (0.31-0.59)[c]
Hispanic	0.75 (0.59-0.96)[c]	0.88 (0.63-1.21)	0.64 (0.41-1.00)[c]
Newborn (Ref: no)			
Yes	0.81 (0.69-0.96)[c]	0.83 (0.67-1.03)	0.78 (0.59-1.03)
Preferred language (Ref: English)			
Spanish	0.95 (0.77-1.19)	1.01 (0.80-1.28)	0.60 (0.33-1.10)
Insurance (Ref: Non-Medicaid)			
Medicaid	0.18 (0.13-0.24)[c]	0.21 (0.14-0.32)[c]	0.14 (0.08-0.24)[c]
Year at the first screening (Ref: 2020 - 2021)			
2022 - 2023	1.63 (1.40-1.91)[c]	1.26 (1.03-1.53)[c]	2.65 (2.04-3.46)[c]
Academic clinic (Ref: no)			
Yes	0.37 (0.31-0.45)[c]	—[d]	—

[a]Categories for other race and ethnicity and other language were suppressed due to small sample sizes. Models were adjusted for screening year to account for temporal trends during the study period (2020 - 2023).

[b]OR: odds ratio.

[c]These estimates indicate statistical significance at $P<.05$.

[d]Not applicable.

Among participants who were not enrolled in WIC at the first screening encounter (n=1235), 66% (n=815) were offered a referral, and 819 had a documented response regarding referral acceptance. Table 3 presents factors associated with accepting a WIC referral among these patients. In the overall model, non-Hispanic Black and Hispanic patients had higher odds of accepting a referral compared with non-Hispanic White patients. Newborn-aged patients were more likely to accept a referral than older children. Medicaid coverage was associated with substantially higher odds of referral acceptance compared with non-Medicaid insurance. In contrast to patterns observed for nonenrollment, patients seen in academic clinics had higher odds of accepting a referral than those seen in nonacademic clinics. Sex, preferred language, and screening year were not significantly associated with referral acceptance overall. Stratified analyses by clinic type showed generally similar patterns, although CIs widened in subgroup models.

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Table . Multivariable logistic regression of the odds of accepting a Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) referral among screened patients with a documented response (N=819)[a].

Patient characteristics	Overall (N=819), OR[b] (95% CI)	Academic clinic (n=503), OR (95% CI)	Nonacademic clinics (n=316), OR (95% CI)
Sex (Ref: female)			
Male	0.76 (0.53-1.08)	0.84 (0.52-1.33)	0.71 (0.41-1.22)
Race and ethnicity (Ref: non-Hispanic White)			
Non-Hispanic Black	2.85 (1.71-4.75)[c]	3.04 (1.37-6.75)[c]	2.70 (1.35-5.35)[c]
Hispanic	2.06 (1.19-3.58)[c]	2.15 (1.03-4.47)[c]	2.09 (0.83-5.25)
Newborn (Ref: no)			
Yes	2.76 (1.89-4.02)[c]	3.14 (1.93-5.11)[c]	2.68 (1.43-5.02)[c]
Preferred language (Ref: English)			
Spanish	1.74 (1.02-2.99)[c]	1.63 (0.91-2.91)	2.79 (0.78-10.00)
Insurance (Ref: non-Medicaid)			
Medicaid	4.51 (2.74-7.44)[c]	3.07 (1.48-6.40)[c]	6.22 (2.60-14.91)[c]
Year at the first screening (Ref: 2020 - 2021)			
2022 - 2023	1.18 (0.83-1.68)	1.51 (0.93-2.44)	0.91 (0.52-1.57)
Academic clinic (Ref: no)			
Yes	4.78 (3.23-7.06)[c]	—[d]	—

[a]Sample restricted to patients who were screened for WIC participation and had a documented response regarding referral acceptance. Models were adjusted for child age, sex, race and ethnicity, preferred language, insurance type, year of first screening, and clinic type.

[b]OR: odds ratio.

[c]These estimates indicate statistical significance at $P<.05$.

[d]Not applicable.

Among those who accepted a WIC referral and had a documented follow-up response (n=438), 61% (n=265) were enrolled in WIC at the last screening encounter. Table 4 presents factors associated with subsequent WIC enrollment among these participants. In the overall model, newborn-aged patients were more likely to be enrolled in WIC at the last screening compared with older children (OR 6.80, 95% CI 3.89-11.86), and patients seen in academic clinics had higher odds of enrollment than those seen in nonacademic clinics (OR 13.29, 95% CI 4.77-37.02). In clinic-specific analyses, associations were generally consistent in the academic clinics, where newborn age remained associated with enrollment. Estimates for the nonacademic clinics were imprecise because of the smaller sample size and sparse cells; however, Medicaid insurance was associated with lower odds of enrollment compared with non-Medicaid coverage in this subgroup. Race and ethnicity estimates in the nonacademic clinics should be interpreted cautiously, as the non-Hispanic White category was omitted due to zero observed enrollment events, precluding direct comparisons with other groups. Sex, race and ethnicity, preferred language, screening year, and days between the first and last screening visits were not significantly associated with WIC enrollment overall. Due to sparse data in the nonacademic clinics, results should be interpreted with caution.

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Table . Multivariable logistic regression of the odds of Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) enrollment at the last screening encounter among patients who were offered a referral with a documented response (N=438)[a].

Patient characteristics	Overall (N=438), OR[b] (95% CI)	Academic clinic (n=384), OR (95% CI)	Nonacademic clinics (n=54)[c], OR (95% CI)
Sex (Ref: female)			
Male	1.04 (0.67-1.64)	0.99 (0.61-1.61)	7.28 (0.55-95.53)
Race and ethnicity (Ref: non-Hispanic White)			
Non–Hispanic Black	1.03 (0.44-2.42)	0.85 (0.31-2.30)	Ref
Hispanic	1.68 (0.71-3.90)	1.28 (0.49-3.37)	1.99 (0.77-5.15)
Newborn (Ref: no)			
Yes	6.80 (3.89-11.86)[d]	7.79 (4.46-13.63)[d]	1.16 (0.20-6.67)
Preferred language (Ref: English)			
Spanish	1.22 (0.67-2.22)	1.31 (0.71-2.46)	0.41 (0.07-2.48)
Insurance (Ref: non-Medicaid)			
Medicaid	1.33 (0.46-3.89)	2.06 (0.71-5.92)	0.06 (0.01-0.72)[d]
Year at the first screening (Ref: 2020 - 2021)			
2022 - 2023	1.17 (0.70-1.97)	1.42 (0.83-2.41)	0.08 (0.00-1.60)
Academic clinic (Ref: no)			
Yes	13.29 (4.77-37.02)[d]	—[e]	—

[a]Multivariable logistic regression adjusted for child age, sex, race and ethnicity, preferred language, insurance type, year of first screening, clinic type, and days between first and last visits; it was not statistically significant and is therefore not shown. Other race and ethnicity and other language categories are suppressed due to small sample sizes.

[b]OR: odds ratio.

[c]In the nonacademic clinic model, the non-Hispanic White category was omitted due to zero observed WIC enrollments. The analytic sample size remained unchanged (n=54).

[d]These estimates indicate statistical significance at $P<.05$.

[e]Not applicable.

Discussion

Principal Findings

Our findings indicate that patient characteristics associated with WIC participation vary across stages of engagement in the WIC referral continuum, including initial enrollment status, referral acceptance, and subsequent enrollment. Consistent with prior literature, we found that non-Hispanic White race, non-Medicaid insurance, and attending a nonacademic clinic were associated with a higher likelihood of not being enrolled in WIC at the first screening encounter. We also observed higher odds of nonenrollment in later years of the study period, which may reflect changes in screening implementation across clinics or broader fluctuations in WIC participation during the COVID-19 pandemic recovery period. Among patients who were not enrolled at the first screening, most accepted a referral when offered, with higher odds of referral acceptance observed among non-Hispanic Black and Hispanic patients, newborn-aged patients, and those with Medicaid insurance. In contrast to patterns observed for nonenrollment, patients seen in academic clinics were more likely to accept a referral and to subsequently enroll in WIC.

These differences may reflect variation in screening workflows and counseling context, as providers in the academic clinic conducted screening directly within the visit note template and may have had more opportunities to discuss WIC benefits with caregivers. Among those who accepted a referral and had a documented follow-up response, newborn-aged patients and those receiving care in academic clinics had substantially higher odds of enrollment. Although subgroup estimates should be interpreted cautiously due to sparse data, in nonacademic clinics, Medicaid insurance was associated with lower odds of subsequent enrollment compared with non-Medicaid coverage. Sex and screening year were not significantly associated with referral acceptance in the overall model. Preferred language showed a modest association with acceptance, although estimates varied across clinic-specific models. Together, these findings highlight important differences in engagement across the WIC participation continuum and underscore the influence of clinical context and patient characteristics on both referral uptake and successful enrollment. Conceptualizing these steps as a continuum highlights potential points where health systems may intervene to improve participation, from identifying unenrolled families to supporting successful referral follow-through.

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For practices planning implementation of a WIC screening and referral tool, screening modality and workflow integration are key considerations. In our sample, slightly more than a third of eligible participants in the nonacademic clinics completed WIC screening (1108/5385, 38%), suggesting meaningful implementation barriers. Although we attempted to standardize workflows through on-site education and partnership with clinic managers, some clinic staff may have viewed screening for FNP participation as outside their scope of practice or as potentially stigmatizing as demonstrated in our prior work, which could have contributed to higher rates of incomplete screening [24]. Additionally, nonacademic clinics relied on an automated EHR alert and screening during rooming—typically by MAs—rather than embedding screening within the provider note template, which could have contributed to differences in uptake of the screener. Prior studies have demonstrated alert fatigue and high override rates in clinical decision support systems [27-29], and our prior qualitative research similarly suggests challenges with alert timing and navigating workflows [24]. Future research could explore alternative methods for effective screening and workflow using an implementation science framework.

Screening during the clinical encounter by the health care provider may also provide the opportunity for more effective patient education about the benefits of WIC, given the knowledge gap among eligible WIC participants [30]. Caregivers report a high level of trust in their pediatricians, and their decision to enroll in the FNP can be influenced by a discussion with their pediatrician [31]. One prior study demonstrated that integrating WIC services into pediatric well-child and obstetric visits yielded 748 new WIC enrollments over a 21-month period, and the program was positively received by participants, staff, and providers [23]. More research is needed on integrating WIC referrals into clinical settings. These considerations may be particularly relevant given that referral acceptance and subsequent enrollment were higher in the academic clinic setting in adjusted models, underscoring the potential importance of workflow and counseling context.

Although consistent with national and state data, our findings suggest that determinants of WIC engagement differ across stages—from baseline participation to referral uptake and subsequent enrollment—highlighting opportunities for targeted strategies [6]. In particular, eligible non-Hispanic White families were least likely to report WIC participation at the first screening and less likely to accept a referral when offered, suggesting a need for tailored outreach and counseling to address barriers such as stigma or perceived lack of need. Prior research has elucidated potential reasons for WIC nonparticipation among this population, including stigma, feeling as if the program benefits are not needed, or worrying about taking away benefits from others [8,22,32]. Future studies should examine how participation in SNAP, including SNAP-only enrollment and changes in SNAP benefits over time, may influence acceptance of WIC referrals and subsequent enrollment decisions.

Policy Implications

There are several policy implications for this research. As health care systems increasingly adopt screening and interventions for health-related social needs, policies are needed that incentivize health care systems and clinicians to communicate with federal assistance programs such as WIC. Building EHR tools for WIC screening and referrals may not be feasible for all health care systems; policies are needed that incentivize EHR vendors to build these tools centrally, so they easily integrate with community partners to specifically address pediatric needs [33]. Furthermore, given that the data systems for patients and WIC clients are separate and unable to communicate with one another, data sharing policies could be modified to reduce the administrative burden of communication [34]. To support these policies, future research is needed to determine whether (1) EHR-based screening and automated referral improve enrollment and retention in WIC and (2) WIC referral by health care systems improves health outcomes. Our next steps for this study include optimizing the screening and referral tool workflow to expand across the entire health care enterprise, including additional counties and pediatric, family medicine, obstetrics, and gynecology clinics.

Limitations

There are several limitations to this research. First, these findings describe a specific EHR-based intervention implemented in 8 clinics in one geographic area. Results may not be generalizable to other settings. Second, FNP participation data were self-reported, and given the inability to verify enrollment in WIC for all participants, it is possible that errors existed in the self-reported data. However, preliminary unpublished data included a validation sample, indicating high accuracy between participants' responses and actual WIC participation, as verified by our county's WIC program. Furthermore, SNAP participation was not included as a covariate because the outcome definition of WIC enrollment included participants receiving both WIC and SNAP, creating overlap between the covariate and the outcome variable. Third, given the way the EHR screening tool was implemented in the academic clinic using the progress note template, if the responses were not documented, we could not calculate the percentage of patients who were not screened, which may introduce selection bias. Finally, we can only comment on associations between patient demographic characteristics collected in the EHR and FNP participation screening responses, WIC referral acceptance, and WIC enrollment. These associations are not necessarily causal, but we hope these data will inform future work as we continue to grow these datasets and optimize clinical workflows in our health care system.

Conclusions

A primary care, EHR-based WIC screening and referral tool can facilitate screening and referral to WIC. Direct, automated referrals to WIC from health care settings are an innovative method for potentially improving access to WIC and promoting health equity. Future research should examine the effectiveness of health care–based referrals on WIC enrollment and retention, the most effective method of referral from health care systems, and the intervention's impact on health outcomes. Qualitative research could explore clinical and patient perceptions to ensure equity in exploring differences by race and ethnicity.

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The authors state that no generative AI was used at any stage of the manuscript.

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Data Availability

Deidentified individual participant data (including data dictionaries) will be made available upon reasonable request from the corresponding author.

Authors' Contributions

Conceptualization: KM, AJT, KHL
Data curation: MCK, KHL
Formal analysis: MCK, KHL
Funding acquisition: KM, KHL
Investigation: KM, MCK, KHL
Methodology: KM, MCK, AJT, KHL
Project administration: KM, KHL
Supervision: KM
Writing – original draft: KM, MCK
Writing – review and editing: KM, MCK, AJT, KHL

Conflicts of Interest

None declared.

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Abbreviations

EHR: electronic health record
FNP: Federal Nutrition Program
MA: medical assistant
OR: odds ratio
SNAP: Supplemental Nutrition Assistance Program
WIC: Special Supplemental Nutrition Program for Women, Infants, and Children

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Original Paper

Development and Usability Testing of the Mobile Childhood Asthma Management Program (mCHAMP) App: Sequential Mixed Methods Study

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Abstract

Background: More than 6 million children in the United States have asthma, and more than 20% are clinically obese. Youth with asthma and obesity are susceptible to poor health outcomes, including greater asthma symptom severity and hospitalizations, reduced physical activity, and poorer quality of life. Mobile health technologies can increase access to chronic disease self-management interventions, and family members can be powerful influencers given their substantial control over a child's behavior and home environment.

Objective: The Mobile Childhood Asthma Management Program (mCHAMP) app is based on the in-person Childhood Asthma Management Program (CHAMP) behavioral family intervention pilot trial of school-aged children with asthma and obesity. In this study, we translated the CHAMP content into digital content and conducted summative testing to measure the usability, learnability, and efficiency of the mCHAMP app.

Methods: We applied a sequential mixed methods approach. The mCHAMP app targeted adult caregivers of children living with asthma and obesity aged 6 to 12 years. A consumer-centered approach was used to guide the identification of user requirements and conduct of summative usability testing. While the mCHAMP app is primarily caregiver facing, it is intended to connect caregivers with registered nurse (RN) interventionists. Therefore, we sought feedback from RNs as key stakeholders.

Results: Caregivers (n=10) were female (n=10, 100%) and mostly African American (n=8, 80%), and half (n=5, 50%) had an annual household income of <US $25,000; most of their children (n=6, 60%) were in the 99th BMI percentile. Post-Study eHealth Usability Questionnaire scores indicated high overall satisfaction, usefulness, and quality of the mCHAMP app. Most caregivers (n=7, 70%) were able to complete all 15 tasks across the 6 modules with 2 or fewer hints. The average total time to complete all tasks was 17 (SD 3.9; range 11.4-24.1) minutes. Most caregivers (n=7, 70%) wanted information in static form but also preferred alternatives (eg, audio or video) to support flexibility with consuming the content. Caregivers expressed the need for more child-facing content as well as tailored decision support related to diet and exercise. RNs (n=5) strongly endorsed their role and

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use of the mCHAMP app to promote self-management among caregivers of children with obesity and asthma. They noted the importance of integrating the mCHAMP app into a local electronic health record and existing workflows.

Conclusions: Caregivers expressed a desire for an intervention that was easy to use and could integrate into their busy family lives. We met this expectation based on the usability, learnability, and efficiency results of our study. The mCHAMP app has the potential to increase self-management for parents and pediatric patients with asthma with multimorbidity, which could improve patient and health system outcomes. The use of mCHAMP may also enable novel clinical outcome studies based on patient-reported data from the app.

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KEYWORDS

health promotion; self-management; mobile health; mHealth; asthma; obesity; pediatrics; usability; family; family caregiver; ambulatory nursing

Introduction

Background

More than 6 million children in the United States have asthma, and more than 20% are clinically obese [1]. Asthma and obesity are leading causes of morbidity, reduced quality of life, and health care costs [2]. Youth with asthma and obesity are especially susceptible to poor health outcomes, including greater asthma symptom severity and hospitalizations, reduced physical activity, and poorer quality of life [3-5]. Children with asthma and obesity can improve their overall health and quality of life when families engage in chronic disease self-management behaviors, including self-monitoring (eg, symptoms and diet), setting and achieving goals (eg, increasing physical activity), modifying the home environment (eg, trigger reduction and healthy food options), and collaborating with a health care provider [6-8].

Caregivers (ie, family members) can be powerful influencers of school-aged children (aged 6-12 years) during this developmental stage given their substantial direct and indirect control over a child's behavior and home environment [9-11]. However, family caregivers often have limited chronic disease self-management knowledge and struggle themselves to adhere to healthy behaviors [12-18]. There is a critical need for interventions that target family caregiver self-management behaviors during school age for children with asthma and obesity to optimize health and model self-management behaviors that can prevent downstream morbidity in adolescence and beyond [19].

Behavioral family lifestyle interventions (BFIs) can reinforce family caregivers' self-management skills, resulting in health benefits for their children [20]. BFIs are informed by social cognitive theory, which posits that caregivers need knowledge and skills to engage in health-promoting behaviors [21,22]. BFIs target family caregivers as primary agents of change for health promotion. Caregivers learn child behavior management skills (eg, modeling and contingency management) to help them motivate and support their children in making healthy choices. BFIs can result in family caregivers developing self-management skills and self-efficacy to regulate their children's behaviors and creating a healthy environment [23,24].

BFIs are the most effective interventions for children with obesity [25,26]. Caregiver self-management skills promoted in BFIs are also critical for successful asthma management [27-29]. However, caregivers report numerous social determinant of health–related barriers (eg, access to health care services and health IT) to attending in-person sessions that limit self-management skill acquisition, behavior change, and benefits to their children [30-32].

Mobile health (mHealth) technologies can increase access to chronic disease self-management interventions. This is especially important given the ubiquity of smartphone ownership across racial and ethnic groups and socioeconomic strata [33,34]. Consumers perceive the usability and acceptability of mHealth interventions as very high. mHealth functionality can be multimodal (ie, text, audio, and visual) to accommodate various literacy levels. mHealth-supported interventions can enable flexibility in accessing and completing intervention components to improve intervention uptake and reduce the time commitment of consumers [35,36]. mHealth-enabled BFIs can reduce barriers for family caregivers in learning and role-modeling self-management skills to improve their children's asthma and obesity [30-32]. In addition, mHealth self-management interventions show promise in improving youth asthma and weight outcomes [37-40]. Individual tailoring to the caregiver via ongoing support from a health care provider can facilitate intervention engagement [39,41,42]. This is particularly important to caregivers of children with asthma and obesity as this multimorbidity adds significant complexity to disease management for caregivers [20]. Caregivers of children with asthma and obesity conveyed in our pilot work that they would value ongoing contact with a registered nurse (RN) as support for self-management. RNs have the requisite knowledge and skills to educate, motivate, and successfully assist families in using self-management skills to facilitate health behavior change, making them the ideal health professionals to support an mHealth-enabled BFI for caregivers of school-aged children with asthma and obesity [43,44].

Objectives

The Mobile Childhood Asthma Management Program (mCHAMP) is based on lessons learned from our in-person Childhood Asthma Management Program (CHAMP) pilot trial, a BFI with families of school-aged children (6-12 years) with

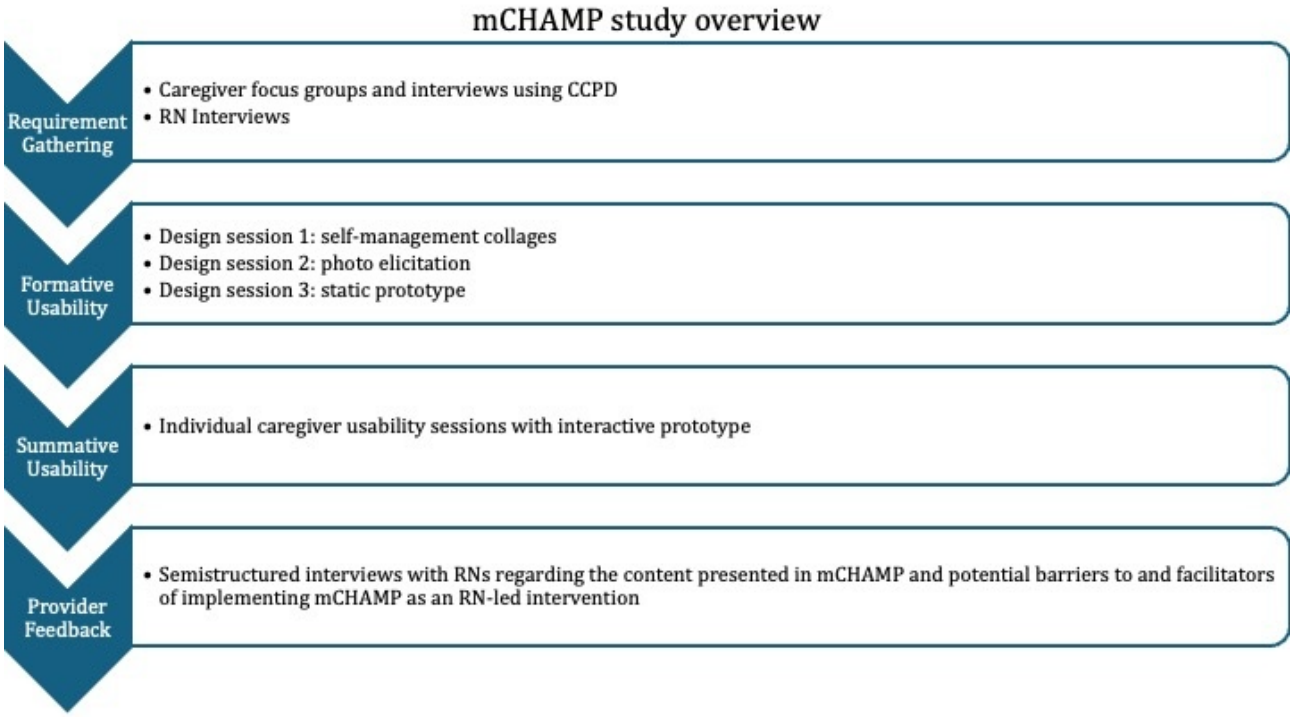
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asthma and obesity [45]. The CHAMP intervention included 16 sessions over 3 months and encompassed topics such as collaborative ways for caregivers and children to establish healthier eating and exercise habits, healthy eating on a budget, goal setting, and progress tracking. In this study, we modified CHAMP into mCHAMP in 2 phases. Following the translation of CHAMP content, summative testing was used to measure usability, learnability, and efficiency. The focus of this paper is the summative usability testing of the mCHAMP app. However, a brief discussion of system development and formative testing is included for context.

Methods

An overview of this sequential mixed methods study is shown in Figure 1. Additional study design details are provided in the published protocol [44].

Figure 1. Overview of the study design. CCPD: consumer-centered participatory design; mCHAMP: Mobile Childhood Asthma Management Program; RN: registered nurse.



Ethical Considerations

The University of Florida Institutional Review Board - mCHAMP (Mobile Childhood Health and Asthma Management Program) approved all study procedures (IRB201801092), and all participants provided informed consent. The participation window ranged from October 2018 to December 2019.

System Development

The mCHAMP app targeted adult caregivers of children living with asthma and obesity between the ages of 6 and 12 years. A consumer-centered participatory design (CCPD) approach was used to identify user requirements, and summative usability testing was completed with caregivers to measure overall usability, learnability, and efficiency [46].

Using CCPD, we iteratively identified salient content and end user needs from the original CHAMP intervention and how to best translate that into the mCHAMP mobile app. Potential end users included family caregivers and nurses. Focus groups were the primary method of engagement with participants during initial system development. However, if participants were not able to attend one of the scheduled focus groups, individual interviews were conducted. The primary goal of these sessions was to identify which components of the CHAMP intervention resonated most with caregivers and the preferred format for those components [45]. Caregivers also described their families' unique barriers to asthma and weight management. The use of CCPD allowed us to better understand the perspective of community members who might benefit from our intervention and allowed us to build the mCHAMP app in line with community needs.

We continued to engage caregivers, starting with formative usability testing and ending with summative testing. Formative testing uses qualitative approaches iteratively to identify and fix usability problems with small samples [47]. We engaged caregivers in 3 formative sessions, which provided feedback on the design of our initial prototype. Following these sessions, we developed an interactive mCHAMP prototype for iOS and Android users in collaboration with MEI Research, a nonprofit organization that specializes in the development of medical education content, including mHealth apps. The resulting prototype was evaluated through summative usability testing, which is the focus of this paper.

Approach

Summative testing is used to evaluate a system's usability and commonly includes metrics such as time on task, errors, user satisfaction, and user interface challenges [47]. Overall usability,

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or satisfaction, was assessed quantitatively using the Post-Study eHealth Usability Questionnaire (PSHUQ) and qualitatively through open-ended questions. To assess learnability, or ease of learning, we used time on task and errors. Efficiency was measured through the number of steps and overall time to complete a task.

Setting and Recruitment

We recruited caregiver participants using purposive sampling from an outpatient pediatric pulmonary clinic and a hospital-affiliated integrated data repository that allows researchers to receive a list of patients who meet inclusion criteria and have consented to be contacted about research studies. Caregiver participants were parents or legal guardians of children who were aged 6 to 12 years, had a physician-verified diagnosis of asthma for at least 6 months before study participation, had a BMI at or above the 85th percentile, and lived with the caregiver participant. Participants were required to speak and read English. We excluded participants who had any significant cognitive impairment or developmental delay that would interfere with study task completion. We recruited RN participants from the pediatric pulmonary division. RN participant inclusion criteria were (1) providing care for children with asthma and (2) having worked in that capacity for at least 1 year. Due to institutional review board restrictions regarding storage of information on potentially eligible patients, we did not collect data on the total number of individuals contacted or response rates.

The summative usability target sample was 10 caregivers. Studies that include 10 participants in summative testing should find an average of 95% of system errors and a minimum of 82% of system errors [48]. In addition to caregivers, we targeted a sample size of 5 RNs for feedback on the final prototype.

Procedures

The interactive mCHAMP prototype used in summative testing included six modules: (1) mCHAMP home screen, (2) Learning Center, (3) Monitoring Healthy Choices, (4) My Goals & Plan, (5) Parent Dashboard, and (6) Communication Center (Figure 2A-F). The home screen provides access to each section of the app. Within the Learning Center, users have access to general information about healthy eating, physical activity, and asthma symptoms in children aged 6 to 12 years. The Monitoring Healthy Choices section allows users to monitor their child's screen time, eating, asthma symptoms, physical activity, and weight over time. In the My Goals & Plan section, we give users a place to set weekly goals. We ask whether they completed their goal, and if not, ask what got in the way. We also give users a place to view their plan and what to focus on during the upcoming weeks. This includes a list of action items related to their goals, the modules they are reviewing, and when they next meet with the nurse. In the Parent Dashboard, users can see how well they are managing their goals. This area includes rewards earned and how their child's health has changed over time. The Communication Center provides a way for users to communicate directly with their nurse when they have questions about the program, their child's asthma symptoms, or making healthy choices. We note that this feature should not be used for any emergency health issues or medication advice. Instead, this is a way for users to list questions for their next scheduled meeting with their nurse.

Summative usability testing sessions were conducted with a research team member and a caregiver. Each participant engaged with the mCHAMP app using a research mobile phone with an operating system that matched their current personal device's operating system. We created a summative usability testing script that asked caregivers (n=10) to complete 15 total tasks across the 6 modules of the mCHAMP app. Study staff provided directed feedback only if participants were unable to complete a task that would impact subsequent tasks. Study staff asked participants to think aloud as they used the prototype and provided nondirective guidance when necessary. Screen recording captured participants' on-screen movements. Following some tasks, open-ended questions were asked (eg, "Would you talk out loud about what this means to you?") before prompting the next task. Following performance of all tasks, participants completed the PSHUQ [49].

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Figure 2. Mobile Childhood Asthma Management Program (mCHAMP)mCHAMP (A) home screen, (B) Learning Center, (C) Monitoring Healthy Choices, (D) My Goals & Plan, (E) Parent Dashboard, and (F) Communication Center.

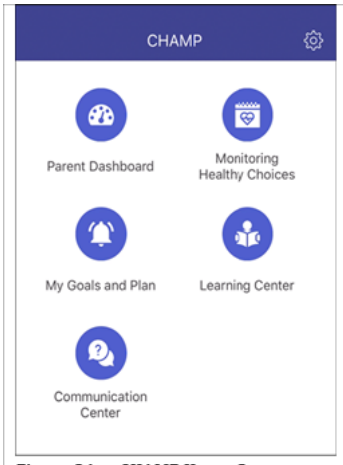


Figure 2A. mCHAMP Home Screen

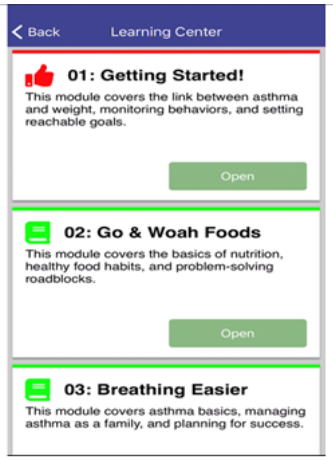


Figure 2B. Learning Center

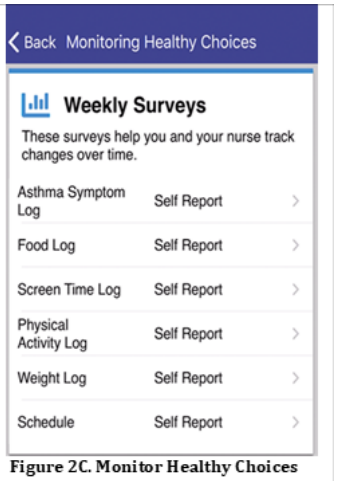


Figure 2C. Monitor Healthy Choices

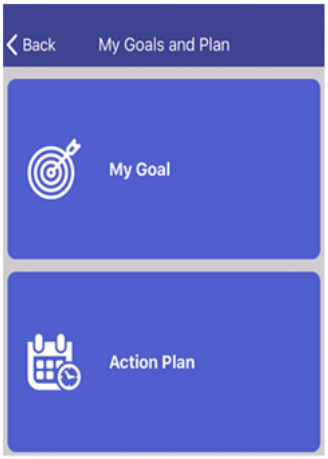


Figure 2D. My Goals and Plan

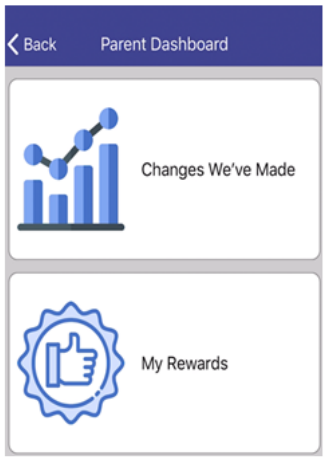


Figure 2E. Parent Dashboard

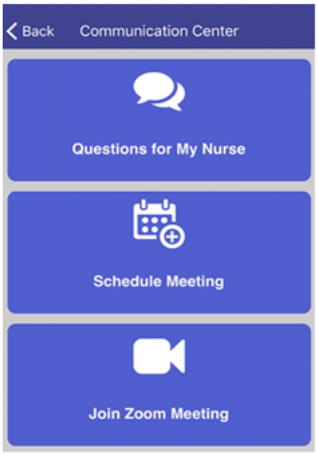


Figure 2F. Communication Center

Nurse Feedback

While the mCHAMP app is primarily caregiver facing, it is intended to connect with RN interventionists. Therefore, in addition to obtaining caregiver feedback, we sought feedback from RNs as key stakeholders. Following summative testing with caregivers, a sample of 5 nurses received a brief overview of the project and a demonstration of the app's functionality. Study staff (RJL and AF) conducted semistructured interviews with nurses. Questions were related to app content, the role of RNs in promoting patient self-management, and future implementation of a nurse-led intervention using this app in a pediatric pulmonology clinic or primary care setting.

Measures

Demographics

Caregivers provided their age, gender, race or ethnicity, marital status, educational level, and household income. They also provided their children's age and gender. RNs provided their gender, race or ethnicity, household income, and length of time working as an RN overall, in addition to time providing care to children with asthma.

Technology Use

Caregivers completed a brief technology use questionnaire adapted from the Health Information National Trends Survey to characterize how often they interacted with technology (eg, computers, cell phones, and tablets) and whether they used technology for health-related tasks or belonged to any social networking sites [50]. Information regarding general use of technology was collected to ensure that differences in usability metrics were not attributable to differences in general experience with technology as opposed to the mCHAMP app itself.

Usability

Overall usability, or satisfaction, was measured using the PSHUQ [49]. The PSHUQ comprises 18 items and uses a Likert scale ranging from 1 ("strongly agree") to 7 ("strongly disagree"). Subscales include (1) system usefulness, which measures the ease of completing tasks; and (2) system quality, which measures satisfaction with the quality of the information and interface. We calculated the mean and SD for each of the individual items. We calculated subscale scores by averaging the items in each subscale. We averaged scores across all items to create an overall satisfaction score. Overall scores can range from 1 to 7, with lower scores indicating a higher degree of satisfaction.

Learnability

Learnability refers to the ability of a novice user to become proficient in a relatively short period [51]. Learnability metrics included number of hints and errors coded in each session. Hints were defined as any statement by the study staff that aided the

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caregiver in completing a task. Errors were defined as actions taken by participants that did not follow the expected steps in the script.

Efficiency

Efficiency is the average time it takes for users to complete a defined set of tasks [52]. Efficiency was measured through the total time to complete the tasks associated with a particular module and the number of individual steps taken to accomplish those tasks. Steps included the count of the following aspects: clicking (any click following the script), errors (any click that did not follow the script), error recovery (any click after the initial error to return to the task), entering text (any action involving the user typing into the app), and scrolling (any action taken to scroll through content on the app).

Analysis

Screen recordings were analyzed using NVivo (version 12; Lumivero) to describe and quantify usability measures. Recordings were coded using an a priori codebook that was developed by team members (RJL, KS, and YX) based on the usability testing script and planned usability metrics. After establishing intercoder reliability, 2 team members (KS and YX) coded these recordings using NVivo. Any disagreements on coding were resolved through discussion. Iterative content analysis was used for the open-ended questions and semistructured RN interviews.

Results

Caregiver Participants

Overview

Caregivers (n=10) were female (n=10, 100%) and mostly African American (n=8, 80%) and had an annual household income of less than US $25,000 (n=5, 50%; Table 1). Most of their children (n=6, 60%) were in the 99th BMI percentile. In terms of technology use, all caregivers (n=10, 100%) reported spending at least 2 hours per day engaging with their smartphone for activities other than phone calls, and half (n=5, 50%) reported 5 hours or more of daily use. All participants also reported belonging to a social networking site, and most engaged with digital health information (eg, websites and health-related apps).

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Table 1. Caregiver demographics and technology use (n=10).

	Values
Caregiver age (y), mean (SD; range)	37.10 (6.76; 29-51)
Caregiver gender (female), n (%)	10 (100)
Caregiver race, n (%)	
African American/Black	8 (80)
Hispanic/Latino White	1 (10)
Non-Hispanic/non-Latino White	1 (10)
Caregiver marital status, n (%)	
Married	2 (20)
Divorced	2 (20)
Single	6 (60)
Caregiver educational level, n (%)	
Did not graduate high school	1 (10)
Partial college or specialized training	5 (50)
College graduate	3 (30)
Graduate or professional degree	1 (10)
Annual household income (US $), n (%)	
<5000	2 (20)
5000-11,999	1 (10)
12,000-15,999	1 (10)
16,000-24,999	1 (10)
25,000-34,999	2 (20)
35,000-49,999	2 (20)
50,000-74,999	1 (10)
Child age (y), mean (SD; range)	10.10 (1.73; 8-12)
Child BMI percentile, mean (SD; range)	97.20 (2.78; 92-99)
Caregiver cell phone use on a typical day within the previous month (excluding time spent talking on the phone; h), n (%)	
2	2 (20)
4	3 (30)
≥5	5 (50)
Caregiver computer use on a typical day within the previous month (excluding work-related use; h), n (%)	
<1	2 (20)
1	2 (20)
2	3 (30)
3	3 (30)
Caregiver tablet use on a typical day within the previous month (h), n (%)	
<1	2 (20)
2	2 (20)
≥5	1 (10)
Did not use a tablet	5 (50)
Caregiver technology use within the previous year, n (%)	
Belonged to social networking site	10 (100)
Used the internet to look up health or medical information	8 (80)

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	Values
Used mobile health apps on their phone or tablet	9 (90)
Used email, the internet, or an app to communicate with a physician or physician's office	7 (70)
Participated in an online support group for people with similar health or medical issues	1 (10)

Summative Usability

Participants' scores on the PSHUQ indicated high overall satisfaction, with a mean rating of 1.13 (SD 0.24) and possible scores ranging between 1 (highest) and 7 (lowest; median 1, range 1-1.67). Caregivers also reported high levels of usefulness (mean 1.08, SD 0.10; median 1.00, range 1.00-1.20) and quality (mean 1.16, SD 0.33; median 1.00, range 1.00-1.90).

Learnability

Most participants (n=7, 70%) were able to complete all 15 tasks across the 6 modules with 2 or fewer hints (Table 2). Overall, participants received 0.53 hints per module on average (SD 0.55; range 0-1.8) and committed an average of 0.38 (SD 0.42; range 0-0.67) errors per module. One data point for hints represented an outlier with a total of 11 hints over the 6 modules and an average of 1.83 hints per module. Data for errors did not include any outliers. All participants were able to complete module 1 (mCHAMP home screen) without hints or errors. Most (n=9, 90%) were able to complete the 5 tasks in the Learning Center with 1 or no hints. Participants were also able to complete the Monitoring Healthy Choices tasks with 1 or no errors (n=8, 80%) and 1 or no hints (n=9, 90%). Module 4, My Goals & Plan, was easily navigated by participants, with nearly all (n=9, 90%) not receiving any hints and only 10% (n=1) of the participants committing 1 error. The 2 tasks in module 5, Parent Dashboard, were more challenging, with half of the users receiving 2 or more hints (mean 1.2, SD 1.4; range 0-3). Users were able to use the Communication Center easily, with 70% (n=7) not requiring any hints; the remining 30% (n=3) required 2 hints each, and only 20% (n=2) of the users committed 1 error each.

Table 2. Learnability and efficiency scores.

Module	Learnability, mean (SD; range		Efficiency, mean (SD; range	
	Hints	Errors	Steps	Time (min)
1. mCHAMP home screen	0 (0; 0)	0 (0; 0)	1 (0; 1-1)	0.1 (0.1; 0.0-0.2)
2. Learning Center	0.6 (1; 0-3)	0.6 (0.8; 0-2)	16.4 (2.6; 11-19)	6.6 (1.8; 3.1-8.6)
3. Monitoring Healthy Choices	0.06 (0.7; 0-2)	0.5 (0.8; 0-2)	20.4 (8.3; 13-34)	3.1 (1; 2-5)
4. My Goals & Plan	0.2 (0.6; 0-2)	0.1 (0.3; 0-1)	14.2 (2; 10-17)	3.2 (1.2; 1.4-4.6)
5. Parent Dashboard	1.2 (1.4; 0-4)	0.9 (1.1; 0-3)	16.8 (2.5; 14-23)	1.6 (0.7; 0.9-2.7)
6. Communication Center	0.6 (1; 0-2)	0.2 (0.4; 0-1)	16 (3.6; 9-21)	3.2 (1.7; 1.2-2.3)

Efficiency

The average total time to complete all tasks across the 6 mCHAMP modules was 17 (SD 3.9; range 11.4-24.1) minutes. Users spent the most time on the Learning Center (mean 6.6, SD 1.8; range 3.1-8.6 minutes), which included 2 videos totaling 1.5 minutes. Users completed module 1, the home screen, most quickly (mean 0.1, SD 0.04; range 0.02-0.17 minutes), followed by module 5, taking an average of 1.6 (SD 0.69; range 0.9-2.72) minutes to view the graphs and access the rewards. Modules 3, 4, and 6 took between 2.49 and 3.23 minutes on average. Table 2 provides efficiency data.

User Preferences

Electronic (Audio or Visual) Media

Participants felt that the videos were a good length (less than 1 minute each). They also liked the use of color and felt that the animation made them enjoyable and inviting to children and caregivers. When asked whether they preferred one video over the other, nearly half (n=4, 40%) of the participants talked about the importance of matching the gender of the character to the child watching, and 10% (n=1) also commented that it was important to depict racial diversity. A few participants (n=3, 30%) preferred the video that gave actionable information about activity and included more peer interactions. However, 10% (n=1) of the participants noted that they preferred the video that depicted how asthma can be isolating to a child because they felt that it was important for children to know that their experience is common. That participant also liked how that video included the experience of the child and the caregiver.

When asked about video content, caregivers were generally positive (n=9, 90%), with only 10% (n=1) stating that it was not valuable. That participant stated a preference for engaging directly with the nurse rather than with videos. Some participants (n=2, 20%) felt that it was important for content to be engaging for both children and adults, whereas 10% (n=1) of the caregivers stated that they would pass the app to their children and say, "Here you go. Mommy got this. You might wanna read it. You might wanna listen at it. It's cute" [U18].

However, there was a strong preference (n=9, 90%) for child-facing content. Participants stated that information about activity levels was particularly important (n=5, 50%), with 20% (n=2) stating that they did not know that being active was

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important for asthma control and 10% (n=1) stating that they sometimes struggled to encourage activity even though they knew that it was the right thing to do. One participant would have liked additional information on identifying the warning signs of an asthma attack. The videos may also meet the needs of health care providers, with one caregiver stating that her physician wished she had a child-friendly video to explain what happens in the lungs during an asthma attack at their last appointment.

Static (Text) Media

Regarding written content, most caregivers (n=7, 70%) were comfortable and wanted the information in a static form but wanted an alternative form of media to support flexibility and choice regarding how to consume the content. Caregivers overwhelmingly supported the idea of having either videos or a "read aloud" audio function (n=10, 100%).

Caregiver Engagement

When asked about the survey task, caregivers reported it being easy to complete (n=9, 90%) and easy to navigate (n=2, 20%). One participant did voice concerns about how accurate they could be regarding entering information as their child spent so much time at school and in other activities where they did not see food or activity choices. There was also one comment about the use of the label "self-report" and that this phrase might be jargon; the use of more plain language for each task (eg, "food log") would be better.

Features that participants discussed in the reward section included a preference for tracking progress toward goals or visibility of status (n=4, 40%), animated congratulations when awards were unlocked (n=4, 40%), streak tracking to encourage consecutive goal achievement (n=3, 30%), and tailored notifications with actionable ideas when goals had not yet been achieved (n=2, 20%). The importance of visibility of status was described by one user as follows:

> *Okay, I did it without my asthma gettin' in the way. It'd convince him to keep goin' forward instead of stoppin' or not wantin' to do it because of his asthma.* [U16]

When asked about the reward center, many users (n=6, 60%) reiterated the desire for child-facing content. Many (n=5, 50%) talked about the value of having both child-facing content and caregiver-facing content. This was sometimes described as having one account per family, with the ability to log in on multiple devices and select either a child or caregiver role. When parent-facing content was discussed, the use of minimalist design using numbers rather than stickers or icons was described (n=2, 20%), and more icons or visual depictions were preferred for child-facing content (n=3, 30%). One user would have liked to see additional nutrition-related content in this area, and one user suggested adding interactive game content to help teach health promotion principles.

The concept of person-centered support was also observed in the preference for tailored notifications, with one user stating the following:

> *Yeah, like at the end of the week, when a child hasn't met their goals, it's okay to not always succeed, as long as you keep trying, or try, try, try again. You get knocked down, try again. Tomorrow's a new day. There's a thousand statements that you could put in there. Just some kind of a support.* [U17]

One participant valued the automated integration of Fitbit data, and another commented on the importance of a mobile app for in-the-moment data entry for logging symptoms. One participant also stated that she would have liked a way to interact with other caregivers (eg, peer support).

Health Care Provider Engagement

When asked about the feature to connect with a nurse, most (n=8, 80%) liked the ability to collaborate with the nurse, with some (n=3, 30%) stating that this feature might improve their access to care. The video component to the nurse communication was important to at least one caregiver, and 20% (n=2) commented about the need to have a specialized nurse knowledgeable about nutrition. The only difficulty discussed regarding the Communication Center was in navigating back to the main content after speaking with the nurse via Zoom.

RN Feedback

Semistructured interviews with 5 nurses who provided care to pediatric patients with asthma were completed. Nurses were recruited from diverse settings, including primary care, specialty care, and clinics serving patients with varying socioeconomic statuses. Inclusion of diverse participants allows for insight into potential need and important contextual factors in diverse settings for future implementation studies.

All 5 nurses strongly endorsed the role of the nurse to include education and promotion of self-management (self-efficacy). For example, nurses indicated that "Oh, yeah, that's our core function" and "that's what nursing does. Nursing is the education point of healthcare." Nurses all endorsed that mCHAMP had necessary activity-related content. One felt that there was room for improvement with the nutritional content. Several nurses also expressed concerns regarding low levels of literacy in the target population. This was further supported by nurses recommending additional video and pictorial content. Nurses liked that both genders were represented in the videos currently integrated into mCHAMP. Nurses also responded favorably to the Parent Dashboard and Communication Center content. They particularly liked the ability to see trends in the caregiver dashboard and the use of video in the Communication Center to enable some visual assessment compared to a phone-only interaction. They liked the use of in situ patient-entered data and the ability to monitor pertinent data in between appointments.

The use of mCHAMP in primary care was endorsed by all but one nurse (4/5, 80%), who felt that she did not have enough knowledge of the primary care environment to provide an informed response. Most participants also supported the use of mCHAMP within specialty care, and some proposed the use of a centralized nurse with specialized asthma experience to enable smaller clinics to participate in the program. Several nurses also stated that integration of mCHAMP data into the electronic

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health record (EHR) would be important to the feasibility and sustainability of the intervention. Nurses also talked about the importance of integrating the intervention into existing workflows to promote health care provider buy-in. To achieve integration of data within the EHR, a health care provider dashboard was recommended.

Discussion

Principal Findings

The overarching goal of this study was to conduct summative usability testing of the mCHAMP app with caregivers and nurses. Overall, the mCHAMP app was viewed positively by caregivers, as evidenced by receiving high ratings for satisfaction, perceived system usefulness, and quality on the PSHUQ. Our results are comparable to findings from other health technology usability studies. Sheehan and Lucero [53] reported similarly favorable PSHUQ scores (mean 1.58; median 1.38) for their Self-Assessment via a Personal Health Record fall prevention system among older adults, demonstrating high satisfaction with system usefulness (mean 1.84) and quality (mean 1.43), with possible scores ranging between 1 (highest) and 7 (lowest). Both studies show that users found these health self-management systems easy to use and of high quality, with our caregivers rating the mCHAMP app slightly more favorably on usefulness (mean 1.08, SD 0.10) compared to the Self-Assessment via a Personal Health Record study. These comparable satisfaction scores across different health domains and user populations suggest that health applications can achieve high user acceptance when developed using well-designed, theory-driven usability frameworks.

Furthermore, our metrics of learnability and efficiency for the mCHAMP app with caregivers were favorable. Caregivers were able to complete our list of prespecified module tasks with few hints, and the average time spent on each module of the app ranged from under 1 minute to just over 6 minutes. Consistent with our usability data, qualitative feedback provided by caregivers during the think-aloud testing indicated that they were pleased with several mCHAMP app features, including the animated videos and ease of completing self-report surveys. Caregivers expressed a desire for an intervention that was easy to use and could integrate into their busy family lives during requirement gathering sessions that we conducted when designing the mCHAMP app. We appear to have met this expectation based on the usability, learnability, and efficiency data from this study.

A main point of innovation for the mCHAMP app is that it leverages the expertise and training of RNs as interventionists to develop caregiver self-management skills. An important finding from our usability testing was that caregivers were indeed enthusiastic about working with an RN interventionist to facilitate their use and uptake of self-management skills via the mCHAMP app. Caregivers stated they liked having the ability to reach out via videoconference to the RN interventionist rather than googling or calling as it would give them the ability to show the RN what was going on rather than being limited to a description over the phone. Previous research has demonstrated that technology-based interventions that incorporate RNs as care deliverers are feasible and efficacious at reducing morbidity in pediatric asthma [54,55]. Given the ubiquity of mobile phones, and in the context of a health care system that emphasizes care within a medical home model of care [56], the use of RNs as interventionists in the mCHAMP app to concurrently target asthma and obesity extends prior work and generates confidence that there is a viable framework for scalability.

Given the central importance of self-monitoring in the self-management of chronic illness, we designed the mCHAMP app to enable caregivers to enter data (eg, asthma symptoms, food logs, and screen time) and synchronize with a Fitbit to facilitate tracking of important health behaviors and progress toward self-management goals [57,58]. Caregivers responded positively to these components of the mCHAMP app and had little difficulty completing surveys during testing. Moreover, a general theme of feedback from caregivers was that they valued how their children's health data could subsequently lead to a more personalized intervention experience. Examples given by caregivers included informing more meaningful interactions with the RN interventionists and that having their children's health data in a central location could increase their accuracy when attending appointments with their children's physicians. We posit that these data, if regularly accessed by the caregiver, could also help strengthen connections between health behaviors (eg, physical activity levels and food intake) and important outcomes (eg, asthma symptoms and weight) in children with comorbid asthma and obesity.

Caregivers noted several areas in which we could make further improvements to the mCHAMP app. Specifically, caregivers wanted flexibility to engage with educational content on the app in multiple ways, including the addition of more videos and read-aloud functions to the current prototype. Notably, while using the Parent Dashboard module, participants required more hints compared with other sections of the mCHAMP app. Our review of the data indicated that most hints were required following the task prompt "Show me how you would access the graphs that show changes in your activity and your child's activity over time," with more than half of the participants requiring at least one hint before selecting the Parent Dashboard. Common incorrect selections by caregivers included them selecting the Learning Center, Monitoring Healthy Choices, or Communication Center modules. The range of actions taken by caregivers suggests that we should refine the mCHAMP app to better differentiate where visual health data are stored to improve usability.

Many caregivers indicated that they wanted the mCHAMP app to include child-focused content. We considered including child-focused content during our initial development of the mCHAMP app but decided to focus on caregivers due to the developmental level of our target sample (aged 6-12 years) and based on previous studies that have demonstrated that in-person caregiver BFIs are as efficacious as those that include caregiver-child dyads [24]. In addition, the emerging data on the added benefit of including children in eHealth or mHealth interventions for child weight management are mixed. However, recent data suggest that including children as active recipients of a technology-based intervention is associated with increased

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efficacy [59]. Thus, an important direction for our future work in this area is to identify developmentally appropriate ways to include children in mCHAMP.

RNs also had a favorable response to the mCHAMP app. They valued the use of caregiver-entered health data, which is consistent with the literature on the benefits of patient-reported outcomes. Systematic use of patient-reported data in between care may support patient-provider communication in addition to fostering clinician awareness of health status in between episodes of care [60]. RNs also recommended collecting data on medication use to provide information that may be important for asthma management. This recommendation is also supported by literature on the use of patient-entered data to facilitate medication adherence among patients with chronic diseases [61]. Finally, RNs also had positive feedback regarding the videoconferencing features of the mCHAMP app as a mechanism to provide support between intervention sessions.

Nurses raised important contextual factors, such as the ability to integrate mCHAMP into the EHR and potentially differing workflows among participating clinics as concerns related to future implementation. These concerns could be mitigated through the use of workflow analysis in future studies and the use of interoperability standards to enable integration of data into the EHR.

Limitations

While our usability evaluation of the mCHAMP app was strengthened by the inclusion of the perspectives of potential end users or family caregivers and health care providers, there are evaluation weaknesses overall that should be addressed in future research. First, we observed that all the usability evaluations were conducted using the iOS operating system based on family caregivers' actual mobile phone type. Second, future research should include additional family caregivers whose children are affected by obesity and asthma that were not included in our study, namely, Hispanic English- and Spanish-speaking caregivers. Third, while our sample size of 10 caregivers was adequate for identifying usability issues, this limits our ability to fully understand the range of experiences and preferences across diverse populations of caregivers managing childhood asthma and obesity.

The homogeneous nature of our sample may not capture usability challenges that could emerge among caregivers with different technological comfort levels or cultural backgrounds. Only 40% of child patients with asthma are coded as Black or African American in the data repository, which does not contain information on obesity. Moreover, without demographic data on caregiver characteristics in the broader repository population, we cannot fully assess the extent of these potential biases. In addition, there are opportunities to engage family caregivers from varied geographic locations and settings, including primary care in urban and suburban clinics with health care providers whose experience may be different from that of health care providers in specialized pulmonary clinics.

Conclusions

Our study was able to identify key components of the original CHAMP intervention to develop and test the usability of the mCHAMP app by engaging stakeholders using the CCPD process. Caregivers and nurses had favorable feedback on mCHAMP. With some minimal revisions, the mCHAMP app could be used in future pilot-testing. This will enable the research team to test the hypothesis that translating CHAMP from an in-person intervention to an mHealth intervention will improve retention rates while maintaining high levels of satisfaction. The mCHAMP app has the potential to increase self-management for pediatric patients with asthma dealing with multimorbidity, which could translate into improved patient outcomes and long-term benefits for health systems. The use of mCHAMP may also enable novel clinical outcome studies based on patient-reported data from the app.

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Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

RJL, DF, and DJ contributed to conceptualization, funding acquisition, methodology, supervision, resources, and writing—review and editing. RJL and DF contributed to supervision. KS, AF, and YX contributed to analysis and writing—review and editing.

Conflicts of Interest

None declared.

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Abbreviations

BFI: behavioral family lifestyle intervention
CCPD: consumer-centered participatory design
CHAMP: Childhood Asthma Management Program
EHR: electronic health record
mCHAMP: Mobile Childhood Asthma Management Program
mHealth: mobile health
PSHUQ: Post-Study eHealth Usability Questionnaire
RN: registered nurse

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Engagement, Acceptability, and Impact of a Parenting App to Support Infant Sleep and Parent Well-Being: Quasi-Experimental Study

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Abstract

Background: Many parents today use digital or mobile health (mHealth) resources for parenting information and support. Thus, interventions or programs to support parenting delivered in this way are a rapidly growing area of innovation and research. Evidence indicates that face-to-face interventions that provide education and support for parents about infant sleep can have positive impacts on both infant sleep and maternal mood. However, there is limited research on the delivery of such interventions via digital or mHealth platforms. SleepWellBaby is an infant sleep mobile app for parents with infants and young children. The app provides parents with a 7-day program that may be repeated according to individual user demand, with information and interactive features aimed at supporting parents to understand infant sleep, and providing advice about strategies to support sleep in a responsive way.

Objective: The study objectives were (1) to determine engagement with, and acceptability of, an mHealth-delivered parenting program to support infant sleep and (2) to investigate the impact of the program on parental fatigue, emotional health, and parenting competence, confidence, and self-efficacy.

Methods: A multimethod quasi-experimental pre-post study design was used. Participants were parents of infants aged under 6 months, recruited through online advertising. Participants completed baseline questionnaires, then 2 further follow-up questionnaires at 7 days and 30 days post baseline. These questionnaires captured participant demographics (baseline) and perceptions of the program (follow-up), in addition to measuring parental fatigue (Fatigue Severity Scale), parent sense of competence, confidence, and self-efficacy (Me as a Parent Scale), and symptoms of anxiety (Generalized Anxiety Disorder 7-item scale) and depression (Edinburgh Postnatal Depression Scale) at all time points. Open-ended text responses were also collected at the 2 follow-up surveys. Questionnaire data were linked with participants' engagement with the program (Engagement Index), measured using app analytics.

Results: Participants' (baseline: n=700; 7-d follow-up: n=339; and 30-d follow-up: n=220) engagement with the program varied; however, the majority reported cessation of app use by 1 month. Most participants were broadly satisfied with the program, finding the app easy to use and understand, and reported they could trust the information on the app. Those participants who had higher engagement or found the program most helpful for their sleep and their infant's sleep showed the greatest improvement

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in their fatigue. Qualitative feedback from participants noted that while many found the app a lifeline with helpful information and features, others noted unintended negative impacts, such as spending too much time on their phone.

Conclusions: Delivery of an infant sleep program via mHealth is effective for and acceptable to many parents. While not preferred by all parents, mHealth is an accessible, low-cost, and high-reach mode of providing information and management strategies for parents experiencing early parenting difficulties.

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KEYWORDS

mobile applications; mobile health; mHealth; digital health; smartphone; infant; parenting; self-efficacy; sleep; fatigue; anxiety; depression; perinatal mental health

Introduction

Sleep and settling difficulties during infancy and childhood are common and can be challenging for many families [1]. In an Australian study, 39% of mothers with infants at 1 month of age reported infant sleep difficulties [2]. While sleep disturbances in early infancy are normal and there is no commonly applied clinical definition of what constitutes a sleep problem in infancy [3], sleep and settling difficulties are generally understood to be related to infant regulation, with sleep difficulties potentially related to *dys*regulation [1]. Infants and their parents are interconnected in the management of infant dysregulation, as an infant needs a primary caregiver to facilitate regulation [4]. To do this, a parent needs to be attuned to their infant and to accurately observe, interpret, and respond to their infant's cues (eg, facial expressions and crying) in a warm, consistent, and timely manner [4,5]. This skillful parenting interaction takes time to develop and can be impacted by many factors, including infant temperament, parental mood symptoms, and parents' confidence and self-efficacy in their parenting [5].

Prevention and early support for families experiencing difficulties are important, as infant regulatory issues can continue into later infancy and toddlerhood [1,6], with significant implications for both child and parental mental and physical health. Disrupted sleep and frequent night waking in infancy and toddlerhood are associated with social, emotional, and behavioral challenges in toddlers [7] and with fatigue and mental health disorders in parents [8]. Thus, infant sleep and settling difficulties can impose a substantial burden on health systems: parents reporting infant regulatory issues often use multiple health services in their search for support [9].

Interventions providing education and/or support to parents regarding infant sleep can have positive impacts on infant sleep and maternal mood [10,11]. A Cochrane review of randomized controlled trials of postnatal education with parents of infants aged 2 months or under found interventions that included education about infant sleep led to greater length of infant sleep at 6 weeks of age [10]. A review and meta-analysis of randomized controlled trials of psychosocial and sleep-focused interventions with mothers and infants aged 12 months and under found a small but significant positive effect on infant sleep and maternal mood, as measured by the Edinburgh Postnatal Depression Scale (EPDS) [11]. A recent umbrella review of 5 systematic reviews (including 24 individual studies involving several thousand families) found that behavioral sleep interventions increased total nighttime sleep in infants and may also help reduce nighttime wakings and improve maternal mental health [12]. However, most interventions in these reviews had multiple components and were based on different approaches to infant sleep, for example, behavioral management versus intuitive parenting, making it difficult to isolate the component or approach that is most effective.

In Australia, early parenting centers such as Tresillian are a primary source of support and intervention for parents who experience challenges with their infant's sleep [13]. Such centers have been part of the Australian health landscape for more than a century and currently provide group, day, and residential programs for parents of children aged 0 to 3 years, with challenges related to sleep, settling, feeding, and/or parenting capacity and confidence, and, in some settings, mental health support [14,15]. While these centers house considerable clinical experience and expertise, there are substantially fewer published studies reporting the efficacy of infant sleep interventions delivered by these centers, compared with behavioral sleep programs overall. However, the available evidence indicates these programs are associated with similar improvements in infant sleep and/or parent mental health to those outlined earlier [13,15-17]. A recent systematic review and meta-analysis of behavioral interventions for problematic infant sleep and unsettled behavior incorporated 16 studies, 8 of which were in Australian early parenting centers [18]. Consistent with earlier meta-analyses, this research synthesis found mild to moderate improvements in infant sleep and maternal mental health across interventions.

Most of the studies and research syntheses outlined earlier were based on face-to-face programs and consultations, and not all parents are able to attend in-person programs. Parents face a range of barriers, including long waiting lists, lack of transport, difficulty accessing childcare, and geographical isolation [19]. In addition, there has been a generational shift in the preferred sources of support sought by parents. Millennial and Gen Z parents, born from 1981 onward, who have themselves grown up in the digital age, naturally choose digital tools to support their parenting [20]. With these factors in mind, and fueled by necessity during the recent COVID-19 pandemic [21], there has been a dramatic increase in online tools and programs for parents over the past decade, to the extent that they are now ubiquitous [20]. An increasing number of these digital or mobile health (mHealth) parenting tools and programs are delivered through smartphone apps. A review published in 2020 found 421 maternal and infant health smartphone apps with approximately

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25% (n=102) developed by a health care provider or affiliated provider [22].

As a problem that causes substantial anxiety for parents, infant sleep is the focus for many new parenting apps. Evidence for the efficacy and/or acceptability of these interventions is still emerging, and findings are mixed. Leichman et al [23] evaluated the real-world effectiveness of an mHealth behavioral sleep intervention among caregivers of 404 infants aged 6 to 11.9 months and found improvements in a range of sleep-related outcomes with the greatest improvements for those infants classified as problem sleepers at baseline.

While apps have been shown to be acceptable to parents for health service delivery [24,25], reviews assessing the quality of information on infant health apps indicate poor quality of information [26,27]. Apps are expensive to develop and maintain—therefore, most parenting apps are commercial enterprises, which may prioritize profit over evidence-based content [20]. Even where free evidence-based apps do exist, parents often prefer their commercial counterparts due to their superior design, interactivity, and customization [20]. Very few of the commercially available apps currently on the Google Play Store or the Apple App Store are developed by or with health organizations [22], and few have been evaluated [28]. Parenting apps take their place in an overwhelming ocean of parenting information available to modern parents. A 2022 Google search for the term "parenting" returned an astonishing 1,850,000,000 results [29], highlighting the need for high-quality information and programs that are appealing, user-friendly, readily available, and easily distinguishable from less sound material [30].

In 2019, the SleepWellBaby app was developed through a partnership between SleepFit, a sleep app development company, and Tresillian, a not-for-profit early parenting support service, in an effort to increase parents' access to high-quality advice, education, and guidance. The content of SleepWellBaby is based on the Tresillian approach to infant sleep and settling. This approach focuses on education about normal infant or child sleep, natural sleep rhythms (eg, day or night and circadian rhythms), infant cues (communication), and responsive settling techniques such as hands-on settling [31]. Tresillian's approach is about supporting positive parent and infant relationships through improving parents' understanding of infant cues and supporting parents to reflect on personal or relational elements that may be impacting how they respond to their infant or child [31].

The purpose of this study was to determine the engagement with and acceptability of SleepWellBaby, an app-based parenting program to support infant sleep, and to investigate the impact of the program on parent fatigue, emotional health, and sense of competence, confidence, and self-efficacy.

Methods

Study Design

This was a multimethod quasi-experimental pre-post study.

Intervention: The SleepWellBaby App

SleepWellBaby is an infant sleep app for parents. The SleepWellBaby app provides parents with a 7-day program that may be repeated as many times as users desire. It is tailored to the infant's or child's age and follows a feed-play-sleep daily rhythm. Parents are prompted to complete daily check-ins and sleep tracking, which help in monitoring progress over the 7-day program. There are also daily top tips, frequently asked questions, and "wisdom" cards on feeding, playing, and sleeping. The information covered includes an understanding of how normal developmental stages impact sleep, natural sleep rhythms (eg, day or night and circadian rhythms), infant cues (communication), tips for creating a safe, conducive sleep environment for infants or children, and support about infant or child settling and resettling [31]. The app also includes information and prompts for parents to access more intensive support as needed, for example, telephone support line and information on how to book a face-to-face appointment with Tresillian. Tresillian is Australia's largest early parenting service located in New South Wales on the east coast of Australia. Tresillian provides services to thousands of families annually [32]. SleepWellBaby, while a separate program, was based on the Tresillian approach, developed with Tresillian clinicians, and is endorsed and promoted by Tresillian.

Recruitment

Potential participants were recruited through online advertising, primarily through paid advertising on Facebook, posts on the Tresillian Facebook and Instagram social media pages, and posts on the Sydney Institute for Women, Children and their Families Twitter/X and LinkedIn social media pages. Eligible for inclusion were parents or carers who were aged 18 years and older, had infants aged less than 6 months, could read and understand the English language, lived in Australia, and had not previously used SleepWellBaby.

Potential participants followed a link to the study landing page containing participant information housed on the REDCap (Research Electronic Data Capture) platform hosted at Sydney Local Health District [33,34] and completed eligibility questions. Eligible participants completed an eConsent form, then completed the baseline survey, and received a code to access the SleepWellBaby app. Participants were recruited from April 30, 2021, to November 30, 2021. SleepWellBaby versions 1.5 to 1.7 were in use during this period.

Measures

Demographic Data

At baseline, each participant reported their age, carer role (eg, mother and father), employment, education, and country of birth. They also reported information related to the family, including relationship status, number of children, main language spoken at home, and postcode. Characteristics of the infant were collected, including infant age, gender, if they were born prematurely, and current milk feeding status.

Engagement

Engagement with the app was measured using an Engagement Index (EI) framework [35]. The EI includes 5 subindices, which

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are scored between 0 and 1. These indices included click depth index, loyalty index, recency index, interaction index, and feedback index. Metrics related to each subindex were extracted from the SleepWellBaby app analytics database (detailed in Multimedia Appendix 1). To calculate an overall EI score out of 100, these subindices are summed, divided by the number of indices, and multiplied by 100. A higher score indicated higher engagement with the app. Using this framework, participant engagement in the first 7 and 30 days was calculated to generate 2 EI scores [35]. In addition, 3 self-report questions were also asked at the 7-day and 30-day surveys: parents were asked whether they were still regularly using the app (yes or no; if no, asked to further select why they no longer use the app), if they thought the program assisted in improving their sleep (program helped parent sleep scale, 5-point Likert scale, "strongly disagree" to "strongly agree"), and if the program assisted in improving their infant's sleep (program helped infant sleep scale, 5-point Likert scale, "strongly disagree" to "strongly agree").

Acceptability

Acceptability of delivering an mHealth infant sleep and settling program was measured in 2 ways. First, a Net Promoter Score (NPS) [36] was collected within the app. Second, a 10-item "Parent Satisfaction Scale" was developed based on items from previous research on parents' engagement with an infant health app [35]. Each item was measured on a 5-point Likert scale, from 1 ("strongly disagree") to 5 ("strongly agree"). The satisfaction scale was designed to sum into a total scale ranging from 10 to 50, with higher scores indicating higher satisfaction with the program. These items were collected at both the 7-day and 30-day follow-up surveys.

In the survey, participants were also prompted to provide text responses through open-ended questions at the 2 follow-up surveys. More than half of the participants provided open-ended text responses on their perceptions of the app. Input was requested across several open-text questions at each of the survey time points. Questions included "Please describe reasons for not using SleepWellBaby" and "Is there anything else you'd like to add about SleepWellBaby?".

Parent Well-Being Outcomes

Aspects of parent well-being measured included fatigue, parenting confidence, and emotional health. These were measured at baseline, 7 days, and 30 days. Fatigue was measured via the 9-item Fatigue Severity Scale (FSS) [37]. This scale measures symptoms of fatigue, asking participants how much they agree with the items on a 7-point scale. This scale has been used in samples of mothers attending residential child and family health services [38]. A total score is calculated and ranges from 9 to 63, with higher scores indicating greater fatigue severity.

The Me as a Parent (MaaP) questionnaire was used to measure parents' sense of competence, confidence, and self-efficacy in their parenting [39]. This 16-item scale was developed and validated in an Australian population of parents, and measures parenting self-regulation incorporating 4 domains that the authors describe as a "…global sense of competency and confidence in parenting" (p.2853) [39]. A total score is calculated and ranges from 16 to 80, with higher scores indicating a greater sense of competence, confidence, and self-efficacy in their parenting.

Emotional health was measured with 3 instruments: a short mood screener designed for the SleepWellBaby app [40], the EPDS [41], and the Generalized Anxiety Disorder 7-item scale (GAD-7) [42]. The EPDS has been commonly used in previous research on sleep programs [11], and both the EPDS and GAD-7 are widely used as screening tools for emotional and mental health. For these 2 scales, a total score is calculated and ranges from 0 to 30 for the EPDS and from 0 to 21 for the GAD-7, with higher scores indicating greater symptoms of depression and anxiety.

Analysis

Engagement

Descriptive statistics, proportions, medians, means, SDs, and 95% CIs of the 7-day and 30-day EI and subindices were calculated. Parents' continued use of the app, program helped parent sleep scale, and program helped infant sleep scale were similarly described. Program helped parent sleep scale and program helped infant sleep scale were measured with a 5-point Likert scale, with responses later collapsed into 3 levels: "strongly agree and agree," "neutral," and "strongly disagree and disagree." The McNemar-Bowker test was performed to compare responses to this question at the 2 follow-up time points.

Acceptability

The questions related to the continued use of the app and the NPS are reported using descriptive statistics (proportions, means, and SD). Exploratory factor analysis was applied to the 10-item Parent Satisfaction Scale, which showed a 1-factor solution with good internal consistency (Kaiser-Meyer-Olkin test=0.854; Bartlett test of sphericity $P<.001$; variance of first factor, 49.355%; Cronbach $\alpha=0.88$ [43]). Therefore, these 10 items were summed, producing a single "satisfaction score." Independent 2-tailed *t* tests were used to explore differences in the NPS and satisfaction score by the following dichotomous demographic variates: education (university qualification or higher vs no university qualification), number of children (1 child only vs 2 or more children), symptoms of anxiety and depression at baseline (baseline EPDS ≥13 and/or GAD-7 ≥15 vs baseline EPDS <13 and/or GAD-7 <15), and parent perception at baseline of infant daytime and nighttime sleep problems (yes or no). Correlation between the satisfaction score and the EI was examined with Spearman ρ.

For the open-ended text responses, thematic analysis was conducted using the following Braun and Clark's 6-step process: (1) familiarization (reading the response), (2) initial descriptive coding, (3) forming themes (by searching for patterns and comparing and contrasting codes), (4) checking themes (internally, checking that the quotes and codes sit together as a theme, and across the dataset, checking that the themes reflect the data, and checking for disconfirming data), (5) naming themes, and (6) reporting the findings [44]. Using Lumivero NVivo (version 13) software [45] (AMM used inductive coding to code all responses and then identified themes). JA and HC

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each read and coded a portion of the data separately. Over several meetings, discussions, and reviews, confirmation of the coding and themes was conducted by all 3 authors (HC, JA, and AMM).

Parent Well-Being Measures

Separate hierarchical multiple regression models were conducted to analyze the impact of engagement with the program on 4 of the outcome variables measuring fatigue (FSS), parenting confidence (MaaP), and emotional health (GAD-7 and EPDS). To ensure that outcomes were analyzed in relation to app *use* rather than the mere *download* of the app, the 7-day EI was the predictor variable for the outcomes measured at 7 days, and the 30-day EI was the predictor variable for the outcomes measured at 30 days. In addition to engagement, another predictor of interest was parents' perception of how the app assisted in improving their own and their infant's sleep (program helped parent sleep scale and program helped infant sleep scale). Several covariates were also included to adjust the models. The blocks were structured as follows: EI (predictor) and target outcome (dependent variable) with baseline score of target outcome (model 1); program helped parent sleep scale and program helped infant sleep scale (model 2); parent age at baseline, infant age at baseline, parent education, number of children, and pregnancy complication reported as baseline (model 3); and baseline score of the 3 other outcome variables (model 4).

IBM SPSS Statistics (version 29) [46] was used for all analyses, and *P* values <.05 were considered statistically significant.

Ethical Considerations

Ethics approval was provided by Sydney Local Health District (RPAH Zone) Human Rights Ethics Committee (Protocol X20-0548 & 2020/ETH03215) prior to the start of the study. All study procedures were conducted in accordance with the ethical standards of the Declaration of Helsinki. Consent was obtained from all participants through an eConsent framework, including participant information and electronic consent form. Participants provided consent for research data collection and consent to access and match these data with the data collected in the SleepWellBaby app. None of the authors were involved in the development of the program.

Results

Participant Characteristics

A total of 1468 potential participants indicated an interest in the app and study. Of these, 798 (54.4%) participants met eligibility criteria and consented to participate, with 700 (87.7%) participants forming the baseline sample following completion of the baseline survey. Participants in the baseline sample who did not complete either follow-up survey at 7 days or 30 days (n=309) were excluded from subsequent analysis (Figure 1).

Of the final cohort included in the 7-day or 30-day follow-up analyses (n=391), most were mothers (n=382, 97.7%), with English as their main language (n=376, 96.2%), born in Australia (n=317, 81.1%), on leave from work (n=339, 86.7%), with a university education (undergraduate: n=152, 38.9%; postgraduate: n=151, 38.6%), in a long-term or married relationship (n=381, 97.5%), with an average age of 33.2 (SD 4.01) years. More than half (n=236, 60.4%) engaged with SleepWellBaby using an Apple device, 25.8% (n=101) used an Android, and the other 13.8% (n=54) were missing these data. Most of the included infants were born at term (n=369, 94.4%), 55.5% (n=217) were male, and most were being fed breastmilk (breastfeeding: n=348, 89% and/or expressed breast milk: n=113, 28.9%), with an average age of 2.6 (SD 1.7) months at baseline and age range spanning 0 to 5.9 months. This was the first child for most participants (n=280, 71.6%). The majority of participants lived in NSW (n=269, 68.8%), followed by Queensland (n=37, 9.5%), and Victoria (n=34, 8.7%). Most participants lived in major cities (n=316, 80.8%), followed by inner regional areas (n=62, 15.9%), then outer regional areas (n=11, 2.8%), with only one participant living in a remote or very remote area (n=1, 0.3%).

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Figure 1. Recruitment and retention flowchart. EI: Engagement Index.

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There were few statistically significant differences in demographics between those lost to follow-up after the baseline survey and those who continued to complete the 7-day and/or 30-day survey (Table 1). A greater proportion of those lost to follow-up were in full-time work (5.5% vs 1.8%; *P*=.03), and fewer were breastfeeding at baseline (83.5% vs 89%; *P*=.04). Fewer participants in the low-risk category (EPDS <10) were lost to follow-up than expected by chance; however, there was no statistically significant difference between the 2 groups in the mean baseline EPDS score or the other 3 parent well-being outcomes (Table 1). We determined that participants who remained in the study for analysis were sufficiently representative on the parent well-being outcomes of the cohort initially enrolled at baseline and a complete case analysis was conducted. As may be expected, both the 7-day and 30-day EI scores were significantly higher for participants included for analysis than participants lost to follow-up (Table 1).

Table . Baseline outcomes and Engagement Index for participants and participants lost to follow-up.

Baseline outcome and engagement index	All participants at baseline (n=700)	Participants included for analysis (n=391)	Participants lost to follow-up (n=309)	*P* value
Me as a Parent Score, mean (SD)	57.26 (7.93)	57.21 (7.72)	57.33 (8.21)	.83[a]
Fatigue Severity Score, mean (SD)	40.95 (9.33)	40.89 (8.96)	41.03 (9.80)	.84[a]
Generalized Anxiety Disorder score, mean (SD)	5.20 (4.28)	4.99 (4.04)	5.46 (4.57)	.16[a]
Edinburgh Postnatal Depression Scale, mean (SD)	8.16 (4.71)	7.87 (4.60)	8.52 (4.82)	.07[a]
Probable depression (≥13), n (%)	120 (17.1)	59 (15.1)	61 (19.7)	.03[b]
Possible depression (10-12), n (%)	123 (17.6)	60 (15.4)	63 (20.4)	.03[b]
Low risk (<10), n (%)	456 (65.1)	271 (69.3)[c]	185 (59.9)[c]	.03[b]
Missing, n (%)	1 (0.1)	1 (0.3)	0 (0)	.03[b]
Positive EPDS Q10[d], n (%)	50 (7.1)	26 (6.7)	24 (7.8)	.68[b]
Negative EPDS Q10, n (%)	650 (92.7)	365 (93.1)	285 (92.2)	.68[b]
Baby has daytime sleep problem, n (%)	540 (77.1)	306 (78.3)	234 (75.7)	.44[b]
Severity of daytime sleep problem, mean (SD)	4.73 (1.20)	4.77 (1.24)	4.69 (1.15)	.43[a]
Baby has nighttime sleep problem, n (%)	474 (67.7)	268 (68.5)	206 (66.7)	.66[b]
Severity of nighttime sleep problem, mean (SD)	4.94 (1.31)	4.91 (1.34)	4.97 (1.29)	.59[a]
Engagement Index over 7 d				<.001[a]
Mean (SD)	—[e]	73.39 (19.23)	51.81 (19.76)	
Median (IQR)	—[c]	78.29 (62.01 - 88.26[f])	52.76 (41.22-63.31[g])	
Engagement Index over 30 d				<.001[a]
Mean (SD)	—[c]	68.52 (17.68[f])	48.17 (17.42)	
Median (IQR)	—[c]	70.47 (57.04-82.24[f])	47.81 (39.98-57.42[g])	

[a]*t* test.

[b]χ^2 test.

[c]Column proportions differ at the .05 level

[d]Question 10 of Edinburgh Postnatal Depression Scale (EPDS) asks about thoughts of self-harm.

[e]Not applicable.

[f]Participants for analysis included n=371, missing n=20 as unable to match participant with app data

[g]Participants lost to follow-up included *n*=264, missing *n*=45 as they did not continue with the survey or the app

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Engagement

Engagement with the program, based on the EI, was higher over the first 7 days (64.42/100), than at 30 days (60.06/100; t_{634}=16.842; P<.001). While the difference is small, it indicates participants used the program more in the first 7 days, compared to the first 30 days (Table 2).

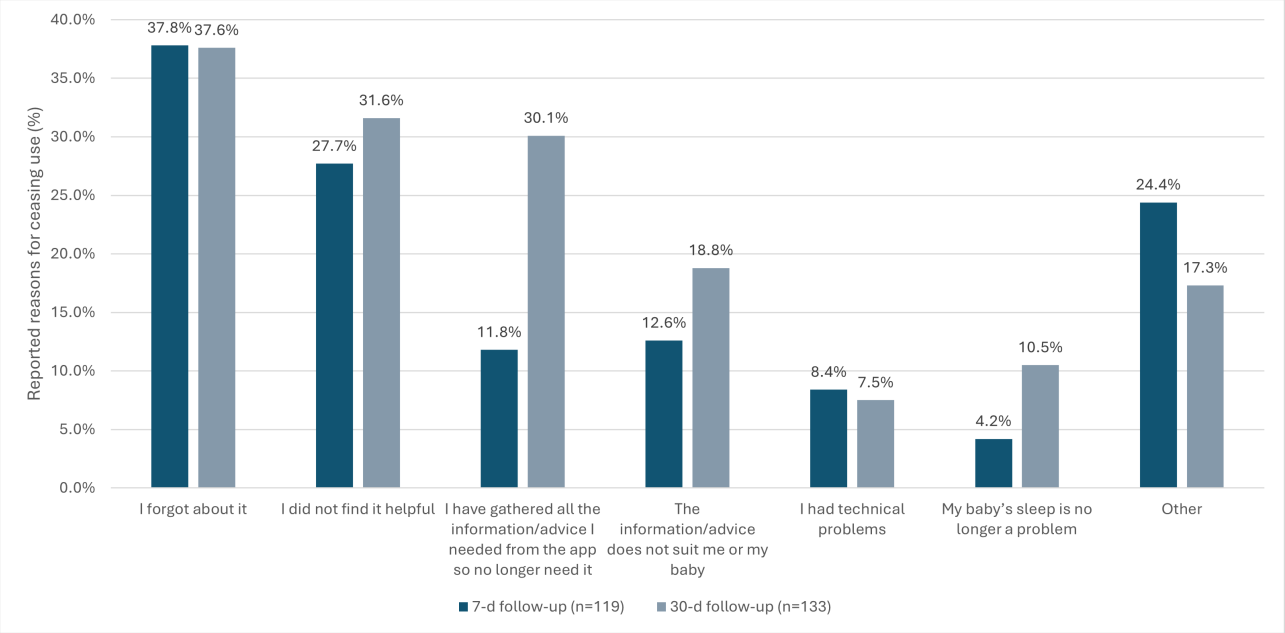
Similarly, self-reported engagement based on the questions in the 7-day survey indicated decreasing use over time. At 7 days, 58.1% (n=227/391) of participants reported that they were still using the app regularly, while at 30 days, only 22.5% (n=88) were still using the app regularly. The most common reason for ceasing regular use was forgetting about the app, and the least common reason was that the infant's sleep was no longer a problem (Figure 2). Participants could provide an open-text response explaining their choice, which was incorporated into the thematic analysis. Responses were diverse as shown in these 3 examples of the open-text response: "Too overwhelming to have to log what my baby is doing. Don't want to continually have to look at the app P96"; "Missed a day and forgot! P127"; and It's tricky to use P1104."

Table . Engagement Index (EI) of app use by participants.

EI	7-d EI	30-d EI
Overall score		
Mean (SD)	64.42 (22.16)	60.06 (20.22)
Median (IQR)	65.14 (50.94 - 84.20)	61.14 (45.54 - 75.51)
Click depth (Ci)		
Mean (SD)	0.56 (0.26)	0.50 (0.26)
Median (IQR)	0.60 (0.40 - 0.75)	0.52 (0.33 - 0.69)
Loyalty (Li)		
Mean (SD)	0.80 (0.27)	0.85 (0.25)
Median (IQR)	0.90 (0.80 - 0.99)	0.93 (0.86 - 0.99)
Regency (Ri)		
Mean (SD)	0.87 (0.22)	0.91 (0.19)
Median (IQR)	0.95 (0.88 - 0.98)	0.97 (0.92 - 0.99)
Interaction (Ii)		
Mean (SD)	0.55 (0.36)	0.30 (0.33)
Median (IQR)	0.43 (0.29 - 1.00)	0.13 (0.07 - 0.40)
Feedback (Fi)		
Mean (SD)	0.44 (0.38)	0.44 (0.38)
Median (IQR)	0.50 (0.00 - 0.80)	0.50 (0.00 - 0.80)

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Figure 2. Reasons for ceasing use of the SleepWellBaby app.



Regarding perception of the program for help with infant sleep, most participants were either reported neutral perceptions or agreed that the program assisted with infant sleep (Table 3). There was a categorical change in perceptions between 7 days and 30 days (McNemar-Bowker test: χ^2_3=8.9; *P*=.03), with a shift from neutral to agree, indicating that more participants agreed that the program assisted with their infant's sleep at the 30-day follow-up than at the 7-day follow-up. Similarly, on the program helped parent sleep scale, there was a categorical change in perception between 7 days and 30 days (McNemar-Bowker test: χ^2_3=8.741; *P*=.03), indicating that more participants agreed that the program assisted with their sleep at the 30-day follow-up than at the 7-day follow-up.

Table . Perception of program impact on infant and parent sleep.

Item	Disagree, n (%)	Neutral, n (%)	Agree, n (%)	McNemar-Bowker test
Did SleepWellBaby help baby sleep?				.03
7-d follow-up	61 (16.5)	201 (54.3)	108 (29.2)	
30-d follow-up	34 (15.0)	103 (45.4)	90 (39.7)	
Did SleepWellBaby help parent sleep?				.03
7-d follow-up	109 (30.1)	176 (48.6)	77 (21.3)	
30-d follow-up	64 (28.3)	91 (40.3)	71 (31.4)	

Acceptability

For those participants who responded to the NPS question (n=306), 39.2% (n=120) rated the app 6 or less (detractors), 30.4% (n=93) rated it 7 or 8 (passives), and 30.4% (n=93) rated it 9 or 10 (promoters). The mean NPS was 7.05 (SD 2.48), indicating that most participants were satisfied with the program. However, based on the difference in the proportions of promoters and detractors, the overall NPS was −8.8% in this sample. On the other hand, the Parent Satisfaction Scale measured out of 50 showed an average of 36.26 (95% CI 35.60-36.93). The areas of language and trust scored the highest, while the areas of content and the sharing feature scored the lowest (Table 4).

There was a positive correlation between the EI and satisfaction score (Spearman ρ=0.52; *P*<.001), indicating those more highly engaged with the app reported higher satisfaction with the app. Whether engagement fostered satisfaction or whether satisfaction fostered engagement is not known. Subgroup comparisons for both the NPS and the satisfaction score found there was no difference in either scores based on baseline depression or anxiety symptoms, number of children, parent's education, or reported infant sleep problems (Multimedia Appendix 2), indicating that a diverse range of parents with varying characteristics found the program acceptable.

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Table . Parent satisfaction scale at 7-d follow-up (n=330).

Area	Question	Mean (SD)	95% CI
Overall score (range 10 - 50)	__[a]	36.26 (6.17)	35.59-36.93
Language (range 1-5)	The language used in the app was easy to understand	4.25 (.623)	4.18-4.32
Trust (range 1 - 5)	I can trust the information on the SleepWellBaby app	4.19 (.650)	4.12-4.26
Notifications—amount (range 1 - 5)	I was happy with the number of notifications or email messages received each week	3.86 (.813)	3.77-3.95
Confidence (range 1 - 5)	I felt confident using this app	3.69 (.917)	3.59-3.79
Notifications—relevance (range 1 - 5)	I found the notifications or messages suited my baby's age and stage of development	3.58 (.840)	3.49-3.67
Notifications—content (range 1 - 5)	I found the notifications or email messages helpful	3.56 (.870)	3.47-3.65
Functionality (range 1 - 5)	The app did everything I expected it to do	3.41 (.967)	3.31-3.51
Content (range 1 - 5)	The SleepWellBaby program covered all of the things about sleep and settling that I wanted it to	3.16 (.999)	3.05-3.27
Feature—sharing (range 1 - 5)	I found it helpful to share the app with my partner/family	3.14 (1.009)	3.03-3.25

[a]Not applicable.

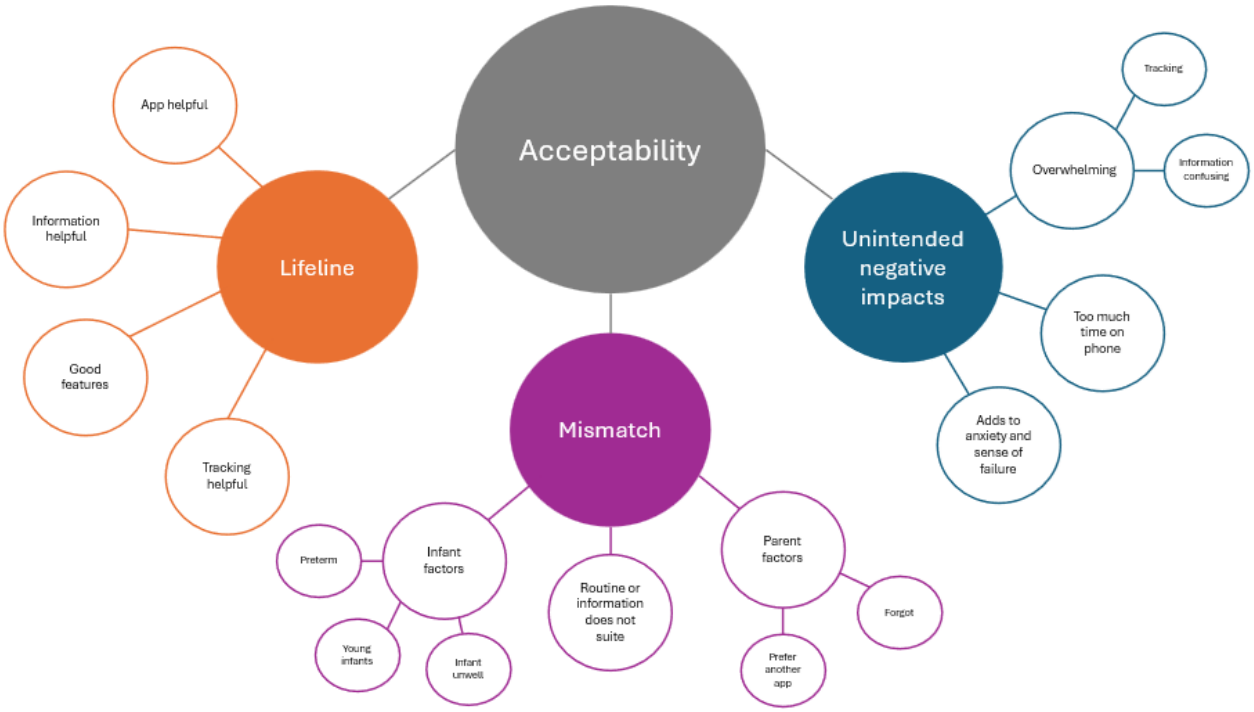
Open-Ended Text Response Findings

Overview

More than half (n=226, 57.8%) of the participants provided responses to the open-ended text response fields. Three themes were identified in these responses that were relevant to the acceptability of the program. These themes and their component parts are summarized in Figure 3. The themes are described in more detail below and illustrated with direct quotations from participants. Participants are identified with their self-identified carer role, age, and infant age (noting for those infants born prematurely, this is chronological age, not corrected age). Two additional themes identified in these qualitative responses focused on challenges with using and recommendations for improving the app interface. These themes related to the earlier version of the SleepWellBaby app used in the study and are therefore not included here.

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Figure 3. Themes on acceptability from open-ended text response.



Theme 1: Lifeline

Responses grouped under this theme indicated satisfaction with the app and an experience of SleepWellBaby as a source of useful resources, information, and support. Participants shared that they found the program to be a helpful support for them as they navigated caring for their infant:

> *This app has helped me find out the sleep rhythm of my baby and taught me to build a sleep ritual which works well at the moment.*
>
> *[Participant ID 624, mother aged 31 years with infant aged 3 months]*
>
> *So great, it felt really personal as though I had someone supporting my journey with check ins and tracking.*
>
> *[Participant ID 312, mother aged 28 years with infant aged 4 months]*
>
> *Please keep it free, parents really need this support.*
>
> *[Participant ID 215, mother aged 31 years with infant aged 2 months]*

This support was noted particularly during time where access to physical services were limited during pandemic-related restrictions:

> *Love it! What a wonderful program which all parents should be able to access for free – particularly in lockdown. It is the lifeline we all need in the mindless and monotonous bedlam of baby sleep while spending so much time at home.*
>
> *[P628, mother aged 33 years with infant aged <1 month]*
>
> *The program and app have taught me so much in the early newborn phase that I feel so much more confident in my ability to manage without support as lockdown continues.*
>
> *[P1085, mother aged 32 years with infant aged <1 month]*

Theme 2: Mismatch

For some participants, however, there was a mismatch between what the program offered and their everyday experiences—they expressed that the routines or information provided did not suit. For some participants, this mismatch related to characteristics of their infant: the app was not appropriate due to factors such as prematurity, very young age, illness, or their infant's rhythm being different from the example routines. For others, it was related to their own dispositions, such as preferring another app or forgetting about the app:

> *It really didn't suit preterm babies—this could really be worked on.*
>
> *[P168, mother aged 31 years with infant aged 3 months (chronological age)]*
>
> *...it needed the chance to adjust for preterm babies. My child was 5 weeks preemie and programs are based on my child's actual age instead of corrected age.*
>
> *[P488, mother aged 31 years with infant aged 3 months (chronological age)]*
>
> *My baby is too young to start a routine.*
>
> *[P412, mother aged 35 years with infant aged <1 month]*
>
> *The program suggested felt a little unrealistic for my 1-month-old, and did make me feel a bit pessimistic.*
>
> *[P535, mother aged 36 years with infant aged 1 month]*

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> *I don't find the app helpful if my baby is off schedule.*
>
> *[P211, mother aged 24 years with infant aged 2 months]*

Theme 3: Unintended Negative Effects

For some participants, features of the app—and, in some cases, the use of an app at all—were experienced as counterproductive, impacting negatively on their well-being, and making it more difficult to focus on being with their baby:

> *Tracking everything felt overwhelming.*
>
> *[P72, mother aged 35 years with infant aged 3 months]*
>
> *I find the information and the way it is presented very confusing.*
>
> *[P532, mother aged 35 years with infant aged<1 month]*

Some participants expressed that some features or use of the app added to their anxiety and sense of failure:

> *I found it was making me more anxious tracking sleep etc.*
>
> *[P78, mother aged 28 years with infant aged 5 months (chronological age)]*
>
> *My baby wasn't sleeping well and it made me feel much worse...the app made me feel I was failing.*
>
> *[P65, mother age not reported with infant aged 4 months]*

Other participants also noted that it contributed to increasing time on their phone, which was seen as undesirable:

> *I rarely ever was able to track in real time, [it] takes attention away from baby when they need it most.*
>
> *[P605, mother aged 32 years with infant aged 5 months]*

Impact on Parent Well-Being

Fatigue

Parents' engagement and self-reported perception of the program had a significant impact on parents' fatigue (FSS). In the final adjusted linear regression model, with all variables of interest included (model 4), 7-day engagement with the app decreased fatigue (Table 5). In this model, a 1-point increase in the 7-day EI score was associated with a decrease in FSS by 0.06 at 7-day follow-up. Similarly, the program helped parent sleep scale was also related to a decrease in FSS score, where a 1-point increase in agreement that the program helped with parent sleep was associated with a 1.7-point decrease at 7-day follow-up.

Fatigue at the 30-day follow-up was unrelated to the 30-day EI. However, in the final adjusted linear regression model (model 4), parent self-reported perception of the program was related to the FSS, where a 1-point increase in agreement that the program helped with infant sleep was associated with a 1.7-point decrease in FSS at 30-day follow-up.

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Table . Impact of the engagement with app on fatigue, parenting confidence, and emotional health.[a]

Parent well-being outcome	7-d		30-d	
		P value		*P* value
Fatigue, adjusted FSS[b] (95% CI)				
Engagement Index	−0.06 (−0.1 to −0.01)	.01	0.02 (−0.05 to 0.09)	.63
Program helped infant sleep	0.41 (−0.93 to 1.76)	.55	−1.74 (−3.48 to −0.004)	.05
Program helped parent sleep	−1.72 (−2.95 to −0.48)	.007	0.81 (−0.96 to 2.49)	.34
Parenting confidence, adjusted MaaP[c] (95% CI)				
Engagement Index	0.03 (−0.01 to 0.06)	.11	0.02 (−0.04 to 0.07)	.57
Program helped infant sleep	1.48 (0.46 to 2.50)	.005	0.53 (−0.72 to 1.78)	.40
Program helped parent sleep	0.11 (−0.82 to −1.05)	.81	0.46 (−0.75 to 1.66)	.46
Emotional Health, adjusted EPDS[d] (95% CI)				
Engagement Index	0.00 (−0.02 to 0.02)	.97	0.01 (−0.02 to 0.04)	.69
Program helped infant sleep	−0.47 (−1.07 to 0.14)	.13	0.13 (−0.57 to 0.84)	.71
Program helped parent sleep	−0.18 (−0.73 to 0.38)	.53	−0.64 (−1.13 to 0.04)	.07
Emotional Health, adjusted GAD-7[e] (95% CI)				
Engagement Index	0.01 (−0.01 to 0.02)	.53	0.00 (−0.03 to 0.02)	.82
Program helped infant sleep	−0.34 (−0.89 to 0.20)	.22	0.15 (−0.49 to 0.79)	.64
Program helped parent sleep	−0.47 (−0.97 to 0.03)	.07	−0.48 (−1.10 to 0.14)	.13

[a]All models adjusted for parent age at baseline, infant age at baseline, parent education, number of children, pregnancy complication reported as baseline, baseline score of target outcome, and baseline score of the 3 other outcome variables.

[b]FSS: Fatigue Severity Scale.

[c]MaaP: Me as a Parent.

[d]EPDS: Edinburgh Postnatal Depression Scale.

[e]GAD-7: Generalized Anxiety Disorder-7.

Parenting Confidence

In the final adjusted linear regression model (model 4), neither the 7-day nor 30-day EI was related to the MaaP score (parenting confidence). However, the program helped parent sleep scale was related to the MaaP at the 7-day follow-up: a 1-point increase in agreement that the program helped with infant sleep was associated with a 1.48-point increase in MaaP at the 7-day follow-up. This demonstrates that participants who agree that the program is helpful for their infants' sleep have a measured improvement in their sense of competence, confidence, and self-efficacy as a parent.

Emotional Health

In the final adjusted linear regression model (model 4), parents' emotional health was not associated with engagement nor with self-reported perception of the program. Neither the EPDS nor GAD-7 scores at the 7-day or 30-day follow-up were related to the 7-day EI score or 30-day EI score (Table 5).

Discussion

Principal Findings

This study provides evidence of the engagement with and acceptability and impact of SleepWellBaby for Australian parents of infants. The SleepWellBaby program is suitable for many parents, and those who found the program useful experience statistically significant improvements in their fatigue and parenting confidence. Many of the participating parents engaged with the app, and the program was acceptable to most parents who provided feedback. Parents reported they were generally satisfied with the program. While acceptability and satisfaction were generally positive, there were some contrasting themes from the participants' open-text response feedback. Importantly, it was noted that the program may at times be mismatched to parent and/or child needs and could be counterproductive with unintended negative impacts on well-being.

Nevertheless, engagement with the program was associated with a statistically significant improvement in parents' fatigue. Parents who had higher engagement or found the program most helpful for their sleep and their infant's sleep showed the greatest improvement in their fatigue. The modeling found that

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a 1-point increase (on a 100-point scale) in the 7-day EI score was associated with a decrease in parent fatigue severity (FSS) by 0.06 at 7-day follow-up. Given that a systematic review of patient-reported fatigue measures has identified minimum important difference for improvement for the FSS ranging from 0.08 to 0.4, this reduction is potentially clinically significant [47]. Similarly, parents' self-reported perception of the program to assist their own sleep at the 7-day follow-up was associated with a 1.72 decrease in FSS, and their infant sleep at 30-day follow-up was also related to improvement in fatigue with a 1.74 decrease. While these changes are modest, it demonstrates that participants who found the program helpful, and engaged more with the program, had measured improvement in their fatigue. Regarding the other outcomes of interest, there was no indication that engagement with the program had an impact on parents' emotional health where neither the EDPS nor GAD-7 scores at the 7-day or 30-day follow-up were related to the 7-day EI score or 30-day EI score. There was some indication that engagement with the program had an impact on sense of competence, confidence, and self-efficacy as parents' agreement that the program helped with infant sleep was associated with a 1.48-point increase in MaaP at the 7-day follow-up.

Engagement with the program was higher for the first 7 days, compared with the first 30 days, which aligns with the design of SleepWellBaby as a 7-day program that may be repeated as needed. For those who reported discontinued use of SleepWellBaby at 7-day and 30-day follow-up, few did so when their infant's sleep was no longer a problem. Around a third of participants had discontinued as they did not find it helpful, felt they had sufficiently gathered the information that they needed, or had simply forgotten about the app. This is similar to feedback from parents about other parenting apps [48] and suggests additional reminder features, such as push notifications, may be useful for supporting engagement. Another avenue of increasing engagement is increasing responsiveness of the app experience to user input or prompts that are based on the tracking data users enter into the app [49].

It is difficult to directly compare engagement with other similar apps due to the diversity of methods for measuring participant engagement [50]. Even among other studies using the same EI criteria, differences in the design and interactive features of each app impact the calculated EI. With this caveat in mind, compared to other studies using the EI criteria, engagement in the current study was similar or higher [24,48,51]. Likewise, the dropout of participants is similar to other evaluations of smartphone applications undertaken in the perinatal period [4,48,51,52].

While engagement and dropout in studies and evaluations of smartphone applications in the perinatal period are mixed, accessing parenting support and information via apps is increasingly popular [30]. A review of maternal and infant health smartphone applications in 2020 found 421 smartphone applications available, with 102 being 'evidence-based apps' as they were developed by a health care provider or affiliated provider [22]. There is a notable difference in parent use and engagement in 'commercial apps,' which are downloaded in the millions, and 'evidence-based apps,' which are downloaded in the thousands [53]. This may be due to marketing approaches and costs associated with keeping the application up to date with the smartphone operating systems. The risk in this market is that 'commercial apps' may not include the best, safest, most up-to-date evidence to support parents [30]. A solution may be partnership, as seen for SleepWellBaby, which combines commercial engagement strategies with evidence-based material [20].

While the NPS was negative in this sample, the 2025 12-month-to-date NPS for SleepWellBaby was 19 (email, November 24, 2025). Additionally, the adequacy of NPS as a standalone metric for use in healthcare has been questioned [54]. Therefore, we also included further questions related to satisfaction. On the basis of these, the program was acceptable to most, who were generally satisfied with the program and perceived most of the features as useful. However, some participants also expressed concerns that the program may at times be mismatched for their current needs and could be counterproductive, with unintended negative impacts on their well-being. One aspect of mismatch was the age and stage of development related to term versus premature infants. In the qualitative feedback, there was equivocal feedback regarding the suitability of the program for young infants (under 3 mo). Some parents did not find the tracking and sample plans realistic for their young infant, although others did. The Tresillian approach to infant and child sleep is child-led and responsive to child needs, and there is an emphasis on facilitating parents to observe, understand, and respond to their infant cues [31]. It may be that the nuance of this message is more difficult to convey via an app and may need additional educational resources (eg, videos).

One element within the theme *unintended negative effect* was that using digital technology made it harder for parents to focus on being with their baby. This tension around digital technology and parenting has been described elsewhere [55]. The parents in Facca's qualitative study described the usefulness of digital technology but felt some guilt about using these devices around their young children [55]. There is emergent research identifying different styles of engagement with apps among parents, such as those who tend to use detailed, consistent tracking and those who use basic, intermittent tracking [56,57]. For SleepWellBaby, tracking is just one feature of the program, and parents can choose not to use tracking while still using other features.

While tracking of infant sleep and daily routines can be a useful tool to identify patterns and routines, qualitative feedback from some parents indicated it was counterproductive to achieving their goals. A recent cross-sectional study on breastfeeding app use found that mothers who tended to use detailed, consistent tracking, compared to those using more basic, intermittent tracking, had higher psychopathological symptoms (eg, symptoms of depression or anxiety) [56]. However, as that was a cross-sectional study, the direction of effect is not clear—ie, whether tracking within the app triggered increased mood symptoms or whether mothers who already exhibited these symptoms were more likely to undertake detailed tracking. In the current evaluation, the EI measure did include app tracking elements in the interaction index, and there was no association between the EI and anxiety symptoms. However, any app that includes tracking in the perinatal period should be developed

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in line with emerging evidence about any relationship between parental symptoms of depression or anxiety and app-based tracking [56].

Strengths and Limitations

A strength of this study was an open recruitment to sample across a general population of parents with minimal exclusion criteria. Yet, while there were limited restrictions on those eligible as the sample was self-selected, the demographic of recruited parents was skewed compared to the general parenting population toward women (mothers) who spoke English as the main language at home, mostly born in Australia, on parental leave from work, university educated, married or in a long-term relationship, and residing in a major city. While reflective of the general demographic of women who access residential parenting support services [14,58], it limits the applicability of these findings to parents with broader demographic characteristics, such as parents with lower educational attainment or those living in regional and rural locations.

The findings are also limited by the quasi-experimental pre-post study design. The lack of a control group and randomization limits the ability to identify the specific impact of the program. However, to offset this limitation, a strength of our analysis is the inclusion of EI, which is an objective measure of participant engagement with the app. Including EI within the models on impact provides some support that change in participant outcomes was related to participant use of the program. The potential for selection and response bias represents an additional limitation of this study. Participants were parents and carers who were motivated to use the SleepWellBaby app and willing to share their experiences and feedback, which may limit the generalizability of the findings. Most participants perceived their infant to have a sleep problem; however, this is unsurprising given the app's purpose of supporting parents to understand infant sleep and providing guidance on responsive sleep strategies. Although the proportion of participant loss to follow-up was comparable to that reported in other studies evaluating perinatal smartphone applications [48,52], attrition remained substantial. Participants who continued and those who did not were very similar in almost all baseline characteristics, although those participants who continued with the study were more highly engaged with the app; we therefore acknowledge the potential for overestimation of the effects of the SleepWellBaby app and limitation of generalizability of the results.

Finally, the evaluation was conducted during the COVID-19 pandemic, between April 2021 and March 2022. This period of data collection overlapped with several public health measures, including stay-at-home orders and limitations on in-person gatherings. There is growing evidence that the pandemic and associated public health measures were associated with poorer mental health outcomes for parents [59,60]. Notably, the NSW government provided funding to give free access to SleepWellBaby for NSW families during times during the pandemic when the strictest stay-at-home orders were in place (March to July 2020 and June to October 2021). Therefore, the findings need to be interpreted with this context in mind.

As noted, this sample was not particularly diverse and included mostly mothers. Few studies have included both parents [61]. One feature within SleepWellBaby is the ability to share with multiple users—however, data on the use of this feature was not collected in this evaluation. Therefore, further research could investigate the use of the program by both parents with a focus on this functionality. Importantly, any further research and evaluation should aim to recruit a diverse sample of parents to identify the efficacy and acceptability among a broader range of parents.

Conclusions

SleepWellBaby is an infant sleep digital smartphone app that offers a useful program suitable to many parents with infants. As is the case with many interventions, it is not one-size-fits-all—not all parents will find accessing early parenting support via an app helpful. Therefore, this is a useful program to be included within a suite of support options for parents, including non–mobile phone-based interventions. SleepWellBaby is available within the early parenting support structures provided in Australia, including primary health child and family services and intensive early parenting services, such as those provided by Tresillian Family Care Centres. Within this context, SleepWellBaby offers a unique accessible support option for many parents that can promote improved parental health and well-being through reduced fatigue and increased parenting confidence.

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Data Availability

The datasets generated or analyzed during this study are not publicly available, as participant consent was not sought for public data sharing. Statistical analysis syntax is available from the authors on reasonable request.

Authors' Contributions

Conceptualization: JA, DS, ST, NR, ED-W
Formal analysis: JA, AMM, HC, JF
Methodology: JA, ST, NR, EDW
Project administration: HC
Protocol development: JA, HC, ST, NR, ED-W
Software: DP
Writing – original draft: JA, AMM, HC
Writing – review & editing: JA, DS, ST, NR, ED-W, HC, AMM, AD

Conflicts of Interest

HC, ST, NR, and ED-W report no conflict of interest. JA and DS have previously been employed by Tresillian. AMM and AD are employed by Tresillian. Tresillian, in conjunction with Sleepfit Solutions, developed the SleepWellBaby program. Sleepfit Solutions declares a financial interest.

Multimedia Appendix 1
Engagement Index equation and subindices.
[DOCX File, 20 KB - pediatrics_v9i1e88948_app1.docx]

Multimedia Appendix 2
Subgroup comparisons of Net Promoter Score and the satisfaction score.
[DOCX File, 16 KB - pediatrics_v9i1e88948_app2.docx]

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Abbreviations

EI: Engagement Index
EPDS: Edinburgh Postnatal Depression Scale
FSS: Fatigue Severity Scale
GAD-7: Generalized Anxiety Disorder seven-item scale
MaaP: Me as a Parent
NPS: Net Promoter Score
REDCap: Research Electronic Data Capture

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Mobile Apps and Websites With Breastfeeding-Related Content in Germany: Cross-Sectional and Evaluation Study

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Abstract

Background: Digital technologies with breastfeeding content have become an important source of information for new parents in Germany. However, little is known about the content and quality of digital breastfeeding information sources.

Objective: The objective of this paper was to evaluate the scope, content, and quality of free-of-charge smartphone mobile apps and websites with breastfeeding-related content in Germany.

Methods: A cross-sectional study of mobile apps and websites was conducted in July 2023. The App Store for iOS and Google Play Store for Android were searched for mobile apps. Bing.de and Google.de were searched for websites. The quality, suitability of information, readability, and coverage of digital information on mobile apps and websites were evaluated. We used the user version of the Mobile Applications Rating Scale, the Health-Related Web Site Evaluation Form, the Suitability Assessment of Materials, and the Flesch Index tool, as well as a self-developed checklist. We report our results according to the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) statement.

Results: Eight mobile apps and 13 websites were included. The quality of information sources was generally good for apps (median 83%, IQR 73% - 87%) and websites (median 86%, IQR 83% - 89%). The suitability of information was good for apps (median 84%, IQR 70% - 89%) and websites (median 89%, IQR 78% - 94%). The coverage of information was good for apps (median 68%, IQR 59% - 86%) and websites (median 82%, IQR 73% - 100%). However, digital information was difficult or challenging to read on most apps (median 59%, IQR 53% - 68%) and websites (median 58%, IQR 47% - 61%). Seven of 8 mobile apps and 9 of 13 websites were commercial, with embedded links to shopping sites without external certificates confirming the trustworthiness of the information.

Conclusions: Assertive action from nonprofit and governmental institutions should be provided to support parents with reliable, unbiased, open-access digital breastfeeding information in Germany.

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KEYWORDS

breastfeeding; mobile app; smartphone; German parents; internet; consumer health information; digital health literacy; content analysis

Introduction

According to the Health Information National Trends Survey (HINTS), approximately 70% of Germans prefer to get their health information from health care professionals, followed by internet research (21%) and friends or family (5%) [1]. However, the credibility of health information provided via an internet search was categorized as middle to low [1].

The most popular digital sources for obtaining perinatal and breastfeeding support are mobile apps, internet forums, and websites [2]. A 2017 survey of Belgian mothers found that more than 90% used the internet to seek information, with “breastfeeding” being the most frequently searched topic [3]. However, parents may be confronted with a large number of results when searching for terms such as “parenting,” which could lead to information overload [4,5]. With the rise in the use of smartphones came a rise in mobile health (mHealth) apps, defined as medical or public health practice supported by mobile

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devices [6]. The willingness of parents to use mHealth apps in Germany appears to be high, as long as apps are free of charge [7].

Breastfeeding is associated with many short- and long-term health benefits for mothers and children. In Germany, 97% of infants are breastfed at birth, but this number drops to 73% by 2 months of life [8]. Digital tools may help to enhance breastfeeding success by providing information and motivation. Many mHealth-based interventions centering around pregnancy and breastfeeding have been developed in recent years and show potential to improve pregnancy care and increase breastfeeding rates and outcomes [9-13]. Alianmoghaddam et al [14] showed that online information about child nutrition and mobile apps can be a good option for breastfeeding promotion. However, in 2025, a systematic review and meta-analysis on the impact of mobile apps for breastfeeding found only a nonsignificant increase in the odds of exclusive breastfeeding, stating that there is insufficient evidence to show sustained beneficial effects on breastfeeding [15].

Information on the content and quality of digital breastfeeding information has been published in many countries, including the United States, Canada, China, Australia, Spain, and Italy [16-22]. Yet, little is known about the quality of digital breastfeeding information sources in Germany. The objective of this paper was to evaluate the scope, content, and quality of free-of-charge mobile apps and websites with breastfeeding information available in Germany.

Methods

Study Design

A cross-sectional study of German websites and mobile apps with breastfeeding content was conducted in July 2023. The App Store for iOS and Google Play Store for Android were searched for mobile apps. Bing.de and Google.de were searched for websites. We followed the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) reporting guideline, omitting items 13 and 15, which were not relevant for this study, as no study participants were recruited and no outcomes were measured [23].

Selection of Mobile Apps

The German App Store for iOS and Google Play Store for Android were screened with smartphones from July 19 to 20, 2023, by 2 reviewers (MZ, JP) using 9 search terms (see Table S1 in Multimedia Appendix 1).

Inclusion criteria for mobile apps were that mobile apps were offered free of charge, were in the German language, and contained information on breastfeeding. Exclusion criteria were restricted access, formatting as an electronic book (eg, e-books, news, magazines, podcasts, blogs, or word documents), games or gaming apps, and mobile apps whose main function was to monitor time or frequency of infant care tasks without providing educational information on breastfeeding.

Two reviewers (MZ, JP) independently screened all mobile apps for eligibility. For each search term, the first 10 mobile apps were selected, and features such as rating, costs, number of downloads, and characteristics of the mobile app were noted. A list of mobile apps was selected, duplicates were removed, lists for Android and iOS were jointly merged, and duplicates were removed again.

Evaluation of Quality, Suitability, and Readability of Mobile Apps

Three validated tools were used to evaluate mobile apps for quality, suitability, and readability. Each mobile app was reviewed independently by 2 reviewers (MZ, JP) and then evaluated using an evaluation form (see Multimedia Appendix 2).

To appraise the quality of mobile apps, the user version of the Mobile Application Rating Scale (uMARS) questionnaire in the original English language was used [24]. The uMARS is an established tool to assess the quality of mHealth apps rated by end users. It consists of 16 items, including 4 objective quality subscales (engagement, functionality, esthetics, and information), 1 subjective quality subscale, and a further subscale to measure the users' perceived impact of the evaluated mobile app [25]. All items were rated on a 5-point Likert scale (1=inadequate to 5=excellent) [24]. See Multimedia Appendix 2 for further information on the specific questions asked.

Suitability of information was assessed with the Suitability Assessment of Materials (SAM) questionnaire, which was validated by students and health care providers from several cultures [26,27]. It rates health-related materials in 6 areas (content, literacy demand, graphics, layout and type, learning stimulation and motivation, and cultural appropriateness). There are 22 questions on a 3-point scale (0=not suitable, 1=adequate, 2=superior). For missing items, the instructions of the SAM were followed. For questions answered as not applicable, 2 points of the possible 44 points were subtracted. Suitability was rated based on scoring (0% - 39% suitable material, 40% - 69% adequate material, and ≥70% superior material). The suitability for a particular population was ranked from 0 (not recommended) to 10 (recommended without reservations) based on socioeconomic and cultural backgrounds of the population [27].

Readability was rated with the Flesch Index online tool, which provides a score from 0 to 100 (0 - 30: hard to read, 30 - 50: difficult to read, 50 - 60: challenging, 60 - 70 normal, 70 - 80: easy to read, 80 - 90: easily to read, 90 - 100 very easy to read) [28]. As the Flesch Reading Ease test was developed for the English language, it needed to be adapted for the German language [29]. For the evaluation, 3 randomly chosen paragraphs were copied into the online tool and the average of the Flesch Reading Ease test results was used for evaluation.

Search Terms for Websites

Websites were identified using Google.de and Bing.de between July 13 and 17, 2023 [30,31]. Google Trends and Ubersuggest were used to identify appropriate search terms [32,33]. Google Trends is a tool to get information about how often users of Google enter explicit search terms. Ubersuggest is a tool to analyze keywords, find ideas for new keywords, and give insights into the ranking of the keywords.

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A layperson was asked to suggest how to search for breastfeeding information and problems. These terms were used to find the most popular search terms for this topic on Ubersuggest and Google Trends for Germany. Twelve German search terms were used (see Table S2 in Multimedia Appendix 1). Before screening each search term individually, the search history and cookies were deleted to simulate the first search of a layperson. For each search term, the first 10 links were selected, as consumers rarely read beyond the first page of search results [34].

Selection of Websites

Two reviewers (MZ, JP) independently screened all websites for eligibility. Search terms used were identified and recorded for each website. Websites with only 2 or fewer of the selected search terms were excluded. The 2 lists from Google and Bing were compiled, and duplicates were removed. Inclusion criteria comprised use of the German language and breastfeeding content. Websites inaccessible because of dead or broken links, websites formatted as PDFs, commercial websites, social media platforms (eg, Facebook), and websites without breastfeeding content were excluded.

Evaluation of Quality, Suitability, and Readability of Mobile Websites

Three validated tools were used to evaluate websites for quality, suitability, and readability. Each website was reviewed independently by 2 reviewers (MZ, JP) and then evaluated using an evaluation form (see Multimedia Appendix 3).

To appraise the quality of information, the Health-Related Web Site Evaluation Form (HRWSEF) was used [35]. The HRWSEF is an evaluation instrument for health educators and clinicians to evaluate the appropriateness of health education websites for clients and patients. It is a 36-item tool including 9 topics (website information, content, accuracy, author, currency, audience, navigation, external links, and structure). Users judge (1=disagree, 2=agree, 0=N/A) whether the website is a good source of information for the patient or whether it should not be recommended. Instructions of the HRWSEF questionnaire were followed for missing information (questions which were not applicable were deleted from the total scoring). Therefore, the total number of points depended on the number of questions answered with “agree” or “disagree.” Quality was rated based on scoring (0% - 74.9% poor quality, 75% - 89.9% adequate quality, and ≥90% excellent quality) [35].

As for mobile apps, suitability of information was assessed with the SAM questionnaire, and readability was assessed using the Flesch Index online tool [27,28]. The readability of the selected website was evaluated by copying 3 links of a paragraph of the sites hit by the search to the online tool, and the average of the Flesch Reading Ease test results was used for evaluation.

Coverage of Information

To assess the coverage of information, 11 basic breastfeeding topics were used, based on the guidelines of the German Healthy Start–Young Family Network [36]. The websites and mobile apps were screened independently by 2 reviewers with technical nutrition and lactation expertise for coverage of the 11 topics (MZ, JP). If the 2 reviewers had a different outcome, the websites and mobile apps were screened again to achieve consensus. The 11 items are listed in the 2 standardized self-developed checklists (see Multimedia Appendix 3 for the apps and Multimedia Appendix 3 for the websites). All items on the checklists were dichotomously answered (yes/no). Then 11 items were summed and converted into percentages for descriptive statistics.

Statistics

Interrater reliability (IRR) testing was undertaken between the 2 reviewers assessing mobile apps and websites by comparing scores from each rating tool. The IRR agreement was assessed using the Kendall coefficient of concordance (Kendall rank correlation coefficient) for ordinal variables [37].

The scores for mobile apps and webpages were summarized using boxplots for each index, where the scores for each index were transformed into percentages to plot all indexes in one plot. Medians and IQR (25th and 75th percentiles) were calculated. Kendall τ correlation was used to examine correlations between Google Play Store ratings, App Store ratings, and the different uMARS scores, Flesch Index, and SAM questionnaire. Values from the 2 app stores were summarized by calculating means. A 2-sided P value <.05 was considered statistically significant. All analyses were performed using R Studio version 4.3.2 (R Foundation for Statistical Computing, Vienna, Austria) [38].

Results

Eight mobile apps and 13 websites with breastfeeding-related content were identified.

German Mobile Apps With Breastfeeding Content

The selection process describing the numbers of mobile apps identified at each stage of the selection process is displayed in Multimedia Appendix 1. A description of all included mobile apps is given in Table 1.

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Table . Description of included mobile apps (n=8).

Name of the app	Published by	Authors	Category	Average user rating on App Store/Google Play Store (range 0 - 5)	Downloads in Google Play Store	Comment
Preglife, Schwangerschaft app	Preglife - Swedish health care company	Midwives, lactation specialists	Medicine	4.9/4.5	>1 million	Breastfeeding information, tracker, mum workouts, meditation, diary, reduction codes for companies
Medela Family - Stillen Tracker	Medela AG - Company distributing products for breastfeeding	Mostly not characterized, midwives and self-called Medela breastfeeding experts	Medicine	4.1/4.5	>500,000	Breastfeeding information, tracker, shop, chatbot, connection to personal pump
Baby+/Dein Baby-Tracker	Philips in collaboration with Health & Parenting	Not specified	Medicine	4.6/4.6	>5 million	Breastfeeding information, tracker, lullabies, diary, and documentation of sentimental milestones
Baby & Essen	Federal Agency of Agriculture and Nutrition	Agronomist, ecotrophologist	Foods + drinks	4.4/3.9	>100,000	Breastfeeding information, mode for fathers, and diary
Keleya: Still- & Beckenboden app	Keleya Digital Health Solutions GmbH	Midwives, breastfeeding counselors, breastfeeding expert	Medicine	4.8/3.5	>5000	Breastfeeding information, meditation, gymnastics, and breastfeeding preparation online courses
Hipp Baby app	HIPP GmbH - food producer	Breastfeeding counselors, midwives, medical educator	Lifestyle	4.4/2.2	>500,000	Breastfeeding information and map to find places for breastfeeding, and changing diapers among others
BabyCare-Gesund & Schwanger	Pregive GmbH - independent research institute	Physicians, midwives	Medicine	4.5/4.7	>10,000	Breastfeeding information, recipes, quizzes, relaxation music, gymnastics, among others
ELTERN - Schwangerschaft & Baby	G+J Medien GmbH - media Publisher	Mostly not characterized, nonspecialized journalists	Medicine	4.6/4.3	>100,000	Breastfeeding information, community, and documentation of sentimental milestones

All included mobile apps were free of charge; however, for some mobile apps, upgrades were available that required a fee. The average user rating of mobile apps ranged from 3.3 to 4.7 (out of 5, with 1 being the lowest and 5 being the highest rating). The Google Play Store showed download numbers ranging from more than 5000 to more than 5 million, whereas no such information was available in the App Store for iOS. Six out of 8 mobile apps were found in the stores under the category “Medicine,” one under “Lifestyle,” and one under “Foods + Drinks.” One mobile app (Baby & Essen) was provided by a governmental agency; all others were commercial in nature.

Included mobile apps not only provided informational content but also other features (eg, 3 apps had a tracker for tracking diapers, breastfeeding meals, and sleeping).

For 3 of the included mobile apps, it was not clearly stated whether health professionals wrote the text. None of the identified mobile apps showed any certification to prove independent and correct health information or had a data protection certification.

The mobile app with governmental affiliation showed no advertisements, whereas all others were commercial in nature. Six commercial mobile apps showed advertisements for

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breastfeeding-related products (eg, pumps, creams, bottles and teats, pacifiers, formula, and supplements) or linked wording within the texts to websites for ordering products. One mobile app (Preglife) showed general family-related advertisements.

There were only 4 mobile apps offering content in a language other than German. The mobile app Baby+ is available in 18 other languages (eg, Turkish, Polish, Russian, and English), the mobile app Keleya: Still- & Beckenboden offers content in the English language as well, Medela in 11 other languages (eg, Russian and English), and Preglife in 9 other languages (eg, Polish and English).

Evaluation of Quality, Suitability, and Readability of Mobile Apps

The quality of the selected mobile apps using the uMARS index ranged from 3.4 to 4.6 (out of 5), with a median of 4.1 (out of 5) (83% [IQR 73% - 87%]). However, the mobile apps differed more in the perceived impact of the uMARS, ranging from 23% to 93%.

The suitability of information showed a median of 84% (IQR 70% - 89%), whereas all mobile apps reached at least half of the points in the suitability for population, and some reached the total of 10 points (Medela, Baby+). The median of the Flesch Index was 59% (IQR 53% - 68%), which is around half of possible points to reach (Figure S3 in Multimedia Appendix 1).

The ratings of the subjective uMARS index and the store rating by the users were correlated (Kendall τ=0.67; P=.03). There was no statistically significant correlation between any of the other scores. Detailed evaluation results of all included mobile apps are given in Table 2.

Table . Evaluation results of included mobile apps (n=8).

Name of the app	uMARS[a] quality mean score (range 0 - 5; %)	uMARS subjective quality (range 0 - 20; %)	uMARS perceived impact (range 0 - 30; %)	Suitability of information (SAM[b]; range dependent 0 - 44; %)	Suitability for population (SAM; range 0 - 10; %)	Coverage of information (range 0 - 11; %)	Flesch index (range 0% - 100%)
Preglife, Schwangerschaft app	4.6 (92)	16 (80)	25 (83)	27/30 (90)	8 (80)	9 (82)	57
Medela Family - Stillen Tracker	4.4 (88)	13 (65)	28 (93)	30/34 (88)	10 (100)	11 (100)	52
Baby+/Dein Baby-Tracker	4.3 (86)	14 (70)	18 (60)	23/32 (72)	10 (100)	7 (64)	69
Baby & Essen	4.2 (85)	12 (60)	24 (80)	22/26 (85)	7 (70)	8 (73)	67
Keleya: Still- & Beckenboden app	4 (80)	13 (65)	22 (73)	34/38 (90)	9 (90)	7 (64)	53
Hipp Baby app	3.7 (73)	5 (25)	12 (40)	31/38 (82)	6 (60)	6 (55)	61
BabyCare-Gesund & Schwanger	3.6 (73)	13 (65)	7 (23)	12/20 (60)	5 (50)	4 (36)	46
ELTERN - Schwangerschaft & Baby	3.4 (68)	6 (30)	14 (47)	23/30 (68)	6 (60)	10 (91)	71

[a]uMARS: user version of the Mobile Application Rating Scale.

[b]SAM: suitability assessment of materials.

German Websites With Breastfeeding Content

The selection process describing the numbers of websites identified at each stage of the selection process is displayed in Multimedia Appendix 1. A description of all included websites is given in Table 3.

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Table . Description of included websites (n=13).

Name and information of the website	Link	Certification	Authors
Familie, the website of a media brand financed with advertisement	[39]	No	Nonspecialized journalists
Kindergesundheit-Info, Federal Center for Health Education	[40]	No	Not characterized
Babelli, a company participating in partner and advertisement program of Amazon.de financed with advertisement	[41]	Certificate of the Health Foundation	Nonspecialized editors, content checked by midwives and a lactation consultant
Team Muttermilch, the website of an IBCLC[a] and pediatrician to inform and sell services	[42]	No	Individual lactation consultant
Medela, a company distributing products for breastfeeding	[43]	No	Mostly not characterized, midwives and self-declared breastfeeding experts
Wikipedia, encyclopedia	[44]	No	Not characterized
Netdoktor, information about health and medicine topics financed with advertisements	[45]	Afgis certification	Physicians, biologists, specialized journalists
Still-Lexikon, information about breastfeeding financed with advertisement and donation	[46]	World Health Organization conformity	Individual bioscientist, journalist, lactation consultant
Eltern, the website of the eponymous journal	[47]	No	Mostly not characterized, nonspecialized journalists
Lansinoh, a company distributing products for breastfeeding	[48]	No	Not characterized
Apotheken Umschau, the website of the eponymous journal	[49]	Afgis certification; certificate of the Health Foundation	Not characterized
Hipp, a company distributing food products for babies and toddlers	[50]	No	Breastfeeding counselor
Windeln, a company selling baby products and a magazine	[51]	No	Mostly not characterized, midwives

[a]IBCLC: international board certified lactation consultant.

Four websites referred to companies selling baby products (Medela, Lansinoh, Hipp, Windeln), 3 referred to parenting or health-related magazines (eg, Eltern, Apotheken Umschau, Windeln), and 1 referred to a media brand (Familie). Of the 4 informational websites, only 1 had a government affiliation (Kindergesundheit-Info). One website was an encyclopedia (Wikipedia), and 1 referred to a mobile app (Babelli).

Seven websites did not specify which professional group wrote the texts, and only 2 websites provided content written by breastfeeding experts. One of the included websites showed a quality logo (afgis), one the certification of the Stiftung Gesundheit, and one other showed both; thus, less than a quarter of the websites had a quality of information certification.

Eight websites showed advertisements for breastfeeding-related products (eg, pumps, creams, bottles and teats, pacifiers, formula and an infant flatulence product) with a direct link to order these products. Two websites showed no advertisements (Wikipedia, Kindergesundheit-Info), 2 websites showed general advertisements (Still-Lexikon, Apotheken-Umschau), and 1 showed advertisement for a breastfeeding book and consultation (Team Muttermilch).

Evaluation of Quality, Suitability, and Readability of Websites

The quality of the selected websites showed a median HRWSEF of 86% (IQR 83% - 89%). The suitability of information varied between 64% and 100%, with a median of 89% (IQR 78% - 94%). The suitability for the German population was rated between 5 and 10 out of a maximum of 10 points, with 5 websites being recommended to the German population without reservation (Familie, Team Muttermilch, Medela, Lansinoh, Apotheken Umschau). The median of the Flesch Index was 58% (IQR 47% - 61%), which is around half of the possible points to reach (Figure S4 in Multimedia Appendix 1). Detailed evaluation results of all included websites are given in Table 4.

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Table . Evaluation results of included websites (n=13).

Name and information of the website	HRWSEF[a]; range dependent 0 - 72, (%)	Suitability of information (SAM[b]); range dependent 0 - 44, (%)	Suitability for population (SAM); range 0 - 10, (%)	Coverage of information range 0 - 11, (%)	Flesch index, range 0% - 100%
Familie, the website of a media brand financed with advertisements	65/68 (96)	36/38 (95)	10 (100)	11 (100)	64
Kindergesundheit-Info, Federal Center for Health Education	60/64 (94)	30/32 (94)	6 (60)	9 (82)	60
Babelli, a company participating in partner and advertisement program of Amazon.de, financed with advertisements	64/70 (91)	35/36 (97)	6 (60)	11 (100)	61
Team Muttermilch, the website of an IBCLC[c] and pediatrician to inform and sell services	59/66 (89)	32/32 (100)	10 (100)	9 (82)	61
Medela, a company distributing products for breastfeeding	58/66 (88)	31/24 (91)	10 (100)	11 (100)	56
Wikipedia, encyclopedia	61/70 (87)	20/26 (77)	5 (50)	8 (73)	42
Netdoktor, information about health and medicine topics financed with advertisements	53/62 (86)	23/30 (77)	5 (50)	10 (91)	46
Still-Lexikon, information about breastfeeding financed with advertisement and donation	58/68 (85)	23/36 (64)	6 (60)	11 (100)	46
Eltern, the website of the eponymous journal	57/68 (84)	25/28 (89)	9 (90)	8 (73)	67
Lansinoh, a company distributing products for breastfeeding	55/66 (83)	28/30 (93)	10 (100)	10 (91)	59
Apotheken Umschau, the website of the eponymous journal	49/60 (82)	34/38 (90)	10 (100)	8 (73)	57
Hipp, a company distributing food products for babies and toddlers	52/64 (81)	27/32 (84)	5 (50)	8 (73)	58
Windeln, a company selling baby products and a magazine	52/68 (77)	28/36 (78)	7 (70)	8 (73)	47

[a]HRWSEF: health-related web site evaluation form.

[b]SAM: suitability assessment of materials.

[c]IBCLC: international board certified lactation consultant.

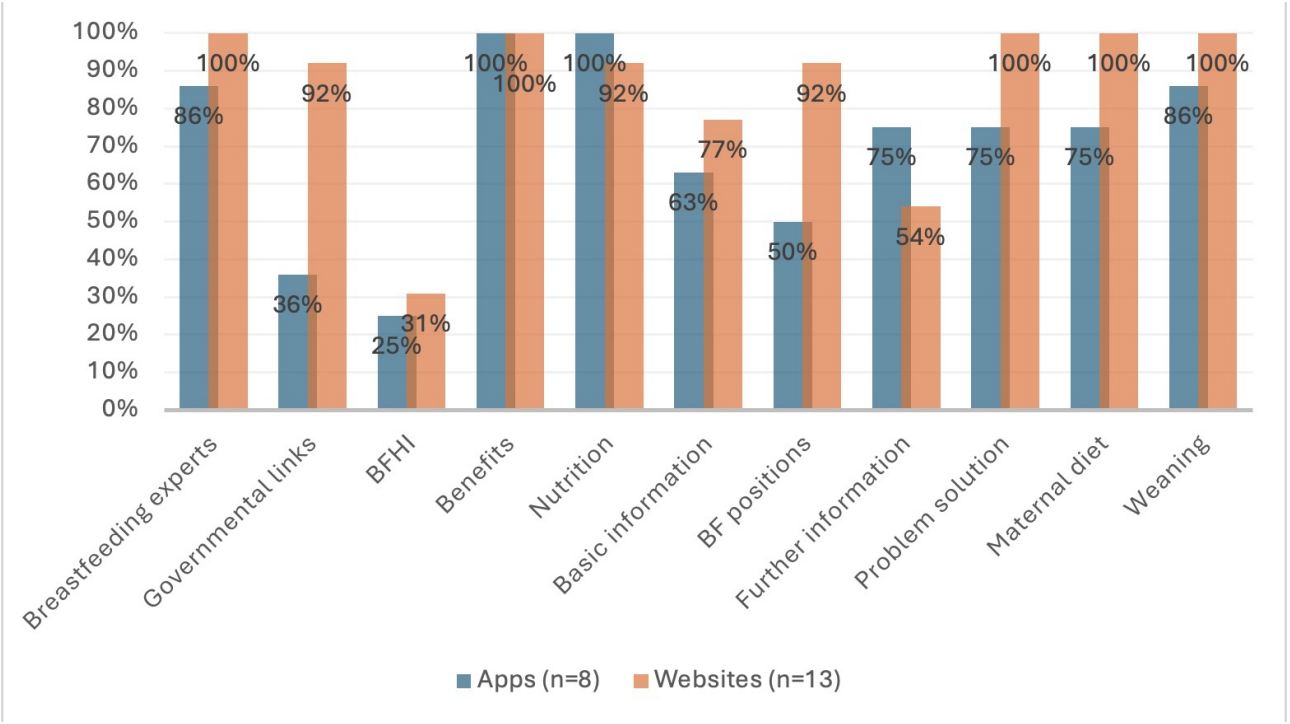
Coverage of Information

The mobile apps reached at least half of the points in the coverage of information (except Baby Care Gesund & Schwanger), and only 1 mobile app reached the total points (Medela) (Table 2). The coverage of information for the analyzed websites ranged between 8 and 11 (out of 11 items), with almost one-third reaching the maximum total points (Table 4).

The results for coverage of information show that websites provided more information for many topics than mobile apps (Figure 1).

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Figure 1. Coverage of basic breastfeeding topics within the mobile apps and websites. BF: breastfeeding; BFHI: Baby-Friendly Hospital Initiative.



Three companies (Medela, Eltern, Hipp) offered both a website and a mobile app. Some differences between mobile app and website content were identified. Website content was of higher quality, suitability of information, and coverage of information, and was easier to read compared with the app from the same company (Table S4 in Multimedia Appendix 1).

Statistics

IRR testing between the 2 reviewers assessing all selected mobile apps and websites showed a Kendall coefficient of concordance values of 0.92 for mobile apps and 0.90 for websites (P<.01) (Tables S5 and S6 in Multimedia Appendix 1).

Discussion

Principal Findings

This is the first cross-sectional study of mobile apps and websites with breastfeeding content in Germany. The 8 apps scored a median of 4.1 (out of 5) on the uMARS scale, indicating good quality. Three of 13 websites were rated as excellent (3/13, 23%), and 10 of 13 as adequate quality (10/13, 77%) as per the HRWSEF. Four of the 8 mobile apps (4/8, 50%) and 9 of 13 websites (9/13, 70%) were rated as difficult or challenging to read based on the Flesch Index. Websites provided more comprehensive information coverage based on the checklist, with a median of 9 of 11 (IQR 8 - 11) topics covered. This was slightly more than mobile apps, which had a median 7.5 of 11 (IQR 6.5 - 9.5) topics covered.

Only 1 mobile app and 1 website had a governmental affiliation, whereas all other websites and mobile apps were commercial in nature. Most mobile apps (6/8, 75%) and websites (8/13, 62%) displayed advertisements for breastfeeding-related products. Only a minority of mobile apps (4/8, 50%) and websites (2/13, 15%) offered content written exclusively by medical and allied health professionals. We found the number of available commercially developed mobile apps and websites written by nonprofessionals to be concerning, since they can potentially provide biased or inaccurate information to parents.

Quality of Mobile Apps and Websites

Overall, we found that German mobile apps with breastfeeding content were of average to good quality based on their mean uMARS quality scores. Findings from studies in other countries that reviewed infant-feeding and pregnancy mobile apps rated the majority as poor or moderate quality [17,20,52,53]. Only 1 review rated 16 parenting mobile apps as good or excellent [18].

Compared with those studies, our reviewer ratings were typically higher for items included in the uMARS objective score than the subjective score. According to our findings based on the subjective uMARS scale, we would not recommend 2 of the 8 mobile apps (2/8, 25%). In addition, we would only recommend 5 mobile apps (5/8, 63%) with reservations. Only 1 mobile app had a high recommendation score (Preglife; Table S3 in Multimedia Appendix 1). Our findings align with Cheng et al [20] and may reflect reviewer bias, as most apps (7/8, 88%) were commercial. Given that the reviewers were health professionals trained in recognizing the effects of advertisements on health behavior, their positionality may have influenced the scoring. Specifically, commercial apps may have received lower ratings because of the reviewers' awareness of how marketing strategies can shape consumer choices and health outcomes. A review of Virani et al [18] found that commercial parenting apps were more popular than governmental, likely because they are more visually appealing and entertaining. Apps that offer additional features, such as trackers, receive higher user ratings—an increase of 27% for each added feature [54]. However, monitoring and tracking breastfeeding seems to be the least effective way to improve breastfeeding outcomes [55].

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Three websites were rated as excellent, and 10 as adequate quality. The selected German websites were of much better quality than those reviewed in previous studies [52,56].

The majority of mobile apps and websites received high ratings for health information, while a smaller proportion was deemed adequate. Previous evaluations reported lower scores, indicating that the quality of these resources has presumably improved in recent years [20,52,56].

Suitability for Population and Readability

Germany is ethnically diverse, with about a quarter of the population having a migration background [57]. In contrast to a review of Australian apps and websites, adequate suitability for population was considered for about half of the reviewed mobile apps and websites in our study [52].

Three-quarters of the websites and half of the mobile apps in this study were considered challenging or difficult to read and understand. A high literacy level is required to understand the content of many mobile apps and websites [20,52,56]. A previous survey in Germany found that 23% of the interviewed persons (n=2902) said the health information provided verbally or written was difficult to understand [1]. For example, print materials and health mobile apps for weight loss could be improved by using simpler language [58]. Apps that are only available in German could at least be improved by using a lower level of literacy if they aim to reach non-native German speakers. Turkish, Polish, Russian, and Syrian people are the largest immigration groups in Germany [57]. The mobile app Baby+ is available in 18 other languages, which is likely the reason it has the most downloads.

Mobile App and Website Authors

Three of 8 apps and 7 of 13 websites provided insufficient information about the qualifications of their authors. In Germany, titles such as “breastfeeding counselor” or “breastfeeding expert” are not certified professions, whereas “International Board Certified Lactation Consultant” (IBCLC) is protected [59]. Among the websites and apps included in this study, only 3 websites and no mobile app were authored by IBCLCs. From the perspective of parents, Hughson et al [12] claimed that users prefer mobile apps that come from a trusted source, whereas Biviji et al [16] found little concern among the users about evidence-based content. Helpful online breastfeeding support can increase the likelihood of breastfeeding [60], but breastfeeding-related advice and information that is potentially produced by unqualified health professionals or lay persons or without clear authorship is concerning.

Coverage of Evidence-Based Content

Content that is not evidence based is harmful because it may spread myths, outdated or inaccurate advice, or contradict current public health recommendations, potentially increasing parental confusion and negatively affecting breastfeeding rates. Additionally, there is a lack of standards for the development of health apps [61]

Our results match previous findings stating that the coverage of information in mobile apps and websites is poor and partially contrary to Infant Feeding Guidelines [19,20,52,53,56]. When screening the apps and websites, the uMARS referred to the quality of information asking “Is app content correct, well written, and relevant to the goal/topic of the app?” (see Multimedia Appendix 2, app evaluation form), and the HRWSEF referred to accuracy asking “The information is accurate” (disagree, agree, or not applicable; see Multimedia Appendix 3, website evaluation form). However, as the user instruction for these tools suggests browsing the website(s) for a few minutes and the app(s) for at least 10 minutes (see Multimedia Appendix 2 and Multimedia Appendix 3), it is not possible to view the complete content. The rating of these questions is therefore based on the content assessed. To highlight the importance of evidence-based information, based on the German guidelines of the German Healthy Start-Young Family Network by the Federal Center for Nutrition, the authors used the self-developed checklist for coverage of information.

Advertisements Within Mobile Apps and Websites

Of the 13 websites reviewed, 8 linked directly to shops for breastfeeding products or breast-milk substitutes or displayed related advertising. One site (Babelli), which claims to be certified by the Health Foundation, linked to welcome gifts from companies producing breast-milk substitutes. Three apps directly referred to companies promoting their own products (Baby+, Hipp, Medela), and 3 others displayed advertisements for breastfeeding-related products or linked parts of their text to online shops. In our view, information intended to support breastfeeding should not include advertising for breast-milk substitutes. Nevertheless, manufacturers use digital platforms to combine breastfeeding information with marketing [62,63]. The International Code of Marketing of Breastmilk Substitutes of the World Health Organization [64], European Union legislation on infant formula [65], and German legislation on infant formula [66] all stipulate that there should be no advertising or other form of promotion of infant formula to the general public. The World Health Organization recently published technical guidance on regulatory measures to restrict digital marketing of breast-milk substitutes [67]. Until now, Germany has only adopted some of the provisions of The International Code; therefore, information on follow-on formula is permitted to be advertised to the general public [68].

Certification

Several certificates for quality of health-related websites exist in Germany, including Action Forum Health Information System (afgis) [69], Stiftung Gesundheit (Health Foundation) [70], and the medical search machine for German-speaking countries (Medisuch) [71]. The HONCode (Health on the Net Foundation) [72] was a reliable certification for ethical and qualitative standards of websites with health-related topics. Although it stopped its service in 2022, some websites still showed the certification at the time of our search. Only 3 websites were certified, and not even a quarter of the websites had any proof for correct medical information.

Strengths and Limitations

One strength of this study is that the quality appraisal of websites and mobile apps was performed using a variety of validated tools.

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The scope of this study was limited to mobile apps and websites with breastfeeding information available in German. Therefore, the findings of this study are not generalizable to websites and mobile apps in other languages.

This study focused on free-of-charge mobile apps, which are used most often. It is plausible that higher quality information might be available on breastfeeding mobile apps that charge a fee. Some health insurance companies offer a mobile app for pregnancy or parenthood with breastfeeding content "free of charge," but these are only available to their insured members through app stores. Our mobile app search did not include mobile apps provided by health insurance companies. Due to the possibility of using Google Trends and Ubersuggest, the selection of websites involved more differentiated search terms compared to mobile apps. This might have increased the likelihood of selection bias.

Conclusion

The reviewed apps and websites were generally of acceptable quality, but many included advertisements for breast-milk substitutes. Credible health authorities should improve visibility through effective keywords, regular updates, and content authored by qualified professionals. Independent certification for noncommercial, accurate health information is needed, and all content should follow relevant guidelines. Texts should be motivating, easy to read, and supported by summaries, visuals, and videos to aid users with limited time or literacy. To reflect diverse populations, providers should use inclusive images and offer translations into commonly spoken languages.

Features such as breastfeeding support, meal and sleep tracking, quizzes, recipes, milestone documentation, and chat functions may enhance user engagement and app ratings and could be integrated by public actors when designing evidence-based health apps.

In conclusion, although current evidence is insufficient to demonstrate sustained beneficial effects of breastfeeding promotion and support on breastfeeding rates through mobile apps alone [15], integration of evidence-based educational content in mobile apps together with personalized remote support nonetheless holds potential to improve breastfeeding outcomes [55,73].

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Conflicts of Interest

MZ, VJ, and MAT report no conflicts of interest. BVK has received reimbursement for speaking at conferences supported by companies marketing nutritional or healthcare-related products and by not-for-profit biomedical associations including the American Academy of Pediatrics, European Academy of Pediatrics, Biomedical Alliance in Europe, United European Gastroenterology, German Society for Pediatrics and Adolescent Medicine, and German Professional Association for Gynecology and Obstetrics.

Multimedia Appendix 1
Search terms for smartphone app with English translation.
[PDF File, 1410 KB - pediatrics_v9i1e78128_app1.pdf]

Multimedia Appendix 2
App evaluation form.
[PDF File, 271 KB - pediatrics_v9i1e78128_app2.pdf]

Multimedia Appendix 3
Website evaluation form.
[PDF File, 257 KB - pediatrics_v9i1e78128_app3.pdf]

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Abbreviations

HRWSEF: Health-Related Web Site Evaluation Form
IRR: interrater reliability
mHealth: mobile health
SAM: Suitability Assessment of Materials
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology
uMARS: user version of the Mobile Application Rating Scale

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Who Is (Not) Engaging With a Digital Parenting Intervention in Tanzania? Analysis of Predictors Using Data From a Factorial Randomized Trial

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Abstract

Background: Digital interventions offer a promising avenue for scalable parenting support in low- and middle-income countries, where in-person coverage remains limited. However, engagement disparities may reduce their potential for population-level impact.

Objective: This study examined caregiver-level predictors of engagement with ParentApp, a smartphone-based adaptation of the Parenting for Lifelong Health (PLH) for Teens program for caregivers of adolescents aged 10 to 17 years.

Methods: This study was nested within a cluster-randomized factorial trial of ParentApp in Mwanza, Tanzania, implemented according to the optimization phase of the Multiphase Optimization Strategy. Clusters (n=16), comprising 614 caregivers (n=205, 33.4% men), were randomized to 3 components: guidance (guided vs self-guided), app design (unstructured vs structured), and digital support (enhanced vs basic). Digitally tracked app engagement outcomes included the number of modules completed, the first module not started, and the first module not completed. Baseline candidate predictors included demographic, socioeconomic, behavioral, and psychological factors assessed via an app-embedded questionnaire. Poisson generalized linear mixed-effects models with random effects for clusters assessed associations between predictors and each outcome. Interaction terms were specified to test whether associations differed by caregiver gender.

Results: Among 614 caregivers, 596 (97.1%) completed the first module; however, engagement declined rapidly thereafter, with only 281 (45.8%) completing module 2 and 49 (7.9%) completing all 12 modules. Overall, mean content completion was 35.6% (SD 33.1%) of the program. Women completed approximately 15% more modules than men (incidence rate ratio 1.15, 95% CI 1.05-1.27, P=.003), despite reporting higher levels of financial stress, food insecurity, child maltreatment, and depressive symptoms at baseline (all P≤.02; Cohen d=0.19 - 0.37). No other caregiver characteristics were significantly associated with engagement.

Conclusions: This is the first known study to investigate caregiver-level predictors of engagement with a digital parenting intervention in a low- and middle-income country. Engagement with ParentApp was broadly consistent across caregiver subgroups, with the exception that women completed significantly more modules than men. To equitably engage men and fathers, future studies should pair father-inclusive, identity-affirming content with implementation strategies that reduce social and economic barriers to participation.

Trial Registration: Pan-African Clinical Trial Registry PACTR202210657553944; https://tinyurl.com/yc2bmsx7

International Registered Report Identifier (IRRID): RR2-10.1186/s12889-023-15989-x

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(JMIR Pediatr Parent 2026;9:e86129) doi:10.2196/86129

KEYWORDS

digital health; mobile phone; parenting; violence against children; predictors; engagement; low- and middle-income countries

Introduction

Parenting interventions are central to global efforts to prevent violence against children and promote family well-being [1,2]. However, access to evidence-based parenting support remains limited in many low- and middle-income countries (LMICs). Workforce shortages and the high costs of in-person delivery restrict service availability, while travel, time, and competing work and caregiving responsibilities make it difficult for many families to participate [3,4]. Promisingly, there is growing evidence that digital parenting interventions can improve parenting and child outcomes, including among hard-to-reach families in LMICs [5,6]. However, program effects are often small and user engagement is low [7], warranting investigation into how these interventions can be designed and implemented to sustain engagement and achieve population-level impact.

Engagement is a key mechanism for behavioral change [8]. Research on engagement with digital interventions has largely been conducted within behavioral science, which typically defines engagement as the extent of program use (eg, amount, frequency, duration, and depth), although its operationalization varies widely across studies [9]. While engagement challenges are not unique to digital delivery, they may be amplified by structural inequalities in digital access and use, particularly in LMICs.

Families living in poverty or rural areas often rely on lower-performing devices, have limited internet connectivity, and face digital literacy challenges [10]. In Tanzania, for example, 82% of the population owns a basic mobile phone, compared with just 35% who own a smartphone [11]. Gender disparities in digital access further compound these barriers. Across LMICs, women are 17% less likely to own a mobile phone and 21% less likely to use the internet than men [12]. These digital divides risk excluding already marginalized families and may deepen health and social inequities if unaddressed. Identifying which caregivers are most likely to engage, or disengage, is therefore essential for developing equitable and effective digital parenting interventions.

Existing evidence on caregiver engagement with digital parenting programs remains limited and inconsistent, with relatively few studies conducted in LMICs [7]. Gender disparities are well documented in in-person programs, where fathers engage at markedly lower rates than mothers [13,14]. In a South African trial of the in-person Parenting for Lifelong Health (PLH) Teens program, fathers represented only 3% of participants and were significantly less likely to attend sessions than mothers [15]. Encouragingly, early evidence from high-income countries (HICs) suggests mothers and fathers engage at similar rates in digitally delivered parenting programs [16,17]. Whether these findings extend to LMICs remains unknown.

Beyond gender, evidence on caregiver-level predictors remains limited. Sociodemographic factors appear to be the most extensively studied in digital parenting interventions, with lower education and income consistently linked to reduced engagement and increased attrition in HICs [17-21]. Similar associations have been reported in in-person parenting programs in HICs [22]. By contrast, findings from a few in-person programs in LMICs suggest that socioeconomic disadvantage does not reliably predict lower engagement [15]. Evidence on behavioral and psychological predictors is comparatively limited and mixed, with positive parenting practices [21,23] and caregiver mental health [16,20,21,24] both associated with higher and lower engagement in digital parenting programs. To our knowledge, no studies of digital parenting interventions have examined these associations in LMICs.

The current study therefore examines caregiver-level predictors of engagement in an early version of ParentApp, a digital parenting intervention developed for caregivers of adolescents in LMICs. Using data from a cluster-randomized factorial trial in Tanzania, implemented in accordance with the optimization phase of the Multiphase Optimization Strategy (MOST) [25], we test whether caregiver demographic, socioeconomic, behavioral, and psychological characteristics predict user engagement. We also explore whether these associations differ by caregiver gender. Findings are intended to inform targeted and inclusive strategies to enhance engagement in ParentApp and, more broadly, support the equitable scale-up of digital parenting interventions in LMICs.

Methods

Study Design

This study was nested within a 2 × 2 × 2 cluster-randomized full factorial experiment implemented across 16 low-income urban and periurban communities in Mwanza, Tanzania [26]. Each community (cluster) was randomly assigned to one of 8 experimental conditions, comprising all possible combinations of 3 components: guidance (guided vs self-guided), app design (structured vs unstructured), and digital support (enhanced vs basic). The trial aimed to optimize user engagement with ParentApp, which was developed in partnership with the United Nations Children's Fund, the World Health Organization, and the Tanzanian national government. The trial was preregistered on the Pan-African Clinical Trial Registry (PACTR202210657553944) on October 11, 2022. Further information about the trial design and findings can be found in the study protocol and related trial publications [26-28].

Participants

Eligible participants were required to be at least 18 years old, be caring for an adolescent aged 10 to 17 years, reside in the same household as the adolescent for at least 4 nights per week during the previous month, and have regular access to an Android smartphone (OS 5.1.1 or higher). To address the

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underrepresentation of fathers in parenting interventions, the study aimed to enroll at least 20% men. Participants were recruited on a rolling basis between October 24, 2022 and December 1, 2022, through local community leaders, who were predominantly men. Community leaders introduced and endorsed the study during community meetings, helping to build trust and acceptability among families.

Interventions

ParentApp

ParentApp is designed to promote positive parenting, prevent violence against adolescents, and reduce risks of sexual violence victimization. It is a smartphone-based adaptation of the in-person PLH Teens program, originally developed and evaluated in South Africa [29] and subsequently implemented across multiple LMICs, including Tanzania [30]. ParentApp was developed to expand reach and reduce costs and logistical barriers of in-person delivery. To support use in settings with limited or intermittent internet access, it operates offline after the initial download.

Development and testing followed a multiphase process guided by the MOST framework [25]. During the preparation phase, co-design, multicountry user testing [31], and pilot studies in South Africa and Tanzania demonstrated that the app was broadly acceptable. The preparation phase also identified opportunities to strengthen delivery through additional human support, greater flexibility in accessing content, culturally adapted imagery, and enhanced digital support for caregivers with lower smartphone literacy. These findings informed the selection of the 3 components evaluated in the optimization-phase factorial trial: guidance, app design, and digital support [26].

The intervention content tested in the factorial trial was organized into 12 modules, delivered via simple text, illustrations, and audio narration in Kiswahili. The introductory module focuses on parental self-care and stress reduction and includes a baseline questionnaire. Modules 2 to 11 introduce evidence-based strategies to support positive parenting and reduce harsh or abusive discipline, while also incorporating mindfulness-based exercises throughout. The final module provides a summary of key concepts and includes a postintervention assessment. Full details on module content, home practice activities, and user interface design are available in Janowski et al [26].

Experimental Components

Guidance

The guidance component compared self-guided use of ParentApp with facilitator-supported delivery. Following onboarding, participants in the self-guided condition used the app independently, whereas those in the guided condition used the app alongside a facilitator-moderated WhatsApp (Meta Platforms, Inc) group corresponding to their cluster allocation. Each group was cofacilitated by a mixed-gender facilitator pair to encourage engagement among both women and men. Following a standardized facilitation manual, facilitators posted weekly reminders and discussion prompts, responded to participants' questions, moderated discussions, and hosted weekly 1-hour live chat sessions throughout the 12-week intervention period to support peer interaction and reflection.

App Design

The app design component compared a structured and an unstructured version of ParentApp. In the structured condition, modules were released sequentially over the 12-week intervention and retained the original abstract blue cartoon characters, which were designed without gender-specific characteristics and developed for cross-cultural implementation during earlier pilot studies. In the unstructured condition, all modules were available immediately following installation, allowing participants to progress through the content at their own pace, and featured culturally adapted, human-like illustrations depicting both women and men in caregiving roles.

Digital Support

All participants received basic digital support consisting of an embedded app tutorial and a group-based demonstration of key app features during onboarding. Clusters allocated to the enhanced digital support condition additionally received a 15‐to 20-minute group-based training session designed to improve general smartphone literacy and users' confidence in navigating their devices.

Procedures

Cluster-level onboarding sessions were conducted in local schools and community centers by staff from Tanzania's National Institute for Medical Research (NIMR) and trained facilitators from Investing in Children and Strengthening Their Societies, a local nongovernmental organization. Sessions included study information, eligibility screening, and informed consent, followed by app onboarding and baseline data collection. After obtaining informed consent, participants were divided into small groups (5‐10 caregivers) to facilitate hands-on support with downloading and installing ParentApp from the Google Play Store. Following installation, NIMR research assistants moved between participants to configure each app according to the cluster's allocated intervention condition before guiding caregivers through the app's core features, including navigation, activity completion, and available resources. Participants then completed the introductory module, which included the embedded baseline assessment. Clusters allocated to the enhanced digital support condition also participated in a brief group-based smartphone literacy session, while those allocated to the guided condition were added to facilitator-moderated WhatsApp groups.

Measures

Engagement Metrics

Engagement was assessed using automatically recorded in-app usage data. Usage data, including app launches, content viewing patterns, and responses to in-app tasks, were uploaded to a Metabase cloud server when participants' devices connected to the internet. Retention was calculated as the number of days between the first app launch and the final synchronization of app usage data with the cloud server. Additional usage data, including visit timestamps, session duration, and frequency of

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actions or pages viewed, were captured via Matomo Analytics (InnoCraft Ltd). These data were used to derive descriptive indicators and the primary and secondary outcomes.

The primary outcome was module completion, defined as the total number of modules completed (range 0 - 12). Secondary outcomes included the first module not started and the first module not completed, which identified the earliest point in the intervention sequence at which participants either failed to initiate or failed to complete a module, respectively. These outcomes were selected to capture cumulative content engagement and early points of disengagement.

Candidate Predictors

Demographic and Socioeconomic Variables

Baseline data were collected via an in-app questionnaire embedded in the first module. Measures were translated and back-translated into Kiswahili. Candidate demographic predictors included caregiver gender (woman or man) and age (y). Additional demographics (eg, household composition) were collected but not analyzed here. Candidate socioeconomic predictors included financial stress and food insecurity, assessed using 2 items adapted from the Financial Self-Efficacy Scale [32]. Financial stress was assessed by asking, "How many times in the past month have you felt worried or anxious about money?" rated on a 0 to 8 or more frequency scale. Food insecurity was assessed by asking, "How many days in the past month did you run out of money to pay for food?" rated from 0 to 30 days. The 2 items were analyzed separately due to differences in response formats.

Behavioral and Psychological Variables

Positive parenting was assessed using 5 items on parental involvement and supervision from the Alabama Parenting Questionnaire [33]. Items were scored from 0 to 8 or more and summed to produce a total score, with higher scores indicating greater positive parenting. Harsh parenting was assessed using 4 items on physical and emotional abuse from the International Society for Prevention of Child Abuse and Neglect Screening Tools-Trial Version [34]. Items were scored from 0 to 8 or more and summed, with higher scores indicating greater maltreatment. Caregiver depression was measured using 3 items from the Center for Epidemiologic Studies Depression Scale [35]. Each item was scored from 0 to 7 and summed, with higher scores indicating greater depressive symptoms.

Statistical Analysis

Analyses were conducted in R (version 4.5.0; R Foundation for Statistical Computing). Sample characteristics were summarized overall and by caregiver gender. Gender differences in age, financial stress, food insecurity, positive parenting, harsh parenting, and depressive symptoms were assessed using 2-tailed Welch independent-samples *t* tests, with Cohen *d* calculated to estimate effect sizes. Engagement across the 12 modules was visualized using Kaplan-Meier survival curves stratified by caregiver gender.

Predictors of engagement were estimated using Poisson generalized linear mixed models with cluster-level random intercepts. Models were fit to multiply imputed datasets to address missing baseline data, and estimates were pooled across imputations [36]. The primary outcome (number of modules completed) was modeled using an offset for exposure, defined as the number of modules available to each participant. Secondary outcomes (first nonstart and first noncompletion) were modeled as event indicators (1=event, 0=none), with an offset for the number of modules at risk. For participants who experienced an event, the number of modules at risk was defined by the module at which the first disengagement event occurred; for those who did not experience an event, it was defined as the total number of modules available.

Each predictor was tested in a separate model, as the aim was to identify caregiver characteristics associated with engagement that could inform future intervention design and optimization. Predictors were group-mean centered within clusters to isolate within-cluster effects. All models adjusted for the experimental components (dummy-coded for guidance, app design, and digital support). Caregiver age and gender (grand-mean centered) were also included as covariates, except when either variable was the predictor of interest. The potential moderating effect of caregiver gender was examined by including an interaction term between the predictor of interest and gender. Gender was represented both as a group-mean centered variable and as a cluster-level mean to disaggregate individual- and cluster-level effects. Model estimates are reported as incidence rate ratios with 95% CIs and corresponding *P* values. The Benjamini-Hochberg procedure was applied to control the false discovery rate across models, with significance determined using the adjusted critical *P* value thresholds [37].

Ethical Considerations

Ethics approval was granted by the University of Oxford's Departmental Research Ethics Committee (R69744/RE001) and the Tanzanian NIMR (NIMR/HQ/R.8s/Vol.IX/3856). Written informed consent was obtained from all study participants at the onboarding session. To support WhatsApp participation and app-server data synchronization, all participants received 1 GB of mobile data per month for the study duration. Participants received US $2 (US $1=TZS 2319.79 as of October 24, 2022) after completing the onboarding session.

Results

Characteristics of the Sample

Baseline characteristics for the full sample and by caregiver gender are presented in Table 1. The trial included 614 caregivers (409 women and 205 men), with ages ranging from 18 to 75 years (mean age 35.94, SD 11.84). Independent-samples 2-tailed *t* tests indicated no significant gender differences in age or positive parenting practices. However, women reported significantly higher levels of several socioeconomic and psychosocial stressors compared to men, including financial stress (mean 4.55, SD 2.73 vs mean 3.72, SD 2.73; *P*<.001; Cohen *d*=0.30), food insecurity (mean 7.88, SD 8.09 vs mean 6.17, SD 7.01; *P*=.009; Cohen *d*=0.22), harsh parenting (mean 7.40, SD 6.42 vs mean 5.07, SD 6.14; *P*<.001; Cohen *d*=0.37), and depressive symptoms (mean 8.53, SD 4.12 vs mean 7.80, SD 3.56; *P*=.02; Cohen *d*=0.19). Although effect sizes were

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small, the findings indicate consistent gender differences in exposure to adversity in the sample.

Table . Caregiver characteristics overall and by gender, with independent-samples 2-tailed *t* test comparisons.

Measure	Overall		Women		Men		Gender comparison[a]	
	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)	Cohen *d*	*P* value
Age (y)	577	35.94 (11.84)	386	35.70 (11.15)	191	36.43 (13.13)	0.06	.51
Financial stress	574	4.27 (2.75)	379	4.55 (2.73)	195	3.72 (2.73)	0.30	.001
Food insecurity	576	7.30 (7.78)	381	7.88 (8.09)	195	6.17 (7.01)	0.22	.009
Positive parenting	614	10.89 (6.78)	409	10.95 (6.84)	205	10.79 (6.69)	0.02	.78
Harsh parenting	614	6.62 (6.42)	409	7.40 (6.42)	205	5.07 (6.14)	0.37	<.001
Parental depression	614	8.29 (3.95)	409	8.53 (4.12)	205	7.80 (3.56)	0.19	.02

[a]Gender comparisons were assessed using 2-tailed Welch independent-samples *t* tests. Cohen *d* represents the standardized mean difference between women and men, with positive values indicating higher scores for women. Effect sizes are interpreted as small (*d*=0.20), medium (*d*=0.50), and large (*d*=0.80).

Program Engagement

Descriptives

Of the 614 enrolled caregivers, 97.1% (n=596) initiated the first module, and 90.2% (n=554) completed it. This initial uptake was followed by a marked decline in engagement. By module 2, only 59.8% (n=367) had started the module, and 45.8% (n=281) had completed it. On average, participants started 4.57 (SD 4.13) modules and completed 3.40 (SD 3.64) of the 12 available modules (Table 2). The mean content completion rate across all 12 modules was 35.57% (SD 33.10%) of the program. Completion rates were higher among participants assigned to the guided delivery, unstructured design, and enhanced digital support conditions.

Table . Modules started and completed: overall and by experimental component[a].

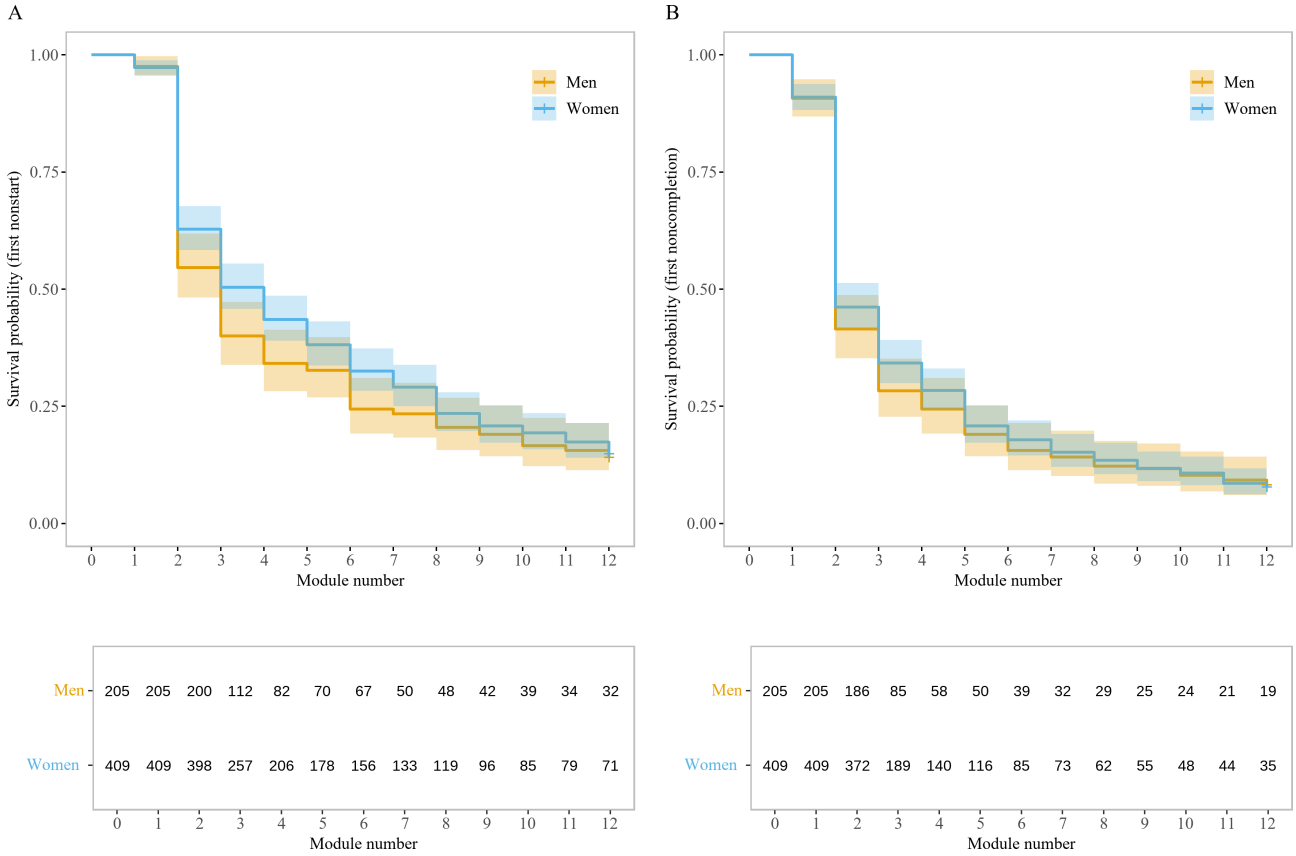
Variable	Overall	Guidance		App design		Digital support	
		Self-guided (n=330)	Guided (n=284)	Structured (n=332)	Unstructured (n=282)	Basic (n=295)	Enhanced (n=319)
Modules started	4.57 (4.13)	4.22 (3.92)	4.99 (4.33)	4.34 (4.03)	4.84 (4.23)	4.43 (4.04)	4.71 (4.21)
Modules completed	3.40 (3.64)	3.09 (3.41)	3.77 (3.85)	2.91 (3.04)	3.99 (4.16)	3.26 (3.51)	3.54 (3.75)

[a]Values are presented as mean (SD); possible range, 0-12 modules.

Kaplan-Meier survival analyses indicated that the median retention time among content users was 31 days (95% CI 25 - 36), defined as the time between first app launch and final data synchronization with the server. As shown in Figure 1, the risk of disengagement was highest immediately after the first module. Women showed a slightly lower risk of disengagement compared to men for both time to first nonstart and time to first noncompletion, although neither difference was statistically significant.

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Figure 1. Kaplan-Meier survival curves for (A) first module nonstart and (B) first module noncompletion, stratified by caregiver gender. Curves show the estimated probability of engaging without a first nonstart or noncompletion, respectively, across the 12-module intervention. Risk tables show the number of participants remaining engaged for each module. Shaded areas indicate 95% CIs.



Predictors of Engagement

Each of the 3 engagement outcomes was regressed on 7 baseline predictors, yielding 21 primary hypothesis tests. To control for the false discovery rate within each outcome, the Benjamini-Hochberg procedure was applied separately to each set of 7 tests [37]. The procedure compares each *P* value to a ranked critical value, and only those below the corresponding threshold were considered statistically significant. Statistically significant effects are highlighted in bold in Table 3.

Caregiver gender was the only baseline characteristic significantly associated with module completion. On average, women completed approximately 15% more modules than men (incidence rate ratio 1.15, 95% CI 1.05 - 1.27, *P*=.003; Table 3). Caregiver gender showed a similar pattern of association with the two secondary outcomes, with women having lower first nonstart and first noncompletion rates than men, although neither association was statistically significant.

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Table . Baseline predictors of program engagement[a].

Predictor	Modules completed		First nonstart		First noncomplete	
	IRR[b] (95% CI)	*P* value	IRR (95% CI)	*P* value	IRR (95% CI)	*P* value
Caregiver gender[c]	1.15 (1.05 - 1.27)	.003	0.90 (0.74 - 1.08)	.25	0.92 (0.77 - 1.10)	.37
Caregiver age	1.02 (0.98 - 1.07)	.29	0.96 (0.90 - 1.04)	.33	0.99 (0.92 - 1.07)	.80
Financial stress	1.02 (1.00 - 1.04)	.06	0.98 (0.93 - 1.01)	.16	0.98 (0.95 - 1.01)	.31
Food insecurity	1.00 (1.00 - 1.01)	.67	1.00 (0.99 - 1.02)	.52	1.00 (0.98 - 1.02)	.41
Positive parenting	1.00 (0.99 - 1.02)	.57	1.00 (0.99 - 1.02)	.71	1.00 (0.99 - 1.02)	.71
Harsh parenting	1.00 (0.99 - 1.01)	.87	1.00 (0.98 - 1.01)	.70	1.00 (0.99 - 1.04)	.93
Parental depression	0.99 (0.98 - 1.01)	.22	1.00 (0.98 - 1.03)	.83	1.01 (0.99 - 1.04)	.32

[a]All predictors were group-mean centered within clusters. Caregiver gender was dummy-coded (0=men, 1=women), with estimates representing effects for women relative to men (reference group). All models adjusted for the experimental components (dummy-coded guidance, app design, and digital support). Caregiver age and gender (grand-mean centered) were included as covariates unless either was the predictor of interest.

[b]IRR: incidence rate ratio.

[c]Effect significant below the Benjamini-Hochberg procedure's critical value.

Moderating Effects of Caregiver Gender

To examine whether the associations between baseline characteristics and engagement outcomes differed by caregiver gender, moderation models were estimated for each of the 7 predictors across all 3 outcomes (Table 4). As with the main-effects models, the Benjamini-Hochberg procedure was applied separately within each outcome to control the false discovery rate. For module completion, interactions between gender and food insecurity and between gender and depressive symptoms approached statistical significance; however, neither met the Benjamini-Hochberg threshold. No significant gender interactions were observed for the secondary outcomes.

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Table . Moderating effects of gender on associations between baseline predictors and program engagement[a].

Predictor and outcome	Main effect		Interaction effect	
	IRR[b] (95% CI)	*P* value	IRR (95% CI)	*P* value
Caregiver age				
Modules completed	1.02 (0.98 - 1.06)	.41	0.92 (0.84-1.00)	.05
First nonstart	0.97 (0.90 - 1.05)	.49	1.09 (0.92 - 1.28)	.33
First noncomplete	0.99 (0.93 - 1.08)	.95	1.08 (0.92 - 1.27)	.33
Financial stress				
Modules completed	1.02 (1.00 - 1.04)	.06	0.99 (0.96 - 1.03)	.76
First nonstart	0.98 (0.95 - 1.01)	.15	1.01 (0.94 - 1.09)	.76
First noncomplete	0.98 (0.95 - 1.02)	.31	1.00 (0.93 - 1.07)	.93
Food insecurity				
Modules completed	1.00 (1.00 - 1.01)	.47	0.98 (0.97 - 1.00)	.03
First nonstart	1.00 (0.99 - 1.02)	.54	1.01 (0.98 - 1.04)	.53
First noncomplete	1.00 (0.98 - 1.01)	.38	1.02 (0.99 - 1.04)	.25
Positive parenting				
Modules completed	1.00 (0.99 - 1.01)	.49	1.01 (0.99 - 1.03)	.37
First nonstart	1.00 (0.99 - 1.02)	.70	0.99 (0.96 - 1.03)	.69
First noncomplete	1.00 (0.99 - 1.02)	.68	0.99 (0.96 - 1.02)	.49
Harsh parenting				
Modules completed	1.00 (0.99 - 1.01)	.95	1.01 (1.00 - 1.03)	.15
First nonstart	1.00 (0.98 - 1.01)	.68	0.99 (0.96 - 1.03)	.74
First noncomplete	1.00 (0.99 - 1.01)	.86	0.98 (0.95 - 1.02)	.33
Caregiver depression				
Modules completed	0.99 (0.98 - 1.01)	.38	0.97 (0.94 - 1.00)	.04
First nonstart	1.00 (0.98 - 1.03)	.86	1.03 (0.97 - 1.09)	.38
First noncomplete	1.01 (0.99 - 1.04)	.32	1.02 (0.97 - 1.08)	.45

[a]All predictors were group-mean centered within clusters. Caregiver gender was dummy-coded (0=men, 1=women), with interaction terms estimating differential effects for women relative to men (reference group). Gender was represented as both a group-mean centered variable (within-cluster effect) and a cluster-level mean (between-cluster effect). Caregiver age (grand-mean centered) was included as a covariate in all models except when it was the predictor of interest. All models also adjusted for the 3 dummy-coded experimental components (guidance, app design, and digital support).

[b]IRR: incidence rate ratio.

Discussion

Principal Findings

This study provides the first known analysis of caregiver-level predictors of engagement with a digital parenting program in an LMIC, with the notable strength of including a large proportion of men and fathers (205/614, 33.4%). While nearly all participants initiated the program, engagement dropped substantially after onboarding, with the steepest decline occurring after the first module. This mirrors broader trends in digital health interventions, where attrition is typically concentrated in the early stages of program use [38]. These findings highlight the importance of prioritizing retention strategies early in the intervention.

Of the baseline characteristics examined, caregiver gender was the only statistically significant predictor of engagement. Women completed approximately 15% more modules than men, a finding that contrasts with several digital parenting studies in HICs, where engagement is often similar across genders [17]. One possible explanation is that women's higher engagement may reflect greater exposure to socioeconomic and psychosocial adversity, including financial stress, food insecurity, depressive symptoms, and harsh disciplinary practices. Women reported significantly higher levels of each of these stressors, which may have increased the perceived relevance of the intervention and, in turn, their motivation to engage.

This interpretation aligns with the Health Belief Model [39], which posits that individuals are more likely to adopt health behaviors when they perceive the risks of inaction as high and the benefits of action as tangible. From this perspective,

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socioeconomic and psychosocial adversity may have served as a cue to action, outweighing emotional or cognitive barriers that might otherwise prevent engagement [40]. That women sustained engagement despite multiple, overlapping stressors is a notable finding. It suggests that digital parenting interventions may offer a feasible and acceptable modality for supporting high-risk caregivers in LMICs.

In contrast, the lower engagement observed among men may reflect a complex interplay of identity, norms, and structural constraints. In Tanzania and many other LMICs, caregiving is typically viewed as a maternal responsibility, while fatherhood is closely tied to provision, protection, and authority [41-43]. When program content is perceived as incongruent with these gendered expectations or fails to affirm men's aspirations as fathers, it may appear irrelevant or incompatible with their roles. This is echoed in global fatherhood research showing that interventions which acknowledge and support men's caregiving identities and align with their aspirations tend to enhance perceived relevance and achieve higher engagement [13,44].

Lower engagement among men may also reflect deeper identity tensions under conditions of economic precarity. Qualitative research from Mwanza, Tanzania describes how many men aspire to be nurturing and involved fathers but face conflicting practical and social pressures from work demands, limited time, and community norms [43]. These experiences not only restrict men's capacity to participate in caregiving but may also lead to internal dissonance when they are unable to fulfill culturally sanctioned roles of fatherhood, a phenomenon that has been described as *moral injury* in fatherhood research [45,46]. Similar findings from Uganda indicate that even when men express egalitarian views, structural constraints and social stigma around caregiving can limit their involvement in parenting programs [47]. These dynamics highlight the need for interventions that actively affirm men's caregiving identities and address the structural barriers that limit engagement. While women reported greater socioeconomic adversity in the present study, integrating digital parenting programs with broader economic and social protection initiatives may help reduce the opportunity costs of participation for both men and women [48].

Although ParentApp was intentionally designed to support all caregivers rather than assuming mothers as the primary users, these findings suggest that additional strategies may be needed to improve engagement among men. Future iterations could benefit from further co-design with fathers to better understand how intervention content, tone, imagery, and delivery align with men's caregiving identities and everyday constraints. Emerging work on digital fatherhood interventions illustrates how user-centered design can be used to develop app-based support tailored to fathers' mental health, well-being, and parenting needs [49]. However, improving engagement among men may require more than tailoring content or delivery; it may also require gender-transformative approaches that actively challenge inequitable norms and support identity shifts in caregiving. As highlighted in a recent systematic review of fatherhood programs in LMICs, gender-transformative interventions foster critical reflection, promote shared decision-making, and engage with normative change at individual and community levels [48]. Promising examples include in-person parenting programs such as REAL Fathers in Uganda [50], Bandebereho in Rwanda [51], and Parenting for Respectability in Uganda [52], which have achieved shifts in father involvement, reductions in intimate partner violence (IPV), and improvements in household dynamics through facilitated dialogue, peer role-modeling, and local leadership.

Emerging evidence suggests that gender-transformative components can be successfully integrated into digital formats. One example is ParentText, a chatbot-based parenting intervention adapted from the PLH program suite and piloted in South Africa and Jamaica. ParentText incorporates content on gender-equitable behaviors and IPV prevention to support shared caregiving, challenge harmful gender norms, and reduce familial violence [53]. Qualitative findings suggest that men valued the anonymity, accessibility, and nonjudgmental tone of the chatbot, which facilitated engagement with sensitive topics such as relationships and caregiving [54]. A parallel pre-post pilot study reported modest reductions in women's experience of IPV and improvements in men's attitudes and gender-equitable behaviors. However, overall engagement with the program and with the IPV-related content in particular was limited, especially among men [55]. Together with the findings of the present study, this emerging evidence suggests that moving beyond one-size-fits-all approaches may be key to improving engagement with digital parenting interventions.

Limitations

Several limitations should be acknowledged when interpreting these findings. First, engagement was operationalized using digital metrics (eg, module completion), which offer behavioral indicators of app use but do not capture content comprehension or real-world application. This reflects a broader challenge in digital health research, where engagement is often equated with usage alone, without consideration of learning or behavior change outcomes [56]. Moreover, these metrics do not capture users' subjective experiences, such as interest, attention, or emotional resonance, which may be equally important in understanding meaningful engagement [9]. Future research should therefore incorporate multidimensional measures that capture both the quantity and quality of engagement, alongside users' subjective experiences.

Second, the range of caregiver characteristics assessed at baseline was limited by the brief, app-embedded format of the survey. Key variables such as perceived digital skills and prior experience with technology were not captured, although these factors have been shown to influence engagement with digital interventions [57,58]. The study also did not measure adolescent-level characteristics, such as child mental health symptoms, which have been positively associated with parental engagement in previous research [56]. Accounting for these variables in future studies may improve the precision of engagement models and support more targeted intervention strategies.

Third, while the overall sample size was relatively large, the study may have been underpowered to detect gender interaction effects, especially given the smaller proportion of men in the sample. Future studies should consider adequately powered subgroup analyses to explore gender-specific patterns of

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engagement. Furthermore, although the sample was drawn from low-income urban and periurban settings, all participants were required to have regular access to a smartphone. As such, findings may not be generalizable to caregivers in rural areas or those with limited access to digital technology. Broader implementation research is needed to understand how structural barriers such as digital access, network reliability, and device sharing influence engagement, including in rural and more resource-constrained settings.

Conclusions

This study provides important evidence on caregiver engagement with a digital parenting program in an LMIC. Across demographic, socioeconomic, behavioral, and psychological factors, only caregiver gender significantly predicted engagement, with women completing more modules than men. The absence of significant associations with other baseline characteristics provides encouraging evidence that socioeconomic and psychosocial factors may not pose substantial barriers to engagement with ParentApp. However, high rates of attrition among both men and women immediately after onboarding highlight early disengagement as a critical challenge. Addressing this challenge will be essential if digital parenting programs are to achieve meaningful and lasting benefits for children and families in LMICs.

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Data Availability

The datasets generated or analyzed during this study are not currently publicly available due to ongoing analyses but will be made available via the Open Science Framework upon study completion. In the interim, datasets are available from the corresponding author on reasonable request.

Authors' Contributions

RJ led the conceptualization, data analysis, and writing of the original, revised, and final manuscript drafts. LDC, YS, GJM-T, and LJvN contributed to the critical revision of the manuscript. GJM-T provided key input on the statistical analysis. All authors read and approved the final version of this manuscript.

Conflicts of Interest

RJ's doctoral research is based on this trial. JML is the chief executive officer, and LDC is a voluntary trustee of Parenting for Lifelong Health (PLH), a charity based in the United Kingdom and South Africa. JML receives occasional fees for providing training and supervision for PLH programs. Members of the research team have worked on other studies of PLH, which contributed funding to their respective universities but not directly to them. The intellectual property for the intervention is owned by the developers of the original intervention under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International Public License. No profit or financial gain will be made from the implementation and dissemination of the intervention.

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Abbreviations

HIC: high-income country
IPV: intimate partner violence
LMIC: low- and middle-income country
MOST: Multiphase Optimization Strategy
NIMR: National Institute for Medical Research
PLH: Parenting for Lifelong Health

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“Daily Growth” Parenting Program Delivered via Ecological Momentary Intervention: Pilot Randomized Controlled Trial of a Prototype

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Abstract

Background: Despite evidence showing that parenting interventions reduce rates of child mental health problems, their reach and engagement remain low. Daily Growth is a digital parenting program designed to improve parent and child emotion regulation using an ecological momentary intervention (EMI) approach. Daily Growth sends twice-daily prompts and delivers 3-minute videos tailored to a recent parenting situation, offering 2 program types (Emotion Coaching and Active Play) to meet different parent preferences. EMI has rarely been tested with parenting programs.

Objective: This pilot aimed to assess the feasibility and acceptability of the EMI design and a prototype of Daily Growth, offering the 2 programs via 10 of 60 planned videos.

Methods: A pilot randomized controlled trial recruited 189 Australian parents of children aged 2‐4 years, randomized to either intervention (n=94) or active control (n=95). Participants completed a 25-minute online survey at baseline and at conclusion of the program period. In the intervening 2 weeks, participants received twice-daily 1-minute pre-EMI surveys via email. Participants who reported any parent or child negative affect or emotion dysregulation received a resource. Participants in the intervention condition were randomized in the moment to receive a 3-minute Emotion Coaching or Active Play video, while participants in the control condition received a link to a parenting website. Participants were sent a 1-minute post-EMI survey. For both conditions, parenting support was tailored to 1 of 5 predefined parenting situations.

Results: Overall, 71% (135/189) of participants completed the 2-week post survey, and over two-thirds completed at least half of the daily pre-EMI surveys. Despite technical issues, most participants would recommend Daily Growth to other parents (53/67, 79%), use the skills learned (46/67, 69%), reported it as easy to use (45/67, 67%), and were satisfied with Daily Growth (40/67, 60%).

Conclusions: This pilot evaluated whether brief EMI resources could engage parents in real time. Findings suggest that the Daily Growth prototype was feasible and well received, supporting further implementation in a larger trial.

Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12624001410549; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=388307

(JMIR Pediatr Parent 2026;9:e87917) doi:10.2196/87917

KEYWORDS

Daily Growth; emotion coaching; Active Play; emotion socialization; intervention; parenting; emotion regulation; child development; ecological momentary intervention

Introduction

Background

Emotion regulation skills influence all aspects of human functioning and are central in the etiology of mental health disorders [1,2]. Parents play a vital role in the development of their child’s emotion regulation skills [3,4], and both parenting beliefs and practices are modifiable. While parenting interventions demonstrate strong effectiveness in improving child emotion regulation and reducing child mental health problems [5,6], their population reach has been extremely low

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(<10% population) [7,8]. This limited reach disproportionately affects fathers, single parents, and Aboriginal and Torres Strait Islander, migrant, culturally and linguistically diverse, and rural or remote families [8-11]. In response, several parenting interventions have transitioned to online delivery formats to increase access. More recently, smartphone-based parenting apps have further expanded access [12-17]. Online and app-based programs have the potential to make support more accessible, cost-efficient, and anonymous, and have been welcomed by users [13-16,18-20]. However, despite demonstrated efficacy, digital parenting interventions continue to face hurdles such as low uptake, engagement, and adherence [21-24], suggesting that online delivery alone does not fully address barriers to uptake and engagement. At the same time, many parenting programs focus on child behavior change rather than emotion regulation [25-27] and are targeted toward school-aged children or adolescents, despite early childhood representing a critical time for children's emotional development [28]. Together, these limitations point to a need for parenting programs that address both how support is delivered (moving beyond access to sustained engagement) and what is delivered, with a focus on emotion regulation in early childhood.

This Study: Daily Growth

This study is part of a larger research project developing and testing Daily Growth, a personalized, stand-alone parenting app for parents of children aged 2 - 4 years. Daily Growth aims to enhance parent emotion regulation and emotion-related parenting skills, ultimately supporting children's emotion regulation and reducing rates of child mental illness. To address barriers to reach, access, and engagement in population-level parenting programs, the platform integrates novel technological approaches successfully applied in adult health settings [29-32]. In collaboration with parents, carers, and community practitioners, we co-designed Daily Growth using the Design Mapping framework to deliver tailored, in-the-moment parenting support using an ecological momentary intervention (EMI) design. The program offers microinterventions (brief 3-minute video resources) matched to specific parenting situations and combines 2 evidence-based parenting approaches: Emotion Coaching and Active Play.

EMIs deliver brief, frequent support via smartphone apps, aiming to seamlessly integrate into daily life [33,34]. In adult mental health settings, EMI approaches have demonstrated improvements in adherence and reductions in mental health symptoms (eg, gambling, stress, anxiety, and body satisfaction), while requiring less time and fewer resources than traditional interventions [31,32,35,36]. Despite this promise, EMI designs have rarely been tested within parenting interventions [13,37,38]. Of the existing studies, one targeted homeless adolescent mothers (n=49) and demonstrated high acceptability and sustained engagement, with participants reporting that the technology supported parent emotion regulation during stressful parenting moments [13]. A second study was a small feasibility study (n=33) exploring daily reflective questions delivered via ecological momentary assessment (EMA) to increase parental awareness of child emotions and support in-the-moment emotion coaching, suggesting that parents can sustain engagement with daily prompts, and that doing so can increase their attention to child emotions in everyday life [37]. A third study has proposed, but not yet tested, an EMI-based mindfulness intervention for parents of children with autism spectrum disorder (n=670) [38]. No studies to date have examined EMI-based parenting programs that are population-based, target the early childhood period, or specifically aim to build children's emotion regulation skills, and it remains unclear whether this approach will be feasible, engaging, and relevant for parents navigating busy daily routines. A further limitation of previous parenting interventions has been their one-size-fits-all approach, which does not align with evidence that parents vary in the situations and approaches that may be most relevant [20,39-41] and beneficial to them [42]. Tailoring brief microinterventions to parents' needs may increase the relevance of parenting support and encourage sustained engagement over time. Additionally, collaborating with end users in mental health research has been shown to improve program relevance, engagement, and effectiveness [43]. Integrating tailoring with a co-design approach may therefore strengthen both the relevance and usability of digital parenting support.

Daily Growth was developed according to these principles, delivering brief, tailored resources informed by input from parent end users and professionals. It provides in-the-moment support through 2 distinct programs, recognizing that parents support child emotion regulation through multiple pathways. Emotion Coaching is based on Gottman et al.'s 5 steps [44,45]: noticing emotions, viewing them as teaching opportunities, responding with empathy, labeling emotions, and problem solving. Daily Growth adds a sixth step (reflect), encouraging parents to pause when calm, consider their responses, and model repair. Active Play offers a nonverbal, embodied approach suited to parents less comfortable with emotional talk. Drawing on evidence that physical activity and imaginative play support mood regulation, calm the nervous system, and strengthen executive function tied to emotion regulation [46-48], the program provides practical play-based activities to support parent-child connection and emotion regulation.

This pilot study evaluates the feasibility and acceptability of the prototype version of Daily Growth and its EMI delivery approach, delivered over 2 weeks, compared with an active control condition. Specifically, we aimed to assess:

1. The feasibility of the prototype version of Daily Growth in terms of parent recruitment rates, retention, and flow through all stages of the study, as well as parent engagement via completion rates of the baseline survey, 2-week post survey, and daily prompts.
2. The acceptability of the 10 prototype video resources and the program delivery method via twice-daily pre- and post-EMI prompts.
3. The descriptive efficacy of the prototype version of the Daily Growth program in improving parent and child emotion regulation, mental health, and emotion coaching parenting behaviors in the moment and postintervention compared with the control condition.

We anticipate that predefined feasibility benchmarks will be met, including meeting the target of recruiting at least 150 participants, attrition below 30%, and average completion of at

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least 50% of pre- and post-EMI prompts. This engagement rate is informed by rates reported in parenting EMI and EMA studies, in which 70% of parents engaged with at least 80% of daily EMA prompts in a general parenting population [37] and approximately 40% of prompts were completed among a vulnerable population of homeless adolescent mothers [13]. Acceptability is considered high if 70% of intervention participants indicate that they are satisfied with the program, informed by satisfaction rates reported in parenting EMA or EMI studies [13,37]. As this is a pilot trial, the primary focus is on feasibility and acceptability rather than efficacy testing. Descriptive outcome data are reported to assess the feasibility of the outcome measurement protocol, including the sensitivity of measures to detect change and the completeness of data collection, in preparation for the definitive trial [49,50].

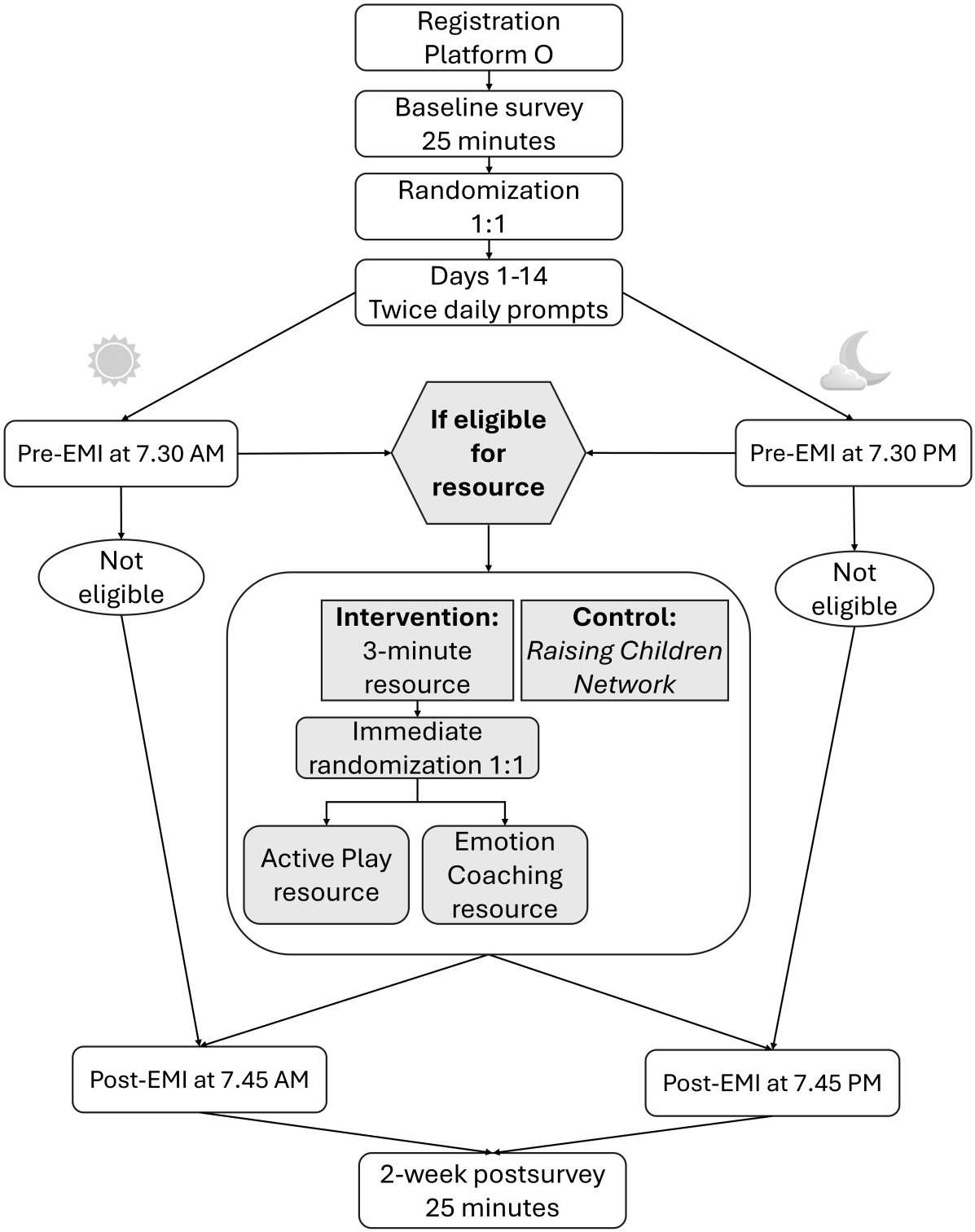
Methods

Research Design

The study design is demonstrated in Figure 1. This study used a pilot randomized controlled trial design with a 1:1 allocation ratio to evaluate the feasibility, acceptability, and descriptive efficacy of a prototype version of the Daily Growth parenting program. The trial was conducted fully online. Participants completed baseline measures via Qualtrics (Qualtrics LLC), followed by a 2-week EMI period during which they received twice-daily pre- and-post-EMI prompts delivered via email. Participants completed a 2-week postprogram survey at the conclusion of the EMI period.

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Figure 1. Overview of trial design and ecological momentary intervention (EMI) schedule. Pre-post–EMI=brief,<1-minute survey before or after ecological momentary intervention. Platform O=Platform delivering the Daily Growth prototype. EMI: ecological momentary intervention.



Ethical Considerations

Study procedures were approved by the Deakin University Human Ethics Advisory Group (HEAG-H 188_2022). Participants provided informed consent online via a checkbox before participation to indicate their consent to participate and be contacted about future research. Participants received a Plain Language Statement outlining the study procedures and purpose, estimated duration of each study component, their right to withdraw at any time, the policy regarding data storage, and contact details for the principal investigator for questions or concerns.

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Participants and Recruitment

Eligibility criteria included residing in Australia, aged 18 years and older, parent or carer of a child aged 2 - 4 years, English proficiency, internet access, and basic digital literacy (able to receive emails and complete online surveys). Recruitment methods included contacting parents from a registry of participants from related studies who had previously consented to be contacted for future research, posting in Facebook parenting groups, and running paid Facebook and Instagram advertisements. Parents were reimbursed with Coles gift vouchers based on EMI survey completion rates (50% - 69%=AU$20 (AU$1=US $0.67 as of March 18, 2023); 70% - 84%=AU$30; and 85% - 100%=AU$50). No formal power calculation was conducted as the pilot aimed to test feasibility rather than efficacy. A target of 150 participants was set to ensure sufficient data for feasibility assessment. The final sample comprised 189 parents and caregivers (94 intervention, 95 control).

Procedure

Participants registered on the online platform "Platform O" and completed a baseline survey via Qualtrics (Qualtrics LLC), an online survey platform. The baseline survey comprised 224 items, taking approximately 25 minutes to complete. The purpose of the questionnaire was to collect demographic information and to assess parent and child emotion regulation, mental health, and emotion coaching parenting practices. No completeness checks were included; however, participants who did not complete the demographics section were removed from the dataset. An attention check was included, and respondents could not review or change their answers. The research team regularly monitored survey responses for suspicious submissions (eg, duplicate entries, bot responses, and participants located outside of Australia) and excluded illegitimate participants. Following completion of the baseline survey, participants were randomly assigned to either the control or intervention condition on a 1:1 basis using Qualtrics' "Randomiser" feature on completion of the baseline survey. Participants were blinded to their allocation but research team members were not. Participants received their first EMI survey, assessing momentary parent and child affect and emotion regulation, the day after completing the baseline survey. Over the subsequent 14 days, participants received twice-daily email prompts to complete a 1-minute pre-EMI survey at 7:30 AM and 7:30 PM, followed by a 1-minute post-EMI survey prompt at 7:45 AM or 7:45 PM. At the end of the 2-week program period, participants were invited to complete a 2-week post survey via Qualtrics.

Daily Growth Program and Control Condition

Daily Growth was developed using an iterative co-design process involving parents and professionals. Guided by a novel Design Mapping framework [51], development was informed by (1) an analysis of online parenting discussions to identify common parenting challenges [52], (2) qualitative interviews with parents to understand current use of active play as a parenting strategy [53], (3) structured workshops conducted to co-design program content and delivery [54], (4) ongoing consultation with an advisory group consisting of parents and professionals, and (5) a technical EMA pilot to optimize the timing of prompts [55]. The present pilot evaluated a subset of the full Daily Growth program to assess the feasibility, acceptability, and descriptive efficacy of the program prior to development of the final 6-week smartphone app.

Participants allocated to the intervention condition received access to a prototype version of Daily Growth delivered via the online platform Platform O. Daily Growth is a parenting program designed for parents of children aged 2 - 4 years, delivering brief microinterventions using an EMI approach. The prototype included 10 brief 3-minute video resources (5 Emotion Coaching and 5 Active Play) tailored to 5 different parenting situations (mealtime, bedtime, getting dressed, screen time, and sibling conflict). Across the 14-day intervention period, all participants received twice-daily prompts linking to a 1-minute pre-EMI survey. Participants who reported parent or child negative emotion or emotion dysregulation were eligible to receive a tailored parenting resource. Eligible participants selected 1 of 5 difficult parenting situations they had recently experienced or were interested in learning about. Participants in the intervention group were then randomized in the moment to receive either an Emotion Coaching or Active Play video resource tailored to their selected situation. Following resource delivery, participants were prompted to complete a post-EMI survey assessing momentary parent and child affect and emotion regulation. Participants allocated to the active control condition were instead provided with a link to the Raising Children Network, an Australian government–supported parenting information website. The Raising Children Network provides high-quality, but general, parenting information and does not include brief tailored intervention strategies comparable with those delivered by the Daily Growth video resources. The full Daily Growth program currently in development will include 60 video resources delivered over 6 weeks via a custom-built smartphone app for iOS and Android, with twice-daily pre-EMI survey prompts delivered via app notifications [56].

Outcomes

Feasibility

Feasibility was assessed through recruitment, retention, and engagement measures. Recruitment was evaluated based on the ability to achieve the target sample size within the recruitment period. Enrolled participants were defined as those who completed at least the demographic portion of the baseline survey. We aimed for equal representation across child age groups and ≥25% fathers. Retention was measured by attrition rates between baseline and 2-week post surveys. We aimed for <30% attrition in the intervention condition, a benchmark informed by previous intervention studies [11,20,57-61]. Engagement was measured based on the proportion of completed prompts per participant and parent-reported barriers to participation. While EMA studies in adult mental health report close to an 80% average engagement [30,62], Daily Growth reflects the unique context of parenthood, providing flexible, light-touch support without being onerous or interrupting in-the-moment parenting. We therefore prioritized sustained participation over high response rates, targeting 50% pre-EMI completion (1 daily survey on average, providing support 2 - 5

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times weekly) and 50% post-EMI completion. Engagement and attrition were analyzed by socioeconomic status, gender, and migrant status, as these demographic variables have been associated with differential access to and engagement with parenting programs [9].

Acceptability

A 25-item user satisfaction measure combined 5-point scales (eg, “The Daily Growth program meets my needs”), multiple-choice questions (eg, “Which parenting resource did you prefer?”), and open-ended questions (eg, “What problems did you encounter while using the program?"). Items assessed content quality, resource design, research experience, perceived effectiveness, and overall program acceptability. The measure was administered at the end of the 2-week program as part of the 2-week post survey. Acceptability was considered high if the majority (>50%) of intervention participants found the program resources and design satisfactory.

Baseline and 2-Week Posturvey Outcome Measures

Study measures are presented in Table 1. The research team selected measures routinely used in large-scale population studies with evidence of good validity and reliability for assessing parent and child emotional and social functioning. The baseline and 2-week post survey collected demographic information and assessed parent and child emotion regulation, mental health, and emotion coaching parenting practices.

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Table . Descriptive statistics (Cronbach α; mean, SD) for baseline and 2-week post survey measures.

Construct	Measure	Subscale	Scale	Items	Baseline			Post survey		
					Values, n	α value	Mean (SD)	Values, n	α value	Mean (SD)
Child measures										
Behavioral problems	MAP-DB[a] [63]	Temper loss	6	6	189	.91	2.01 (0.92)	135	.90	1.96 (0.87)
Behavioral problems	MAP-DB [63]	Noncompliance	6	4	189	.89	2.13 (1.00)	135	.88	2.17 (1.01)
Behavioral problems	MAP-DB [63]	Aggression	6	5	189	.88	1.10 (0.92)	135	.89	1.07 (0.92)
Depression	SMFQ[b] [64]	N/A[c]	3	13	189	.73	2.90 (2.61)	133	.79	3.17 (3.04)
Anxiety	SCAS[d] [65]	GAD and sep anxiety[e]	4	4	189	.71	3.16 (1.90)	134	.73	3.22 (1.93)
Emotion regulation	EERBQ[f] [66]	Mindfulness	7	2	189	.72	4.01 (1.56)	134	.71	4.56 (1.44)
Emotion regulation	EERBQ [66]	Verbal help-seeking	7	3	189	.71	3.38 (1.43)	134	.78	3.91 (1.57)
Emotion regulation	EERBQ [66]	Verbal venting	7	3	189	.74	3.81 (1.45)	134	.69	4.11 (1.33)
Emotion regulation	EERBQ [66]	Physical venting	7	3	189	.78	2.79 (1.41)	134	.78	2.95 (1.45)
Emotion regulation	EERBQ [66]	Emotion reactivity	7	6	189	.75	4.01 (1.00)	134	.73	3.91 (0.98)
Negative affect	PANAS-C-P[g] [67]	Negative affect	5	5	189	.82	8.84 (3.09)	133	.77	9.09 (2.89)
Parent measures										
Emotion regulation	DERS[h] [68]	Total	4	19	189	.94	38.23 (13.92)	133	.94	38.00 (13.35)
Emotion regulation	DERS [68]	Nonacceptance[i]	4	3	189	.85	6.25 (3.01)	133	.87	6.28 (3.11)
Emotion regulation	DERS [68]	Goals	4	3	189	.88	7.51 (3.11)	133	.86	7.47 (2.88)
Emotion regulation	DERS [68]	Impulse control difficulties	4	6	189	.88	11.25 (4.71)	133	.88	11.46 (4.52)
Emotion regulation	DERS [68]	Strategies	4	5	189	.89	9.59 (4.43)	133	.89	9.26 (4.13)
Emotion regulation	DERS [68]	Emotional clarity: lack of emotional clarity	4	2	189	.89	3.66 (1.62)	133	.85	3.53 (1.48)
Psychological distress	K6[j] [69]	N/A	4	6	189	.82	5.63 (4.11)	133	.81	5.71 (3.98)
Affect	I-PANAS-SF[k] [70]	Negative affect	5	5	189	.79	9.25 (3.46)	133	.83	9.17 (3.69)

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Construct	Measure	Subscale	Scale	Items	Baseline			Post survey		
					Values, n	α value	Mean (SD)	Values, n	α value	Mean (SD)
Affect	I-PANAS-SF [70]	Positive affect	5	5	189	.78	15.09 (3.71)	133	.80	15.12 (4.00)
Stress	DASS[l] [71]	Stress	5	7	189	.86	16.00 (8.76)	133	.81	15.35 (7.73)
Emotion parenting[m]	CTNES-SF[n] [72]	Emotion dismissing	7	12	189	.69	2.54 (0.80)	133	.72	2.57 (0.81)
Emotion parenting	CTNES-SF [72]	Emotion coaching	7	9	189	.87	6.19 (0.82)	133	.91	6.22 (0.91)
Reflective functioning	PRFQ[o] [73]	Prementalizing	5	6	189	.53	1.75 (0.66)	133	.72	1.81 (0.79)
Reflective functioning	PRFQ [73]	Certainty about mental states	5	6	189	.78	3.56 (1.11)	133	.77	3.59 (1.09)
Reflective functioning	PRFQ [73]	Interest and curiosity	5	5	189	.76	5.28 (0.91)	133	.87	5.21 (0.96)
Emotion beliefs[p]	PBACE[q] [74]	Anger	6	6	189	.78	25.06 (4.87)	133	.83	24.97 (5.44)
Emotion beliefs	PBACE [74]	Control	6	5	189	.77	11.99 (4.41)	133	.74	11.89 (4.16)
Emotion beliefs	PBACE [74]	Manipulation	6	4	189	.89	9.96 (4.95)	133	.90	9.65 (5.00)
Emotion beliefs	PBACE [74]	Autonomy	6	7	189	.88	17.52 (6.63)	133	.88	17.78 (6.53)
Emotion beliefs	PBACE [74]	Stability	6	4	189	.64	11.95 (3.65)	133	.71	11.53 (3.78)
Family climate[r]	SEFQ[s] [75]	Positive emotion expression	9	11	189	.95	7.19 (1.59)	133	.94	7.27 (1.58)
Family climate	SEFQ [75]	Negative emotion expression	9	12	189	.91	3.66 (1.44)	133	.90	3.56 (1.41)
Parental conflict[t]	CCS[u] [76,77]	Verbal conflict	5	4	189	.86	2.49 (0.70)	122	.83	2.41 (0.68)

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Construct	Measure	Subscale	Scale	Items	Baseline			Post survey		
					Values, n	α value	Mean (SD)	Values, n	α value	Mean (SD)
Parental conflict	CCS [76,77]	Physical conflict	5	1	189	N/A	0.23 (0.42)	122	N/A	0.16 (0.37)

[a]MAP-DB: Multidimensional Assessment of Preschool Disruptive Behavior [63].

[b]SMFQ: Short Mood and Feelings Questionnaire [64].

[c]N/A: not applicable.

[d]SCAS: Spence Children Anxiety Scale [65].

[e]GAD and sep anxiety: Generalized anxiety disorder (3 items) and separation anxiety disorder (1 item) combined.

[f]EERBQ: Early Emotion Regulation Behavior Questionnaire [66].

[g]PANAS-C-P: Positive and Negative Affect Schedule for Children [67].

[h]DERS: Difficulties in Emotion Regulation Scale [68].

[i]Nonacceptance: Nonacceptance of emotional responses.

[j]K6: Kessler Psychological Distress Scale [69].

[k]I-PANAS-SF: short-form International Positive and Negative Affect Scale [70].

[l]DASS: Depression, Anxiety and Stress Scale [71].

[m]Emotion parenting: emotion-related parenting.

[n]CTNES-SF: Coping with Toddlers Negative Emotions Scale—Short Form [72].

[o]PRFQ: Parental Reflective Functioning Questionnaire [73].

[p]Emotion beliefs: beliefs about children's emotions.

[q]PBACE: Parents' Beliefs About Children's Emotions Questionnaire [74].

[r]Family climate: family emotional climate.

[s]SEFQ: Self-Expressiveness in the Family Questionnaire [75].

[t]Parental conflict: interparental conflict.

[u]CCS: Co-Parental Communications Scale [76,77].

EMI Survey Measures

Measures Overview

Momentary parent and child emotion dysregulation and negative affect were reported via twice-daily 1-minute pre- and post-EMI surveys at 7:30 AM and 7:30 PM. These prompts did not expire, and parents could respond at their convenience. The twice-daily EMI surveys were identical to each other except for 1 pre-EMI item asking about difficult parenting situations in the previous 24 hours. Item selection and the schedule for delivering survey prompts were informed by a previous EMA study identifying the most suitable state-based items for capturing in-the-moment parent and child emotion dysregulation and negative affect and times at which parents were most likely to respond to prompts [55]. If a participant scored at or above the predetermined cutoff value on any item of the pre-EMI survey, they were eligible to receive a resource. Eligibility thresholds were defined across 4 domains: parent negative affect (≥1), child negative affect (≥1 for anger and ≥2 for sadness), parent emotion dysregulation (≥1), and child emotion dysregulation (≥2). These thresholds were selected to indicate at least mild elevations in negative affect or emotion dysregulation, warranting in-the-moment support.

Parent and Child Affect

Parent and child negative affect were measured using 3 items drawn from the short-form International Positive and Negative Affect Schedule (I-PANAS-SF) [70] to capture momentary emotional states ("upset," "angry," and "sad"). Items included "Indicate to what extent your child feels this way right now" and "Indicate to what extent you feel this way right now." Parents rated items on a 10-point scale from 1 (not at all) to 10 (extremely), reflecting how they or their child felt "right now, in this moment." These state-based items were selected to align with the trait-based I-PANAS-SF included in the baseline and 2-week post surveys, enabling comparison between momentary and general affect. The resource eligibility thresholds for parent and child negative affect were ≥1 for parent negative affect, ≥1 for child anger, and ≥2 for child sadness.

Parent and Child Emotion Regulation

Parent and child emotion dysregulation were assessed using 3 items from the state-based version of the Difficulties in Emotion Regulation Scale (S-DERS) [78]. Items included "My emotions feel overwhelming" and "I am having difficulty controlling my behaviours." As the original S-DERS was developed for adults, 1 item was adapted to assess child emotion regulation ("My child is having difficulty controlling their behaviours."). Parents rated items on a 10-point scale from 1 (not at all) to 10 (extremely), reflecting their or their child's current emotional state. The resource eligibility thresholds for parent and child emotion regulation were ≥1 for parent emotion dysregulation and ≥2 for child emotion dysregulation.

Statistical Analysis

To evaluate feasibility in terms of participant recruitment, retention, and engagement (aim 1), data from the baseline, 2-week post, and EMI surveys were analyzed using descriptive statistics. Pearson pairwise correlations examined associations between demographic characteristics and engagement with pre- and post-EMI surveys and the 2-week post survey. To evaluate

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acceptability of the program content and delivery method (aim 2), acceptability items from the 2-week post survey were analyzed descriptively to assess participant feedback about the Daily Growth program. To assess feasibility of the research methods in evaluating the efficacy of Daily Growth (aim 3), 2 sets of analyses were conducted in line with the two survey streams: (1) baseline to 2-week post survey outcomes: Bonferroni-adjusted linear regression analyses were conducted for parent and child outcomes. Each model used a postintervention outcome (eg, parent or child emotion regulation and mental health) as the dependent variable and study condition (intervention or control) as the independent variable. Two models were estimated for each outcome: an unadjusted model examining the association between assigned condition and the 2-week post survey outcome, and an adjusted model controlling for the baseline value of the outcome. Effect sizes were also calculated, with Cohen *d* reported for the unadjusted model and η^2 reported for the adjusted model. (2) EMI outcomes: Post-EMI survey data were analyzed using linear mixed-effects regression models, with condition as the fixed effect and participant as the random effect. Two models were estimated for each outcome: an unadjusted model examining the association between assigned condition and post-EMI outcome, and an adjusted model controlling for the pre-EMI value of the outcome. All analyses were intention-to-treat and used the maximum available data, resulting in variation in sample size per test.

Protocol Deviations and Technical Issues

Several technical issues occurred during the pilot. First, approximately half of the participants did not receive post-EMI surveys due to a programming error that sent surveys only if participants completed their pre-EMI survey within 15 minutes of the invitation email. This was corrected midway through the trial by removing the time restriction and sending post-EMI surveys to all participants regardless of resource eligibility. For analysis, participants were categorized into group 1 (affected by the issue) and group 2 (unaffected by the issue), with both groups balanced across control and intervention conditions and showing no other differences. Second, a programming oversight allowed participants to complete EMI surveys multiple times; only first completions were retained for analysis. Third, EMI survey prompts did not account for participants' time zones, resulting in prompts sent outside intended times for participants residing outside Victoria, New South Wales, Tasmania, or the Australian Capital Territory. Finally, 57 EMI survey responses and 2522 Platform O prompts missing participant IDs were excluded from analysis.

Results

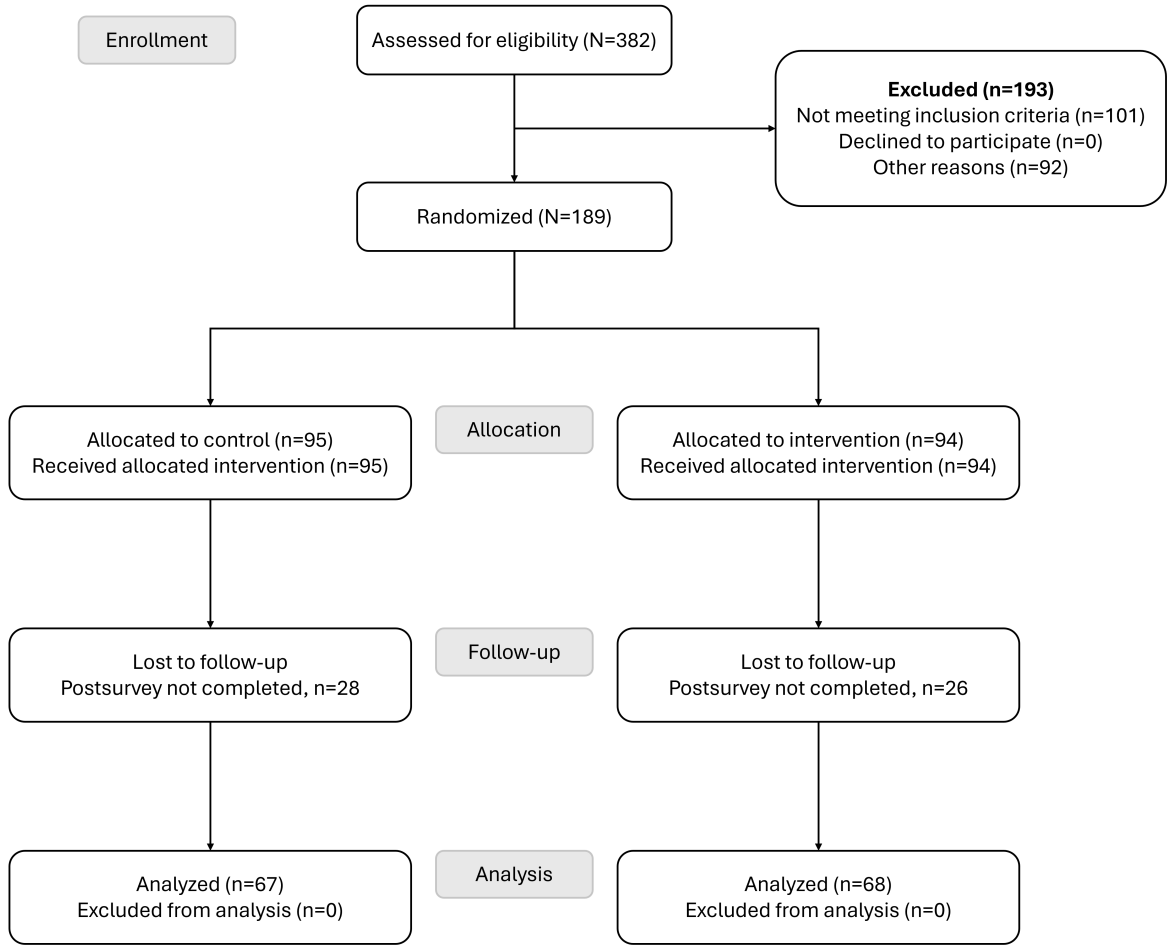
Feasibility Outcomes

Participant Flow

Participant flow is presented in Figure 2. Of the 382 participants assessed for eligibility, approximately half were excluded for reasons including not meeting inclusion criteria, incomplete demographic data, residing outside Australia, being identified as bots, having no EMI prompts assigned, lacking a participant ID, or being duplicate entries. Overall, 71% (135/189) of the participants who completed the baseline survey also completed the 2-week post survey, meeting the prespecified target of <30% attrition.

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Figure 2. Participant flow through enrollment, screening, baseline completion, 2-week post survey completion, and analysis.



Participant Demographics

Participant demographics are presented in Table 2. The study enrolled 189 parents and carers of children aged 2 - 4 years, exceeding the recruitment target of 150 participants. Randomization resulted in groups that were broadly comparable on baseline demographic characteristics. The mean participant age was 36.4 (SD 5.2) years in the control group and 36.7 (SD 4.8) years in the intervention group; the overall sample mean age was 36.6 (SD 5.0) years. Most participants were mothers, and the predetermined recruitment target of 25% fathers was not met. Compared with the most recent census of Australian families [23,79,80], single parents and parents of Aboriginal and Torres Strait Islander descent were overrepresented in the study sample. Parents with a low income, born overseas, who speak another language, and those without a university degree were underrepresented.

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Table . Comparison of demographic characteristics across control and intervention conditions, the total sample, and the Australian population (N=189)[a].

Variable	Control, n (%)	Intervention, n (%)	Total sample, n (%)	Australian population, %
Participant's sex				
Female	82 (86.3)	82 (87.2)	164 (86.8)	50.7
Male	13 (13.7)	11 (11.7)	24 (12.7)	49.3
Nonbinary	0 (0)	1 (1.1)	1 (0.5)	—[b]
Child's sex				
Female	46 (48.4)	47 (50.0)	93 (49.2)	—
Child's age, years				
2	17 (17.9)	20 (21.3)	37 (19.6)	—
3	29 (30.5)	31 (33.0)	60 (31.7)	—
4	49 (51.6)	43 (45.7)	92 (48.7)	—
Single parent	9 (9.5)	9 (9.6)	18 (9.5)	4.2
Number of children in the home				
1	15 (15.8)	17 (18.1)	32 (16.9)	42
2	56 (58.9)	53 (56.4)	109 (57.7)	39
3	17 (17.9)	20 (21.3)	37 (19.6)	14
4+	7 (7.4)	4 (4.3)	11 (5.8)	5
Level of schooling				
Did not complete high school	8 (8.4)	14 (14.9)	22 (11.6)	20.7
Completed high school	87 (91.6)	80 (85.1)	167 (88.4)	79.3
Highest qualification				
No tertiary qualification	9 (9.5)	4 (4.3)	13 (6.9)	38.8
Trade certificate or diploma	19 (20.0)	20 (21.3)	39 (20.6)	17
Bachelor's degree	31 (32.6)	38 (40.4)	69 (36.5)	20.3
Postgraduate degree	36 (37.9)	32 (34.0)	68 (36.0)	8.1
Participant born overseas	14 (14.7)	15 (16.0)	29 (15.3)	27.6
Language other than English	8 (8.4)	4 (4.3)	12 (6.3)	22
Aboriginal/Torres Strait Islander	6 (6.3)	4 (4.3)	10 (5.3)	3.8
Low income (AU$ <52,000 per year)	13 (13.7)	13 (13.8)	26 (13.8)	21

[a]Australian population data are from the Australian Bureau of Statistics [23,79]. Population includes Australian parents living with a dependent child.

[b]Not available.

EMI Completion

EMI completion rates over the 2-week study period are presented in Figure 3. On average, participants completed close to two-thirds of the pre-EMI surveys, exceeding the prespecified engagement target of 50%. However, post-EMI survey completion was lower and fell below the prespecified 50% target. Completion rates did not differ substantially between conditions. For pre-EMI surveys, the majority of the participants (57.7%) completed at least 75% of surveys. Around 1 in 6 (17.5%) participants completed fewer than 25% of pre-EMI surveys. In contrast, post-EMI survey completion was low, with most participants (58.2%) completing fewer than 25% of surveys, and only about 1 in 10 (9%) completing at least 75%. Twenty-three participants in group 1 (ie, affected by technical issues) did not receive any post-EMI survey prompts. Figure 4 presents the average pre-EMI survey completion rates across study time points. Completion rates fluctuated between 60% and 80% across the 2-week period.

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Figure 3. EMI survey completion rates across intervention and control conditions. Technical issues affected group 1 (ie, the post-EMI survey was not consistently sent). No technical issues affected group 2. EMI: ecological momentary intervention.

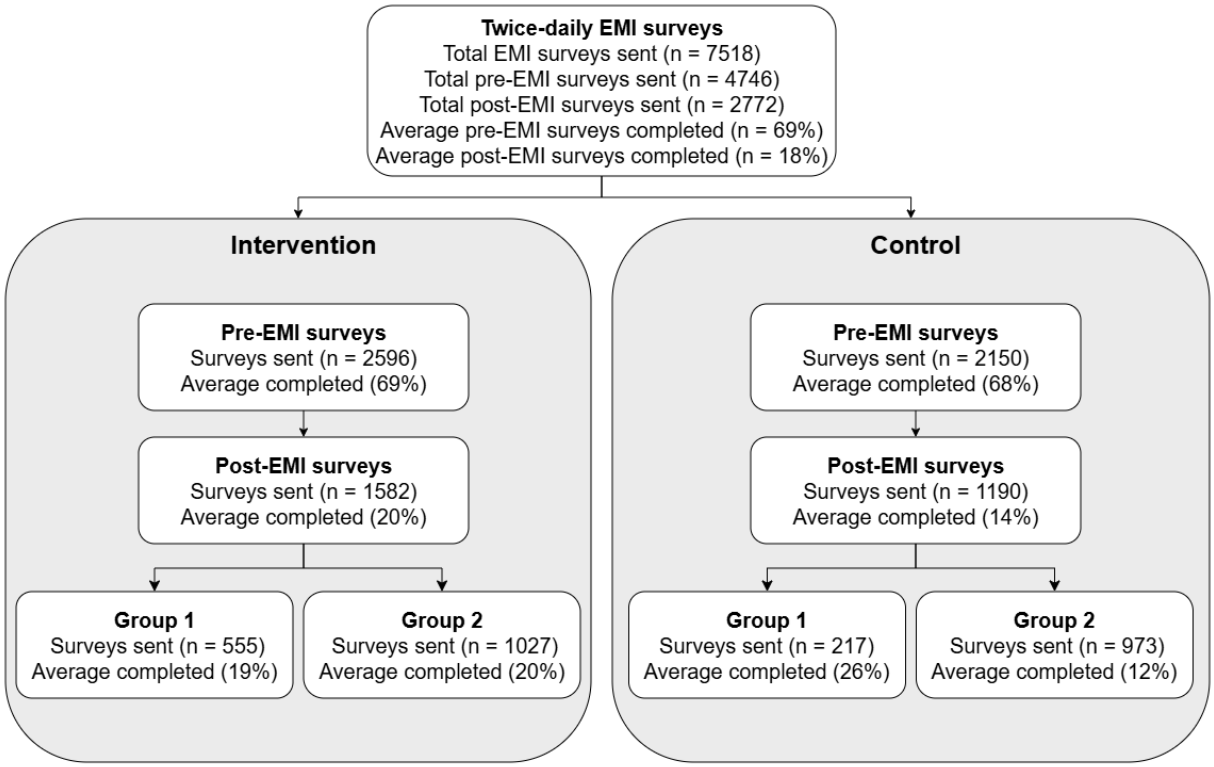
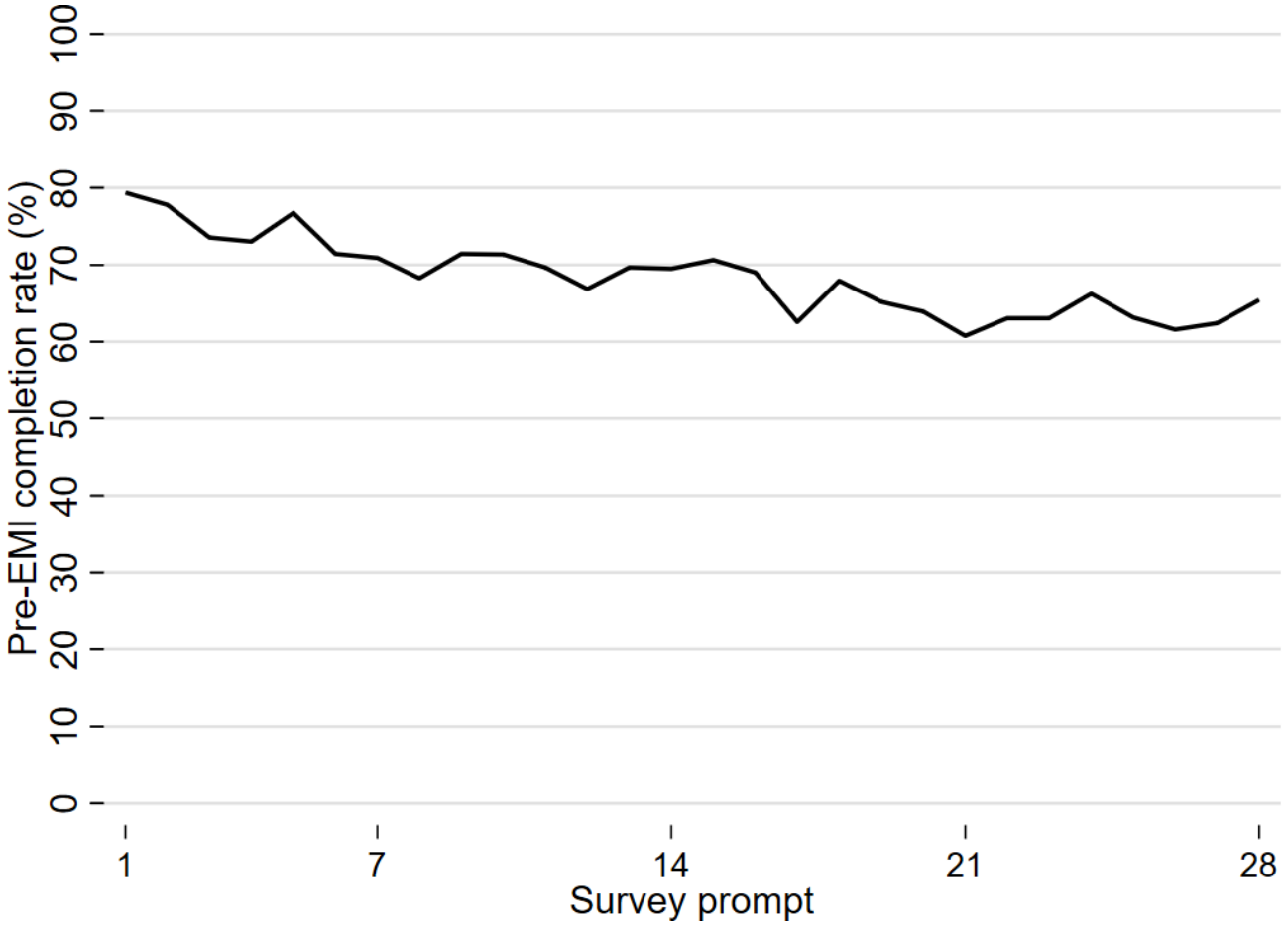


Figure 4. Average pre-EMI survey completion rates by survey time point across the 14-day intervention period. EMI: ecological momentary intervention.



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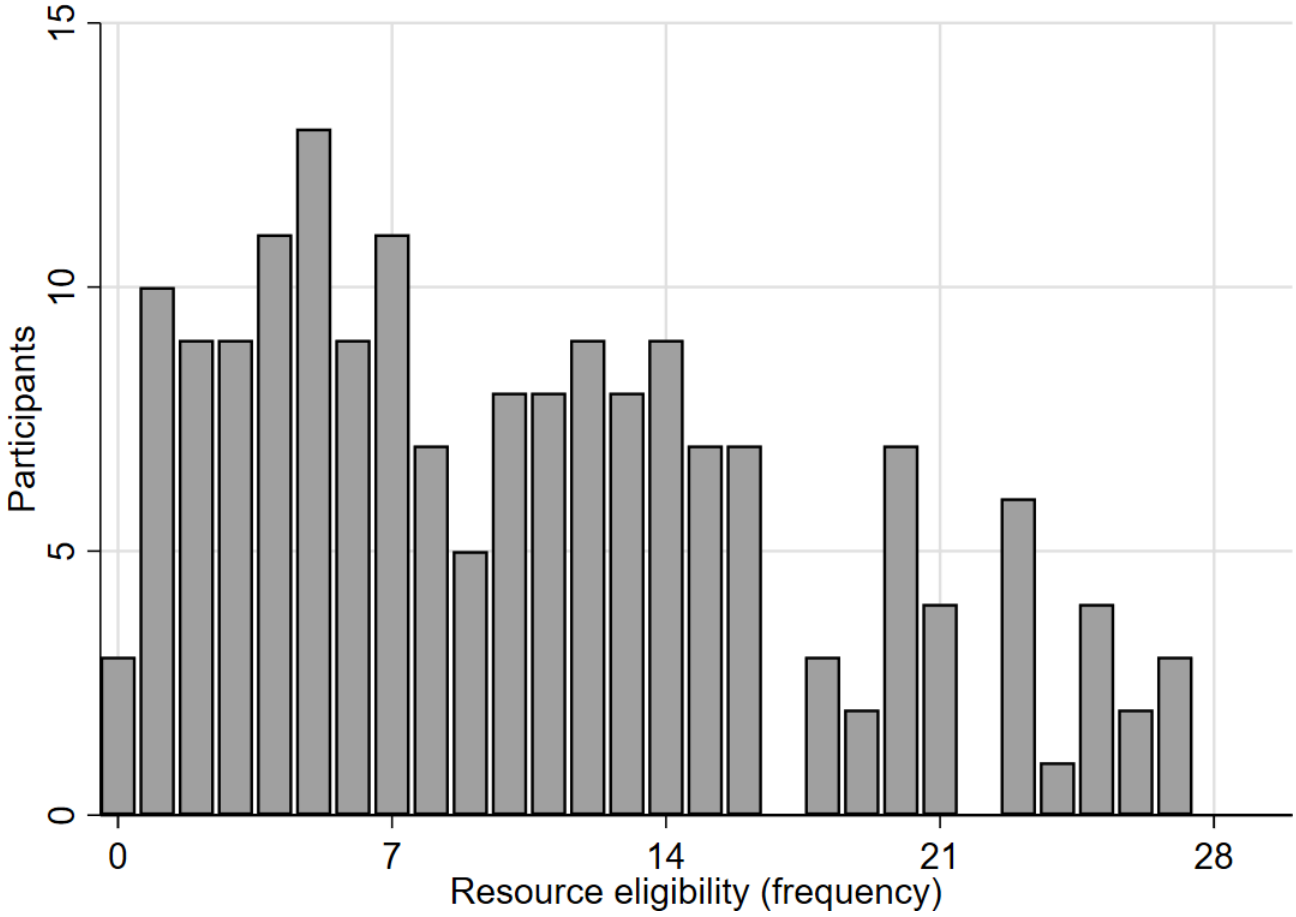
Demographic Characteristics and Engagement

Prespecified Pearson pairwise correlations were conducted to examine associations between pre-EMI survey completion rates and participant demographic characteristics. There was evidence for a small association between participants' pre-EMI survey completion rate and child's age (r=0.15; P=.046), suggesting that completion rates were slightly higher among parents of older children. However, we found no evidence to suggest associations between any other demographic characteristics and pre-EMI completion rates.

Resource Eligibility

Figure 5 presents the number of survey responses per participant that were eligible to receive a resource (ie, scored above the cutoff on the pre-EMI survey). Among all completed pre-EMI surveys, 56% met criteria for receiving a resource, with an average of 43% eligible pre-EMI surveys per participant. On average, parenting support was offered once per day based on the pre-EMI survey cutoff.

Figure 5. Frequency distribution of resource eligibility per participant by day of participation over 2 weeks.



Acceptability

Program acceptability results are shown in Table 3. Interpretation of acceptability outcomes was limited by an error in the survey response options, as both ends of the scale were labeled "Strongly disagree," (ie, participants were shown as Strongly disagree, Disagree, Neutral, Agree, and Strongly disagree), meaning that it was not possible to determine whether participants intended to select the lowest or highest level of acceptability. It is also likely that responses are skewed, as participants who would have selected "Strongly agree" may instead have selected "Agree," given that the "Strongly agree" option was not available. Notably, only a small number of participants selected either "Strongly disagree" response option. For example, for the item "Overall, I am satisfied with the Daily Growth program." only 3% (2/67) selected "Strongly disagree."

As shown in Table 3, the majority of intervention participants who completed the acceptability survey found the Emotion Coaching and Active Play resources useful, with over two-thirds agreeing that the program was easy to use. Just less than half of the participants felt that Daily Growth met their needs, and more than half reported overall satisfaction. Almost half of the participants indicated that the program helped them manage challenging parenting situations, while more than half reported that it improved their understanding of their child's emotions. For nearly half of the participants, the program also strengthened their bond with their child. Additionally, two-thirds planned to continue using the skills they learned. Most participants (94%) reported that the Daily Growth resources were about the right length, and the majority (79%) indicated that they would recommend the program to other parents. However, consistent with the technical issues described earlier, approximately one-third of the participants (31%) reported encountering issues while using the app, most commonly relating to not receiving some EMI surveys.

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Table . Acceptability of Daily Growth at 2-week post survey (N=67).

Item	Strongly disagree[a], n (%)	Disagree, n (%)	Neutral, n (%)	Agree, n (%)	Strongly disagree[a], n (%)
I am satisfied with Daily Growth	0 (0)	10 (14.9)	15 (22.4)	40 (59.7)	2 (3)
Daily Growth meets my needs	1 (1.5)	13 (19.4)	21 (31.3)	30 (44.8)	2 (3)
I found Emotion Coaching useful	0 (0)	1 (1.5)	20 (29.9)	43 (64.2)	3 (4.5)
I found Active Play useful	0 (0)	1 (1.5)	27 (40.3)	36 (53.7)	3 (4.5)
Daily Growth was easy to use	0 (0)	7 (10.5)	10 (14.9)	45 (67.2)	5 (7.5)
I will use the skills I learned	0 (0)	3 (4.5)	14 (20.9)	46 (68.7)	4 (6)
Daily Growth helped me...					
parent with partner	4 (6)	17 (25.4)	23 (34.3)	21 (31.3)	2 (3)
manage parenting challenges	1 (1.5)	7 (10.5)	27 (40.3)	29 (43.3)	3 (4.5)
understand child's emotions	0 (0)	9 (13.4)	15 (22.4)	39 (58.2)	4 (6)
strengthen parent-child bond	0 (0)	9 (13.4)	26 (38.8)	30 (44.8)	2 (3)

[a]Due to a survey error, both ends of the acceptability scale were labeled "Strongly disagree," limiting interpretation of responses. It is possible that some participants selected "Agree" in place of "Strongly agree," since the latter option was not available. Few participants overall selected "Strongly disagree."

Descriptive Efficacy

Two-Week Post survey Outcomes

Descriptive statistics for the outcome measures are reported in Table 4. Internal consistency (Cronbach α) for most measures was similar to values reported in the original validation studies [63-66,68-75,81]. Multivariable regression analyses examining condition differences are also presented in Table 4. Two models were estimated for each outcome: an unadjusted model and a model adjusted for baseline values. Findings were largely consistent across models, with significant results differing only for overall parent emotion regulation. Specifically, the between-group difference in overall parent emotion regulation was statistically significant in the unadjusted model but did not remain significant after adjusting for baseline scores. Overall, results indicated greater improvements from baseline to 2-week postintervention in the intervention group than in the control group in parent emotion dysregulation, including nonacceptance of emotional responses, parent psychological distress, and parent negative affect. No significant improvements were evident for any child outcomes.

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Table . Associations between condition status and parent and child 2-week post survey outcomes[a].

Outcome	Unadjusted					Adjusted for baseline				
	Effect size[b]	*B* value	LL[c]	UL[d]	*P* value	Effect size[e]	*B*	LL	UL	*P* value
Child outcomes										
Behavioral problems										
Temper loss	0.20	−0.17	−0.47	0.13	.26	0.00	0.03	−0.20	0.25	.81
Noncompliance	0.10	−0.11	−0.45	0.24	.54	0.00	−0.02	−0.28	0.23	.87
Aggression	0.23	−0.21	−0.52	0.10	.19	0.00	0.02	−0.20	0.24	.86
Depression	0.30	−0.92	−1.95	0.12	.08	0.02	−0.72	−1.54	0.10	.09
Anxiety	−0.05	0.10	−0.56	0.76	.77	0.00	0.17	−0.39	0.73	.55
Emotion regulation										
Mindfulness	0.08	−0.11	−0.61	0.38	.66	0.00	−0.11	−0.50	0.28	.59
Verbal help-seeking	−0.17	0.27	−0.26	0.81	.32	0.01	0.19	−0.18	0.57	.31
Verbal venting	−0.11	0.14	−0.31	0.60	.53	0.01	0.22	−0.12	0.56	.21
Physical venting	−0.13	0.19	−0.31	0.69	.45	0.02	0.29	−0.06	0.64	.10
Emotional reactivity	0.26	−0.25	−0.58	0.08	.14	0.00	−0.09	−0.31	0.14	.45
Negative affect	−0.05	0.15	−0.85	1.15	.77	0.01	0.38	−0.47	1.23	.37
Parent outcomes										
Emotion regulation										
Total	0.37	−4.84	−9.36	−0.32	.04	0.01	−1.87	−4.62	0.89	.18
Nonacceptance[f]	0.49	−1.49	−2.53	−0.45	.01	0.04	−0.90	−1.65	−0.15	.02
Goals	0.22	−0.62	−1.61	0.36	.21	0.00	−0.25	−0.97	0.46	.49
Impulse control difficulties	0.26	−1.16	−2.71	0.38	.14	0.01	−0.50	−1.53	0.54	.35
Strategies	0.29	−1.19	−2.60	0.21	.10	0.00	−0.16	−1.04	0.72	.72
Emotional clarity[g]	0.25	−0.37	−0.87	0.14	.15	0.02	−0.31	−0.71	0.08	.12

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Outcome	Unadjusted					Adjusted for baseline				
	Effect size[b]	*B* value	LL[c]	UL[d]	*P* value	Effect size[e]	*B*	LL	UL	*P* value
Psychological distress	0.40	−1.57	−2.92	−0.23	.02	0.04	−0.91	−1.71	−0.11	.03
Positive affect	0.01	−0.03	−1.41	1.35	.96	0.01	0.66	−0.34	1.65	.19
Negative affect	0.39	−1.40	−2.65	−0.15	.03	0.04	−0.94	−1.72	−0.16	.02
Stress	0.20	−1.52	−4.17	1.13	.26	0.02	−1.58	−3.50	0.33	.11
Emotion-related parenting										
Emotion coaching	−0.03	0.03	−0.28	0.35	.84	0.00	0.01	−0.24	0.25	.97
Emotion dismissing	0.18	−0.15	−0.43	0.13	.29	0.00	−0.09	−0.31	0.14	.44
Reflective functioning										
Prementalizing	−0.02	0.02	−0.25	0.29	.90	0.00	0.04	−0.16	0.24	.68
Certainty	−0.13	0.15	−0.23	0.52	.44	0.00	0.10	−0.18	0.38	.48
Interest and curiosity	0.00	0.00	−0.33	0.33	.99	0.02	0.21	−0.05	0.47	.12
Emotion beliefs[h]										
Anger	−0.10	0.57	−1.30	2.44	.55	0.00	0.16	−1.12	1.45	.80
Control	0.17	−0.69	−2.12	0.74	.34	0.00	−0.38	−1.43	0.68	.48
Manipulation	0.08	−0.39	−2.10	1.33	.66	0.00	0.31	−0.80	1.42	.58
Autonomy	0.08	−0.52	−2.77	1.73	.65	0.00	−0.44	−2.02	1.13	.58
Stability	0.28	−1.06	−2.35	0.23	.11	0.00	−0.34	−1.47	0.79	.55
Family climate[i]										
Positive emotion expression	−0.10	0.15	−0.39	0.69	.58	0.00	0.01	−0.32	0.35	.94
Negative emotion expression	0.05	−0.07	−0.55	0.42	.79	0.00	−0.06	−0.39	0.28	.74
Verbal conflict	0.16	−0.11	−0.35	0.13	.37	0.01	−0.08	−0.24	0.08	.31

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Outcome	Unadjusted					Adjusted for baseline				
	Effect size[b]	*B* value	LL[c]	UL[d]	*P* value	Effect size[e]	*B*	LL	UL	*P* value
Physical conflict	0.00	0.00	−0.05	0.05	≥.99	0.00	0.01	−0.04	0.05	.81

[a]Participant condition status, that is, their assignment to either the intervention or control condition, was entered as the independent variable. Two models were estimated: an unadjusted model and a model adjusted for the corresponding baseline value.

[b]Effect size for adjusted models=η^2.

[c]LL: lower limit.

[d]UL: upper limit.

[e]Effect size for unadjusted models=Cohen *d*.

[f]Nonacceptance: nonacceptance of emotional responses.

[g]Emotional clarity: lack of emotional clarity.

[h]Emotion beliefs: beliefs about children's emotions.

[i]Family climate: family emotional climate.

In-the-Moment Post-EMI Outcomes

Table 5 presents the linear mixed model regression analysis of post-EMI survey outcomes. Two models were estimated for each outcome: an unadjusted model and a model adjusted for corresponding pre-EMI values. Findings were consistent across both models, demonstrating a significant association between condition and momentary parent negative affect. No additional significant effects were found. Intraclass correlation values indicated that a small proportion of variance in outcome measures was attributable to individual differences.

Table . Associations between condition status and parent and child post–ecological momentary intervention survey outcomes[a].

Outcome	Unadjusted					Adjusted for pre-EMI[b]				
	B value	LL[c]	UL[d]	*P* value	ICC[e]	*B* value	LL	UL	*P* value	ICC
Child outcomes										
Emotion regulation[f]	0.31	−0.30	0.93	.314	0.33	−0.11	−0.53	0.32	.615	0.10
Negative affect										
Sad	0.00	−0.48	0.49	.990	0.14	−0.03	−0.44	0.38	.872	0.05
Angry	0.11	−0.33	0.54	.634	0.25	−0.05	−0.37	0.26	.732	0.13
Parent outcomes										
Emotion regulation										
Overwhelming[g]	−0.33	−0.80	0.15	.176	0.37	−0.23	−0.49	0.04	.099	0.11
Behaviors[h]	−0.23	−0.71	0.25	.347	0.58	−0.17	−0.51	0.16	.305	0.41
Negative affect (upset)	−0.50	−0.95	−0.05	*.029*	0.48	−0.37	−0.71	−0.04	*.028*	0.32

[a]Participant condition status, that is, their assignment to either the intervention or control condition, was entered as the independent variable. Two models were estimated: an unadjusted model and a model adjusted for the corresponding pre-EMI value.

[b]EMI: ecological momentary intervention.

[c]LL: 95% CI lower limit.

[d]UL: 95% CI upper limit.

[e]ICC: intraclass correlation.

[f]"My child is having difficulty controlling their behaviours" EMI item.

[g]"My emotions are overwhelming" EMI item.

[h]"I am having difficulty controlling my behaviors" EMI item.

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Discussion

Principal Findings

This pilot randomized controlled trial evaluated the feasibility, engagement, and acceptability of a small-scale prototype of the Daily Growth parenting program, a digital intervention designed to provide in-the-moment support for parents using an EMI approach. Overall, the study met its recruitment target and demonstrated a high retention rate. Engagement with pre-EMI surveys exceeded expectations, translating to parents on average completing a survey once per day. Participants responded positively to the program and found the resources useful. However, post-EMI survey completion rates were lower than anticipated, with parents responding approximately 1 in 5 times, and certain demographic groups were underrepresented. Together, these findings offer valuable insights for refining the program and guiding future research.

Feasibility

This pilot study exceeded the recruitment target of 150 participants and retention rates were high compared with similar parenting interventions [20,82,83], indicating a high level of participant interest and engagement. This may be attributed to Daily Growth's user-centered design, including flexible and tailored support based on parent needs. Nevertheless, some attrition occurred between screening and baseline, as well as during the 2-week intervention period, highlighting opportunities to refine the enrollment process and strengthen engagement strategies. Engagement with pre-EMI surveys exceeded expectations. Overall, engagement with the daily prompts throughout the study period was at a similar level to other EMA or intervention studies [23] and close to the recommended rate of 80% [10]. Notably, the predefined engagement benchmark for this study was 50%, as Daily Growth is intended to be a light-touch, accessible program that would not be overly burdensome for busy parents. Achieving engagement levels substantially above this target therefore provides strong preliminary support for the acceptability of the delivery schedule. However, engagement with post-EMI surveys was lower than the target of 50% completion, which may be attributed to having separate online systems. As EMI survey prompts were delivered via email, while surveys and videos were delivered through Platform O, it is possible that once parents completed the pre-EMI survey and were directed to a video or website elsewhere, they did not return to their email to click on the post-EMI survey prompt. Using a smartphone app with push notifications could help streamline this process by keeping all prompts and resources within a single, integrated system. Additionally, providing onboarding instructions to emphasize the importance of completing all survey components may further support engagement. It is also important to note that technical issues affected the post-EMI surveys and should be addressed in future implementations.

This pilot study demonstrated Daily Growth's potential to engage a diverse group of parents, an ongoing challenge in online parenting intervention studies [20,84]. However, fathers, migrant parents, and parents with a low level of education were underrepresented, consistent with patterns in previous intervention research [20,82-86]. Fathers may perceive parenting programs as less relevant to them or feel that their contributions are undervalued, while migrant parents may face barriers such as language, accessibility, or differing cultural expectations [20,82-86]. Although the primary focus of this pilot was not on recruiting a representative sample but rather on testing the technical feasibility and engagement with the Daily Growth prototype, future iterations should aim to increase inclusivity by incorporating father-specific recruitment strategies and ensuring that program materials are broadly accessible to better reach underrepresented groups.

Acceptability

Participants responded positively to Daily Growth, with most finding the resources useful and willing to recommend the program to others. These findings suggest that the Design Mapping framework and EMI approach successfully enhanced parent satisfaction, consistent with previous studies finding these approaches acceptable [13,37,87-91]. Approximately half of the participants reported that the program fully met their needs or helped them manage parenting challenges, a reasonable outcome given the pilot offered only 10 videos covering 5 parenting situations. The full Daily Growth program, featuring 90 video resources across 3 program types, will address a broader range of parenting challenges and better accommodate diverse family needs. Participants also reported technical difficulties, particularly with post-EMI survey prompts. Improving technical infrastructure to streamline user experience and minimize disruptions remains a priority for future iterations.

Descriptive Outcomes

Descriptive outcome data were collected to test the feasibility of the program evaluation methods, more specifically to assess whether the measures are sensitive to change, whether outcome data can be collected completely, and whether the measurements are viable to use in a larger trial. The prototype version of Daily Growth showed significant reductions in momentary negative affect (EMI outcomes) in participants in the intervention condition compared with the control, suggesting that the program's real-time delivery may effectively support parents during challenging situations. These findings align with previous emotion-focused parenting interventions [92-95] and EMI-based parenting programs [13,37] and indicate that brief, targeted support can help parents manage their emotions more effectively. Furthermore, baseline to 2-week postintervention improvements in parent emotion regulation and mental health outcomes were observed, including reduced nonacceptance of emotional responses, psychological distress, and negative affect.

Notably, the between-group difference in total parent emotion dysregulation was significant in the unadjusted model but did not remain significant after adjusting for baseline scores. This likely reflects the strong stability of emotion regulation over time and limited statistical power in this pilot sample. Furthermore, no significant effects emerged for baseline to 2-week post survey child outcomes or broader parenting behaviors such as emotion coaching. The program was designed to target parent emotion regulation and parenting behaviors; hence, child outcomes represent more distal targets. Given the pilot's brief duration (2 weeks), limited intervention content

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(only 10 of the total 60 videos were available), and small sample size, detecting changes in these outcomes was not the focus of the current trial. Child emotion regulation develops gradually through repeated parent-child interactions, and meaningful shifts in parenting practices typically require sustained exposure to intervention content. The full 6-week Daily Growth program, with substantially more content and longer intervention exposure, provides a more appropriate test of child-level impacts in a larger, adequately powered trial.

Implications for Future Research

Several directions for future research and program refinement should be considered. First, investigating how parent gender influences program efficacy warrants attention, as mothers and fathers often differ in their parenting approaches [96-98], suggesting opportunities for targeted tailoring. Second, although baseline parental mental health was assessed, this pilot study was not powered to examine whether feasibility, acceptability, or descriptive efficacy outcomes differed by mental health status. Future trials could explore mental health as a potential moderator of engagement and program effects, as these parents may have greater needs for support and may engage differently with EMI program delivery [99]. Furthermore, optimizing intervention timing deserves careful consideration. While in-the-moment delivery can be highly effective [29,100], some parents may be more receptive to learning new skills when not experiencing high emotional dysregulation [101]. Future research should systematically examine timing and delivery strategies that maximize both learning and immediate support, potentially offering parents flexibility when they access content.

Strengths and Limitations

This study makes several important contributions. The randomized controlled trial design minimizes bias and provides a robust test of full trial methods. Most notably, this represents one of the first applications of an EMI approach to digital parenting interventions. Beyond enhancing engagement through regular prompts, the EMI design generated valuable real-time data on parents' momentary experiences and immediate responses to brief video interventions. These findings provide early support for EMI's viability in early childhood parenting support and demonstrate that twice-daily prompts are generally acceptable to parents. However, several limitations warrant consideration. First, the pilot tested only a 2-week prototype, whereas the full program spans 6 weeks. While short-term feasibility was demonstrated, sustained engagement with twice-daily prompts over extended periods remains uncertain. Second, the sample, although adequate for pilot testing, was relatively small and underrepresented fathers, migrant parents, and those with lower educational attainment, limiting generalizability. A third limitation is that the prototype platform was not able to capture the number of resources watched by each participant, meaning that intervention exposure could not be quantified beyond the EMI survey data. Technical issues also affected data quality and user experience. Approximately half of the participants did not receive post-EMI survey prompts due to a programming error, and prompts did not account for time zones, resulting in some participants receiving surveys outside intended times. In addition, multiple completions of EMI surveys and missing participant IDs resulted in the exclusion of a portion of responses. These issues highlight the importance of refining the technical infrastructure prior to a fully powered trial. Finally, the limited intervention content (10 videos covering 5 situations) constrained our ability to detect changes in child outcomes or broader parenting behaviors, which likely require more comprehensive exposure to demonstrate effects.

Conclusions

Reaching diverse families and sustaining their engagement remains one of the greatest challenges for universal parenting programs. This pilot study demonstrates that delivering parenting support through an EMI approach is both feasible and acceptable. Testing a small-scale Daily Growth prototype, we found that brief, tailored video resources successfully engaged parents in real time. High recruitment and retention rates, combined with positive parent feedback and engagement exceeding expectations for pre-EMI surveys, provide compelling evidence that tailored EMI approaches can overcome traditional barriers to reach and engagement in digital parenting programs. However, low post-EMI completion rates indicate the need for refinements to reduce participant burden and improve response rates. These promising findings establish a foundation for a larger trial to rigorously assess efficacy, optimize delivery methods, and enhance accessibility for underrepresented groups, particularly fathers and migrant parents. Beyond demonstrating feasibility, this study advances digital parenting interventions through its innovative co-design approach. Daily Growth represents a new model for scalable, data-driven parenting support that has the potential to improve parenting practices and child mental health outcomes at a population level.

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Funding

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Data Availability

The datasets used to analyze the results of this study are available from the corresponding author upon request.

Authors' Contributions

Conceptualization: EMW, SE, TSB, MB, EO, MF-T
Data curation: TSB, SH-R, EO, EMW
Formal analysis: TSB, SH-R, EMW, SE, MF-T
Funding acquisition: EMW
Investigation: SH-R, TSB, SE, KB, EO, GLK, EMW
Methodology: EMW, TSB, MF-T, EO, GLK, SE
Project administration: EMW, SH-R, SE, TSB, EO
Resources: EMW, EO
Software: EO
Supervision: EMW
Visualization: EMW, TSB
Writing – original draft: SE, EMW, KB
Writing – review & editing: SE, EMW, TSB, KB, MB, MF-T, GLK

Conflicts of Interest

None declared. We note that the authors or evaluators are identical to the developers or sponsors of the intervention.

Editorial Notice

This randomized study was retrospectively registered because at the time the study began, the authors were not aware of the requirement for prospective registration of pilot studies. The editor granted an exception from ICMJE rules mandating prospective registration of randomized trials, because the risk of bias appears low and the study was considered formative, guiding the development of the application. However, readers are advised to carefully assess the validity of any potential explicit or implicit claims related to primary outcomes or effectiveness, as retrospective registration does not prevent authors from changing their outcome measures retrospectively.

Checklist 1
CONSORT-EHEALTH checklist.
[PDF File, 1183 KB - pediatrics_v9i1e87917_app1.pdf]

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Abbreviations

EMA : ecological momentary assessment
EMI : ecological momentary intervention
I-PANAS-SF: short-form International Positive and Negative Affect Schedule
S-DERS: state-based version of the Difficulties in Emotion Regulation Scale

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Review Paper

Evaluating Mobile Information Apps for Parents of Preterm Infants After Hospital Discharge: Systematic App Review

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Abstract

Background: After hospital discharge, parents of preterm infants need accessible and reliable information to gain confidence and skills in their child-caring abilities and parental autonomy. Parental need for information after hospital discharge includes topics related to prematurity, such as crying, feeding, sleeping, infant care, general health, and neuromotor development. However, parents report difficulty in finding and understanding this information. Mobile apps have the potential to improve information provision.

Objective: The aim of this systematic app review was to (1) identify mobile apps for parents of preterm infants targeting the period after hospital discharge and (2) evaluate the content, quality of the app, and understandability and actionability of the information material.

Methods: We systematically searched for apps in the Apple App Store, Google Play Store, and Google, along with a literature search using PubMed. Multiple keywords were used (eg, “preterm baby,” “app,” and “home”). Apps were included when they provided information for parents on topics and content related to prematurity after hospital discharge. To examine app content related to the postdischarge period, apps were reviewed, and topics were identified. The Mobile App Rating Scale (MARS) was used to measure the app’s quality, and the Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT-AV) was used to measure the understandability and actionability of the information material.

Results: After the initial search, the titles and descriptions of 196 apps were screened for eligibility. Eventually, 9 English apps were included in the review. Information related to the postdischarge period constituted only a small part of the app’s content. Most commonly addressed topics related to the period at home were vaccinations, follow-up, feeding, and using home oxygen. Using the MARS, only one of the 9 apps received a good score for overall quality (“MyPreemie app”; Graham’s Foundation), and 7 apps received an acceptable score. Only 4 apps scored high on understandability of the PEMAT-AV, and 6 apps scored high on actionability. No Dutch apps were identified.

Conclusions: The current availability of mobile information apps for parents of preterm infants targeting the period after hospital discharge is limited. A total of 9 English apps were identified, which contained a small portion related to the postdischarge period. This content is not comprehensive for the postdischarge period: topics indicated as relevant by parents, such as crying in preterm infants, diaper change in preterm, or parental well-being after preterm birth, are often missing. The overall quality of the apps is only acceptable. Although the reliability of the information was close to good, the understandability of the apps was moderate. Recommendations for future app development include more relevant and understandable information related to the postdischarge period, which meets the demand of parents of preterm infants.

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KEYWORDS

preterm; mHealth; mobile information applications; review; infant; infancy; neonate; neonatal; newborn; premature; health information; education; information quality; mobile health; app

Introduction

Yearly, 13.4 million babies are born preterm (PT; <37 weeks of gestation), of which 2 million infants are born very preterm (VPT; <32 weeks of gestation) [1]. VPT infants are frequently discharged from the hospital before their term date [2], and parents often feel inadequately prepared to take their vulnerable infant home [3]. Without the continuous professional support of the neonatal intensive care unit (NICU), parents lack confidence or competence in infant caregiving. Parents report practical, emotional, and financial challenges at home and the need for practical support regarding baby caregiving tasks, feeding, medication, or managing unexpected health issues [4]. The uncertainty about the health, growth, and neuromotor development of their VPT infant can heighten parental anxiety and negatively affect parents' caregiving behavior [5]. Parental confidence and competence in caring for their VPT infant can be increased by professional support and tailored information, and is thus an important approach to improve parental and infant outcomes [6,7]. Caring for a VPT infant after hospital discharge can be more demanding for parents than caring for a typically developing infant. VPT infants show different behaviors, such as reduced activity, alertness, and responsiveness, that require specific parenting skills to interpret their baby's cues [4]. Parents therefore require information on common topics specifically targeting prematurity, such as crying (how to comfort a preterm infant), feeding (how and when to transition to solid foods), sleeping (recognize pattern of sleep and fatigue in their baby), infant regulation (help their baby to regulate), infant care (diaper change in a very small infant), general health (when to contact a pediatrician), and neuromotor development (differences in milestones between term and preterm infants) [5,8]. This information, specific to premature infants, is, however, not available on the internet [6]. Parents appreciate that general parenting websites provide accessible information on newborn topics such as feeding and digestion, but the content is perceived as less appropriate for parents with a VPT infant [6]. Therefore, practical and tailored information is necessary to increase knowledge and skills to support parents to feel confident in taking care of their preterm baby at home. To accommodate their underlying emotional needs, parents prefer information that is strength-based and confirming or reassuring in their caregiving [8].

Almost all parents in the NICU use their smartphones to search for information regarding prematurity on the internet [9]. For instance, in the Netherlands, information is provided by the Dutch parent organization (Care4neo) [10]. Facilitated by the ease of use, the 24/7 availability, and the ability to make information attractive, mobile health (mHealth) apps are promising tools to provide health information [11]. In general, parental knowledge about infant development is associated with better caregiving behavior and improved infant development [12]. Mobile apps have the potential to improve parental well-being and parenting in the perinatal period [13]. mHealth apps vary in quality, but many are of moderate quality or out of date [11,14]. A previous review on information apps targeting parents with an infant who was still admitted to the NICU showed that only a quarter of the apps for parents were considered of good quality [15]. For optimal support, parental needs for information should be incorporated in the content of the app [16]. Parents have ongoing information needs, but what they want to know changes over time [8]. After discharge home, when hospital staff support is lacking, parents need different information to feel competent in their caregiving than during their initial hospital stay.

For health care professionals and parents, it is important to be able to use high-quality apps, include engagement, functionality, aesthetics, and information quality. Therefore, the information content of mHealth applications needs to be understandable for all parents, irrespective of health literacy levels. Since preterm birth has been consistently associated with lower socioeconomic status [17], low health literacy is also a prevalent issue in parents of VPT infants. Health literacy refers to the skills needed to function effectively in the health care environment [18], and low health literacy is associated with poorer use of health care services and poorer health outcomes [18]. Parents with lower health literacy may encounter difficulties in obtaining, processing, using, and interpreting information in mHealth applications [19]. To benefit from mHealth, parents require digital health literacy skills, such as using digital devices, searching for and understanding information, and evaluating the validity of the information [20]. However, to date, little is known about the quality, understandability, and actionability of available mHealth apps designed to support parents of VPT infants after hospital discharge. Therefore, the aim of this app review was (1) to identify mobile information apps for parents of preterm infants targeting the period after hospital discharge and (2) to evaluate the content, quality of the app, and understandability and actionability of the information material.

Methods

Study Design

This systematic review of mobile apps followed systematic review methodology adhering to PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) standards [21] (Multimedia Appendix 1) and published conduct and reporting recommendations for systematic app store reviews [22].

Search Strategy

To ensure the identification of relevant mobile apps, a comprehensive search was conducted, using 4 different strategies. Apps were directly searched in (1) Apple App Store for iOS and (2) Google Play Store for Android. In addition, mobile apps were also searched via (3) Google and (4) PubMed. The search in the app stores and Google was performed in December 2023. The search in PubMed was performed in May

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2022. In the first 3 search strategies, keywords were used both in Dutch and in English.

The different search machines implied different search strategies. In the app stores, separate key terms (in Dutch and English) were used in the search field: “preterm baby,” “preemie,” “premature,” “NICU,” and “discharge.”

For the Google internet search, the term “app” was always used and combined with terms “preterm baby,” “preemie,” “prematurity,” NICU,” “Neonatology,” and “incubator.”

The PubMed search combined terms “parent,” “mother,” “father,” or “caregiver” AND “premature birth,” “premature infant,” “preterm,” “prematurity” AND “mobile application*,” “smartphone application*,” “health app*,” “mobile app*.” No MeSH (Medical Subject Headings) terms were used for the PubMed search. The aim of the Google internet and PubMed search was to identify more apps that were subsequently retrieved from one of the App Stores.

The search in the Apple App Store and PubMed provided a certain number of apps and papers. These were all reviewed for eligibility. In the Google Play Store, the search yielded a continuous stream of apps, many of which were not relevant to our inclusion criteria. Therefore, we limited the screening to the first 50 apps that were displayed in the search results. These are typically ordered by relevance and popularity and align with how parents would conduct such a search. In the Google web search, the first 2 pages of results were reviewed to evaluate whether an app for parents of preterm infants was described. The search ended when 2 pages did not contain new hits. Limiting search results is a common practice in app and website reviews, as later results are less likely to be accessed by parents, often align less with the search criteria, and parents are unlikely to continue their search beyond a certain point [11,15,23].

App Selection

Several inclusion and exclusion criteria were used to select the mobile apps (Table 1). The free-of-charge criterion was used because we wanted to ensure that apps were available to all parents regardless of their socioeconomic status, income, or willingness to pay for a mobile app.

Table 1. Inclusion and exclusion criteria for app selection.

Condition	Inclusion criteria	Exclusion criteria
Topic	VPT[a] infants	Typical developing infants
Timing of information	Period after hospital discharge	Only during hospital stay
Language	English or Dutch	Other languages than English or Dutch
Access	No access code	Access code required
Information in the app	Directed to parents	Not directed to parents
Download	App available for download	App not available for download
Charge	App is free of charge	Paid app

[a]VPT: very preterm.

After removing duplicates between the two app stores, the Google and PubMed search, the app descriptions and features were first screened in the Apple App Store or Google Play Store by one researcher (RG) and discussed within the research team for eligibility. Apps that fulfilled the inclusion criteria were then downloaded. Two reviewers (RG and MJ-V) screened the apps for inclusion in the full app review and discussed the eligibility within the research team.

Data Extraction and Quality Assessment

For each app, the following data was collected: name of the app, operating system, developer and its affiliation, language, target population, year of last update, and a brief description of the app. To evaluate the postdischarge hospital content, a list of topics per app was created. To evaluate the quality of the apps and the understandability and actionability of the information material, two independent reviewers (MJ-V and RG) trained themselves to use the Mobile Application Rating Scale (MARS) [24] and the Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT-A/V) [25]. Thereafter, all included apps were independently evaluated by the two reviewers, and disagreements were resolved until consensus was reached. When no consensus was reached, the research team was involved. For each instrument, a structured data retrieval form was composed, using a spreadsheet in Microsoft Excel.

MARS

The MARS is a tool for assessing the quality of mobile health apps. The MARS consists of 4 objective scales: “engagement” (5 items: fun, interesting, customizable, interactive, and well-targeted to audience), “functionality” (4 items: app functioning, easy to learn, navigation, and gestural design), “aesthetics” (3 items: layout, graphics, and visual appeal), and “information quality” (7 items: accuracy of app description, measurable and achievable goals, quality of information, quantity of information, visual information, credibility, and evidence-based). Each item is rated on a 5-point rating scale, ranging from 1 “inadequate” to 5 “excellent.” Each item has specific descriptions for these rating anchors. Some items have the option “not applicable”. In addition, there is one scale for “subjective quality” (4 items: recommendation of the app, estimated frequency of use, willingness to pay, and overall star rating of the app). The first 3 items are rated on a 5-point scale, and the last item on a 3-point scale. The overall mean score for the 4 objective subscales is calculated, excluding the items rated

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as not applicable. The MARS has a high internal consistency (α=.90) and high interrater reliability (intraclass correlation coefficient [ICC]=0.79) [24]. For this study, we used the Dutch version of the MARS [25].

PEMAT-A/V

The PEMAT-A/V is an instrument that assesses the understandability and actionability of audiovisual patient education materials [26]. The PEMAT-A/V consists of 2 scales: understandability (13 items) and actionability (4 items). Understandability is defined as the ability of people from diverse backgrounds with varying levels of health literacy to comprehend educational material and extract key messages. Actionability is defined as the ability of learners to identify what actions can be taken on the basis of educational material information. Understandability includes 19 items evaluating the content, word choice and style, number usage, organization, layout and design, and use of visual aids. Actionability contains four items and evaluates whether the material (1) identifies an action the user can take, (2) the user is directly addressed, (3) breaks down an action into manageable steps, and (4) explains how to use the charts, graphs, tables, or diagrams to take action. Items are rated with “disagree” (0 points) or “agree” (1 point). Some items have the additional option “not applicable.” The PEMAT-A/V is designed to be completed by professionals and helps them select education material that is understandable and actionable. The PEMAT-A/V items are based on other instruments and concepts for developing educational material and are reliable for raters not trained in the use of the PEMAT-A/V. The researchers read the information in the apps and considered each item from a parental perspective, specifically a parent with low health literacy skills. The researchers did have experience with developing information for people with low health literacy skills. The scores for the two scales are calculated as a percentage, ranging from 0-100. A higher score reflects more understandability or actionability. An expert panel established the face and content validity. Interrater reliability was moderate according to Cohen κ (0.50), but with a high absolute agreement of 80% and high agreement when calculated by Gwet agreement coefficient 1 (0.71). Internal consistency was strong (Cronbach α=0.76), and the average item-total correlation=0.62. Construct validation was established based on differences in actionable and poorly actionable material, as well as a strong negative correlation between grade level and both consumer-testing results and PEMAT-A/V scores [26].

Data Analysis

Data analysis was performed using IBM Statistical Package for Social Sciences software (IBM SPSS; version 26). The MARS item scores were averaged for the engagement, functionality, aesthetics, and information subscales. These scores for app quality were then averaged, creating a mean (SD) app quality score. Descriptive statistics were used to summarize the results of the MARS and the PEMAT-A/V. To evaluate consistency between raters, the ICC between the raters was calculated for the MARS and the PEMAT-A/V. Rater agreement was examined by ICC based on a 2-way mixed-effects model. An ICC of <0.50 is considered poor, 0.51-0.75 as moderate, 0.76-0.89 as good, and >0.90 as excellent.

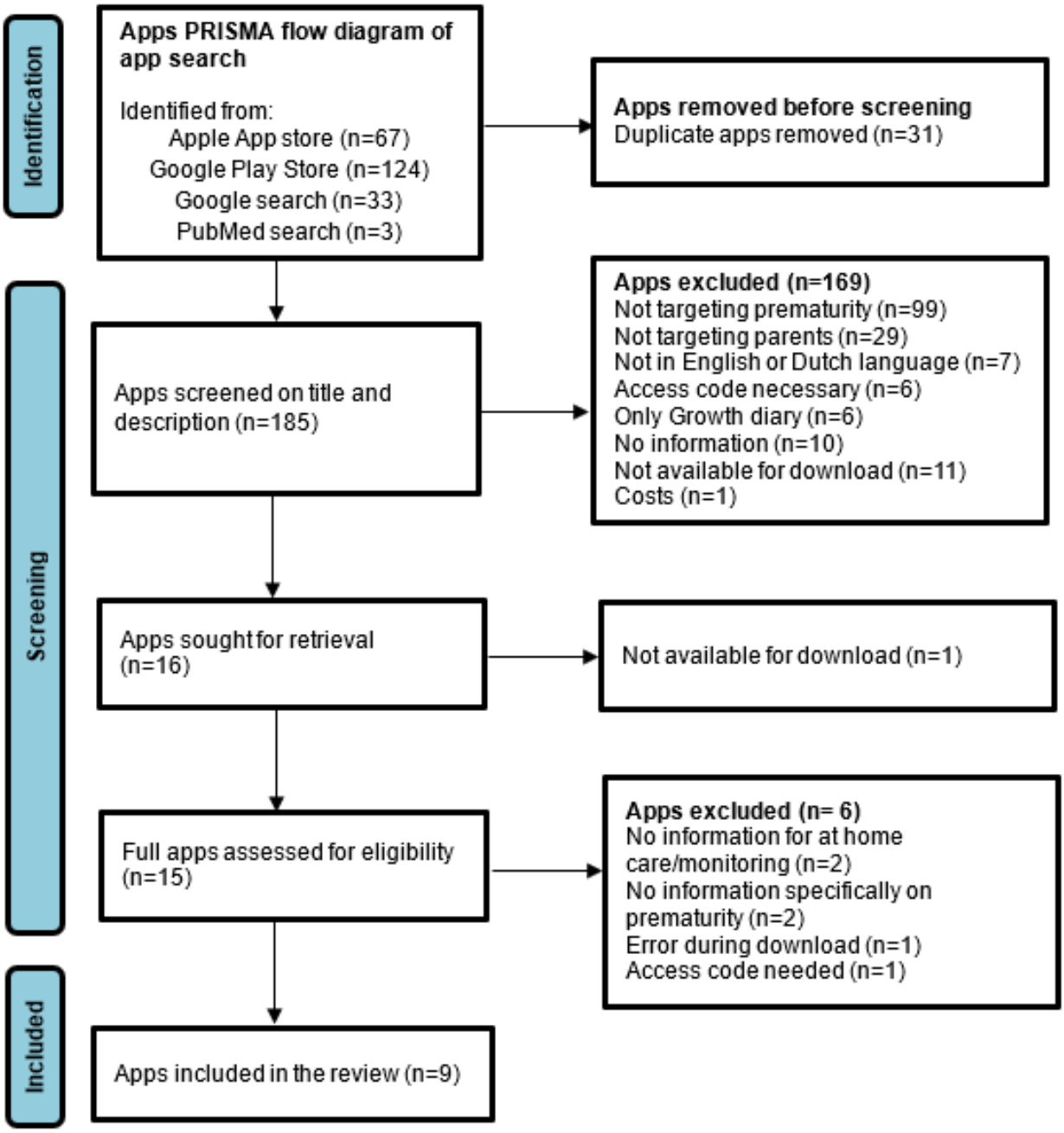
Results

Search Results

The search yielded 191 apps in the Apple and Google Play stores, and additionally 36 apps in Google and PubMed. After removing duplicates, 185 apps remained (Figure 1). Based on the title and description in the app stores, 169 apps were excluded. The majority of the excluded apps did not contain information on preterm-born infants (n=99; 58%), did not target parents but health care professionals (n=29; 17%), or did not contain information, but for instance only growth diaries (n=6; 4%). Only one app was excluded because it was a paid app. A total of 12 apps (6%) that were identified via Google or PubMed could not be retrieved anymore in the app stores. The remaining 16 apps were downloaded and screened for inclusion in the full app review. One app was not available for downloading. Finally, 9 apps fulfilled the inclusion criteria and were included in the final analysis. The majority of the apps were available in both app stores (n=5), 3 apps were only available in the Apple App Store, and 1 app was only available in the Google Play Store. In addition, 2 apps were also described in a scientific paper. One paper describes the content of the MyPreemie app, based on an earlier book, Preemies: the Essential Guide for Parents of Premature Babies, supplemented with new tools [27]. The co-design approach of the Preterm Connect app has been described across 3 settings with different social, economic, and cultural participants [28]. The preliminary findings show similar parental needs, but different preferences across the study populations.

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Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram of search for apps for parents of preterm infants after hospital discharge.



Characteristics of the Apps

The apps were developed in the United States of America (n=4; A2, A4, A7, and A9), the United Kingdom (n=2; A3 and A5), Australia (n=1; A6) and New Zealand (n=1; A1), and South Africa (n=1; A8; Table 2). All 9 apps were in English; no Dutch apps fulfilled the inclusion criteria. One app (A2) had information in 25 languages, and another app (A4) was also available in Spanish. The apps were developed by reputable sources, including hospitals (n=4; A1, A3, A6, and A7), nongovernmental organizations (n=3; A2, A4, and A5), and universities (n=2; A8 and A9). The last update of the app varied between 3 weeks and 3 years, with the majority of the apps updated more than a year ago. The size of the apps varied between 7.2 and 102.2 MB. In addition, 3 apps were downloaded more than 1000 times (A1, A2, and A4) and received positive ratings ranging from 4.0 to 4.9 on a scale from 0-5.

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Table 2. General characteristics of the apps for parents of preterm infants after hospital discharge.

ID	Name	Operating system	Country	Version	Last update	Target population	Developer	Affiliation	Brief description	Languages	Size (Mb)	Rating	Downloads
A1	Babble NZ Neonatal Family App	Apple iOS; Android	New Zealand	2.7.1	2021	Parent with a baby in the NICU[a].	Neonatal unit at Midcentral Health	Hospital	A reliable source of information about the NICU.	English	7.2	4.9 (n=10)[b]; N/A[c,e]	1000+
A2	Birth & Beyond	Apple iOS; Android	The United States	1.16	2022	Mothers of newborn babies.	Global Health Media Project	NGO[d]	48 videos in 30 languages.	25 languages	10.7	4.8 (n=26)[b]; N/A[e]	10,000+
A3	Family Delivered Neonatal Care (IFDC)	Apple iOS	The United Kingdom	1.1.11	2023	Parents in the NICU.	Imperial College healthcare NHS trust	Hospital	The app offers up-to-date and comprehensive educational material, a developmental timeline, and diary functions to document the neonatal journey.	English	29.2	N/A[e]	N/A
A4	MyPreemie app	Apple iOS; Android	The United States	2.3.1	2020	Families of premature babies.	Graham's Foundation	NGO	Toolkit for the practical and emotional needs of families of premature babies.	English; Spanish	35.4	4.0 (n=182)[b]; 5 (n=1)[e]	10,000+
A5	My Prem Baby	Apple iOS	The United Kingdom	1.8.1	2023	Parents of a premature baby.	Tommy's	NGO	Track and monitor the journey with your premature baby.	English	50.9	N/A[e]	N/A
A6	Neonatal Care and Me	Apple iOS; Android	Australia	N/A	2021	Parents of a baby in the NICU, the special care nursery of pediatrics.	South Western Sydney Local Health District	Hospital	Tools while the baby is in the hospital and beyond, and while being guided by a health professional.	English	102.2	N/A[b]; N/A[e]	N/A
A7	Our Journey in the NICU	Apple iOS	The United States	2.1	2020	Families of children in the NICU.	Phoenix Children's Hospital	Hospital	Identify what families need to know before taking their child home from the hospital.	English	8.2	N/A[e]	N/A

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ID	Name	Operating system	Country	Version	Last update	Target population	Developer	Affiliation	Brief description	Languages	Size (Mb)	Rating	Downloads
A8	Preemie Mom Care	Android	South Africa	2.0.5	2020	Mothers of hospitalized premature infants.	UCT Human Computer Interaction lab	University	Provides supportive information to mothers of hospitalized premature infants as they partake in the care of their infant.	English; Afrikaans; Xhosa	24.8	N/A[b]	500+
A9	Preterm-Connect	Apple iOS; Android	The United States	1.8.5	2023	Parents of a preterm baby.	Chih H Wang	University	Connect with other women through forms for preterm birth. Articles and videos about caring for a preterm baby and yourself.	English	63.5	N/A[b]; N/A[e]	50+

[a]NICU: neonatal intensive care unit.

[b]Rating in Google Play.

[c]N/A: not available.

[d]NGO: nongovernmental organization.

[e]Rating in Apple App Store (range 0-5).

App Content

Most of the information in all apps was directed to the period in the NICU. The quantity of information for the posthospital discharge period was limited. Some apps have one “chapter” that covers the postdischarge period (A5, “at home with baby;” A9, “Parenting at home”), whereas other apps have subthemes within a chapter (A4, “Preemie Parenting” and “going home”). Topics that were addressed varied widely between the apps (Table 3). The most common topics that were covered in the apps related to the period post discharge were: vaccinations, follow-up, and recognizing signs of illness. More practical information was provided on feeding, using home oxygen, and sleep (Table 3). Less often, the apps provided information on aspects that were reported as relevant by parents [5,8] as diaper change (A5 and A9), crying (A1, A7, and A9), or parental well-being (A4, A5, and A9).

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Table 3. Most common postdischarge topics and functionalities of the apps.

App content	Number of apps	App IDs
Common topics post discharge		
Feeding	7	A2, A3, A4, A5, A6, A8, and A9
Vaccinations	6	A1, A2, A3, A4, A5, and A9
Follow-up	6	A1, A3, A4, A5, A8, and A9
Signs of illness in a baby	5	A1, A2, A7, A8, and A9
Sleep	5	A1, A3, A5, A7, and A9
Home oxygen	4	A3, A4, A5, and A7
Bathing	4	A5, A6, A7, and A9
Functionalities		
Monitoring or tracking (diary, growth, and weight)	3	A4, A5, and A6
Making notes or saving questions	3	A4, A5, and A7
Sharing information	3	A2, A4, and A5
Saving articles	3	A1, A2, and A9
Community groups	1	A9

Besides information provision, the apps also included other functionalities, including monitoring and tracking of infants' weight and height, amount and duration of feeding, or parental mood (A4, A5, A6, and A7; Table 3). The option of making notes was also provided by 4 apps (A3, A4, A7, and A9). Sharing information from the app with others was available in 3 apps (A2, A4, and A5). Community groups were only incorporated in a single app (A9).

Quality of the Apps (MARS)

The interrater reliability of the MARS of the two raters was high (ICC=0.99, CI 0.98-0.99). The overall mean quality (range 0-5) of the 9 apps was 3.4 (SD 0.5; range 2.3-4.3; Table 4). The majority of the apps (n=7) scored between acceptable to good, one app (A7) scored below acceptable, and only one app (A4) scored above good. There was a difference in the ratings between the 4 objective MARS scales. Engagement was rated as poor to acceptable (mean 2.8, SD 0.6; range 1.8-3.4), specifically due to low scores on entertainment, customization, and interactivity. The aesthetics domain was acceptable (mean 3.2, SD 1.0; range 1.7-5). Information quality and functionality were close to good (mean 3.8, SD 0.6; range 2.3-4.3), and (mean 3.9, SD 0.5; range 3.3-4.8), respectively. Several apps received a good score (>4) for information quality (A2, A4, A5, A6, and A9), functionality (A2, A3, A4, and A8), aesthetics (A4 and A6), and overall mean quality (A4). None of the apps received a good score for engagement. The subjective quality (total range 0-18) ranged from 8 to 16, with a mean of 12.6 (SD 3.0). A total of 7 apps (A1, A2, A3, A4, A5, A6, and A9) received a good score for subjective quality.

Understandability and Actionability of the Apps (PEMAT-AV)

The interrater reliability of the PEMAT-AV between the two raters was high (understandability ICC=0.89, 95% CI 0.55-0.98; actionability ICC=0.91, 95% CI 0.59-0.98). The mean understandability of the apps was 78% (SD 12%), ranging from 55% to 100% (Table 4). Only a single app (A2) scored the maximum of 100% for understandability. Lower ratings were obtained when lacking a summary of the information or visual cues to draw attention to key points. The mean actionability was 85% (24%; range 33% to 100%). Lower ratings were obtained when not addressing the user directly or not breaking the action down into manageable, explicit steps. A total of 6 apps (A2, A3, A5, A6, A7, and A9) received the maximum score of 100% for actionability.

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Table 4. Quality of the apps and the understandability and actionability of the information material.

ID	Name	MARS[a]						PEMAT A/V[b]	
		A[c]	B[d]	C[e]	D[f]	Mean[g] (SD)	E[h]	U[i]	AC[j]
A1	Babble	3	3.5	3.7	3,8	3.5 (0.3)	14	75	33
A2	Birth & Beyond	2.2	4.8	2	4.2	3.3 (1.2)	10	100	100
A3	IFDC	3.4	4	3.3	3.5	3.6 (0.3)	14	75	100
A4	MyPreemie app	3.2	4.8	5	4.2	4.3 (0.7)	16	82	67
A5	My Prem Baby	3.2	3.8	3	4	3.5 (0.4)	14	55	100
A6	Neonatal Care	3	3.6	4	4.3	3.7 (0.5)	15	83	100
A7	Our Journey in NICU	1.8	3.3	1.7	2.3	2.3 (0.6)	8	75	100
A8	Preemie Mom Care	2.4	4	3.3	3.4	3.3 (0.6)	8	82	67
A9	PretermConnect	3.4	3.5	3	4.2	3.5 (0.4)	14	75	100
	Mean (SD)	2.8 (0.6)	3.9 (0.5)	3.2 (1.0)	3.8 (0.6)	3.4 (0.5)	12.6 (3.0)	78 (12)	85 (24)

[a]MARS: Mobile App Rating Scale.

[b]PEMAT-A/V: Patient Education Materials Assessment Tool for Audiovisual Materials evaluation.

[c]Engagement.

[d]Functionality.

[e]Aesthetics.

[f]Information quality.

[g]Overall mean quality.

[h]Subjective quality.

[i]Understandability.

[j]AC: actionability.

Discussion

Principal Findings

This app review provides insight into the availability, content, quality of the apps, and the understandability and actionability of the information material for parents of preterm infants after hospital discharge. A total of 9 apps were identified that provided information after hospital discharge, but the amount of information on the postdischarge period was limited in all apps. Only one app was of overall good quality, while the mean overall quality was between acceptable and good. The understandability and actionability of the apps were respectively moderate and good.

Although our inclusion criteria focused on the postdischarge period, the apps in this review contained primarily information for the NICU period. The lack of high-quality and understandable apps found in this review is in contrast with the needs of parents of VPT infants after hospital discharge. Parents of VPT infants have reported challenges when they are at home regarding the availability and usability of information [8]. For parents who struggle to seek information, finding an app with appropriate and reliable content will be even more difficult, particularly for those with low health literacy skills [29]. Health care professionals, such as nurses, pediatricians, or pediatric physical therapists, have a responsibility to support parents in their search for relevant and reliable information during their hospital stay. As parental competence was found to decrease after discharge home, it is an important strategy to improve parental confidence in taking care of their VPT infant [30]. When parents and infants are at home, without direct access to a health care professional, apps have the potential to provide health information to parents and can be accessed when and where needed.

Mobile apps can, however, not replace in-person care. Effective use of apps requires guidance from health care providers, as combining digital tools with professional support has been shown to enhance parental confidence [31]. This is even more important for parents with limited health literacy or digital literacy, who are at higher risk of misunderstanding or misapplying information [18,19]. Our findings confirmed that the understandability of many apps is limited, largely due to complex medical terminology and text-heavy formats. This can particularly exclude parents with low health literacy, widening the existing digital divide [32]. Improving understandability, for example, through audio, video, simplified language, and multilingual options, along with professional support, is essential to make apps usable and effective for all parents.

Apps that cover both the period in hospital and after discharge can be beneficial to parents by providing relevant information throughout the different phases. In a previous review of 18 apps in the NICU context [15], only 5 were included in our review, indicating that most NICU apps do not cover topics post-discharge. There was variability in the amount of postdischarge information, the topics, the emphasis within the topics, and how the information was presented. Unfortunately,

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the topics do not seem to correspond with the information needs of parents upon discharge [5,8], such as daily infant care, neuromotor development, as well as the impact of prematurity on parents. Instead, most topics are focused on vaccinations, follow-up, and using home oxygen.

Despite the use of Dutch search terms, no Dutch apps were retrieved in the App stores that fulfilled the inclusion and exclusion criteria. The Dutch apps that were found in the Google search were no longer available in the Google Play Store or Apple Store. The majority of the apps evaluated in this review were last updated over one year ago. This lack of updates is in line with a scoping review about problems and barriers related to the use and implementation of apps [33] and, consequently, impedes usability and user experience, which ultimately affects the effectiveness of applications. Apps without active maintenance quickly become outdated due to evolving technology, guidelines, and operating systems [34]. This underscores the necessity of a viable business model and continuous refinement and maintenance after initial development [35]. Sustainable funding for apps is essential, but there are currently few resources available. Partnerships between industry and research may offer a possible solution for some apps.

Only one app had good overall quality, whereas the mean overall quality of the apps was merely acceptable. This is in agreement with an earlier app review, where the mean overall quality was also acceptable [15]. Specifically, aspects within the domains of engagement and aesthetics could be improved. The apps scored particularly low on the engagement domain of the MARS, lower than acceptable. This subscale assesses whether the app is fun, interesting, customizable, interactive, and well-targeted to the audience. Lack of engagement is a common barrier related to the use of mHealth apps and is associated with low adherence [33]. Different functionalities can facilitate parental engagement with an app. A low rating on the Engagement domain suggests improvements are needed. Increasing engagement through entertainment appears not suitable for an app that provides information related to prematurity. However, the app could be customizable or interactive, and should certainly be well-targeted to the audience. If not, this latter aspect would certainly hinder the use of the app. A positive finding from our review was that the domain “information quality” of the apps was close to good. Reliable information is important as it may decrease parental stress and support better caregiving behavior [12]. This also matches the parental needs for reliable information and is probably a result of the reputable sources (hospitals and universities) that developed the apps. This is in contrast with two previous studies in which only 31% and 40% of the websites provided accurate and reliable information for parents of premature babies [6,11].

The understandability of the apps was scored as moderate, largely due to the primarily text-based information, indirect communication with users, and frequent use of medical terminology. In contrast, the app Birth and Beyond (Global Health Media Project) circumvented this problem by using only videos, in multiple languages. During stressful periods, such as hospital discharge, information should be presented in a clear and accessible manner, particularly for parents with low health literacy. For these individuals, the digital divide can be further exacerbated when the information is difficult to comprehend. The hospitals, universities, and nongovernmental organizations create apps with reliable information, but it may not be easily understood by all users. To meet the informational needs of all parents, apps need to be more understandable. Co-design that incorporates both health care professionals’ and parents’ perspectives can enhance app understandability by identifying the preferences and needs of the target group [34]. Reducing text, written at accessible reading age levels, using multiple languages, and incorporating audio and visual formats may improve understandability.

Only 2 papers were retrieved that described the development of an app [27,28], indicating a general lack of transparency about co-creation. None of the 9 apps have been assessed for their impact on parental outcomes. A study on the NICU2HOME app (CF Garfield) [31,36] showed that parental self-efficacy and satisfaction with care improved in parents of preterm infants. This mobile app has not been included in this review, as an access code was required. More research is needed to evaluate the use of apps, parental satisfaction, and the effects of app use on parental outcomes.

Limitations

First, only English and Dutch apps, free and without an access code, were included in the search, thereby possibly missing potential relevant apps. Second, other online resources that provide information to parents, such as websites, were also excluded. Also, progressive web applications were not captured in our search, as these are not available in the searched app stores. Third, the search for apps is time-dependent. Some apps are only available for a short time in the app stores, and replication of the search is therefore difficult. This became clear when apps identified through Google or PubMed were not available in the app stores. During the initial screening of app descriptions and features, followed by a secondary screening for inclusion, app content has been checked to decide whether it also contained information related to the postdischarge period. Fourth, it may be possible that apps have been excluded during the initial screening because the description did not refer to information related to the postdischarge period. However, this information was then likely not substantial and would also not appeal to parents. Fifth, the assessment of the quality of the apps and the understandability and actionability of the information material has been done by the MARS and PEMAT A/V. These are validated tools used by professionals. The researchers were familiar with the parental needs for information [8] and did consider the parental perspective during the evaluation of the apps. However, direct information from parents of a preterm infant has not been taken into account. As parents are the key users, their experiences are most valuable, and their engagement is important to ensure the content meets their needs. A next step would be to include parents to evaluate their experiences with good-quality apps. Finally, although it was evident that information on the postdischarge period was limited, we did not quantify the amount of information provided in the apps. Topics on postdischarge information were identified using a checklist and compared to previously recognized parental needs for information. While the lack of information on the posthospital discharge period was apparent, no specific

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measurement was conducted to assess the extent of information for the hospital or home environment. Furthermore, an assessment of the relevance of the topics was also lacking. Future work may establish new methods to incorporate these aspects.

Recommendations

During the post hospital-discharge period, parents of preterm infants need evidence-based, reliable, and practical information. Mobile apps have the potential to offer this information in an accessible way. Currently, few good quality apps exist that contain reliable and understandable information, as the My Preemie app or Preterm Connect. However, more relevant information that matches the needs of parents of VPT infants after hospital discharge is necessary. Future development of digital support tools should also consider solutions that bridge the gap between in-hospital and at-home care by extending access to apps currently limited to the NICU setting. Co-design with parents has been shown to improve the relevance and understandability of health apps [37]. We not only recommend that future apps should be developed or adapted in co-creation with end users, but also that the development process is clearly reported. Research into the use and satisfaction of the parents should establish what information is key for parents, as well as how to deliver this information. In addition, the accessibility and understandability of an app need to be evaluated among parents with a preterm-born infant. The next step would be to evaluate the effect of the information app on parental outcomes as parenting skills, knowledge, and confidence.

Conclusion

The current availability of mobile information apps for parents of preterm infants targeting the period after hospital discharge is limited and not in line with the high parental demand. A total of 9 English apps were identified containing information on the postdischarge period. However, the apps contained limited content for the period at home. The overall quality of the apps was just acceptable, but the information quality was close to good. The understandability of the apps was moderate. Developing apps in co-creation with the end-users to better match their needs and increase the understandability is recommended.

Acknowledgments

No generative artificial intelligence tools have been used in any portion of the manuscript.

Data Availability

The datasets generated and analyzed during this study (ie, the MARS and PEMAT scores from two independent reviewers) are available in the Figshare repository [38]. The mobile apps assessed in this review are publicly accessible via the Apple App Store and Google Play Store.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA 2020 checklist.
[PDF File (Adobe PDF File), 69 KB - pediatrics_v9i1e67085_app1.pdf]

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Abbreviations

ICC: intraclass correlation coefficient
MARS: Mobile App Rating Scale
MeSH: Medical Subject Headings
mHealth: mobile health
NICU: neonatal intensive care unit
PEMAT-AV: Patient Education Materials Assessment Tool for Audiovisual Materials
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PT: preterm
VPT: very preterm

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Impact of a Real-Time Virtual Rounding Queue on Neonatal Intensive Care Unit Rounding Practices: Survey Study of Clinicians' Perceptions

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Abstract

Background: While family-centered rounds are considered the standard of care, coordinating the presence of all stakeholders without knowing when the medical team will arrive can make their implementation challenging. To address this barrier, we created novel software, Q-rounds, that is integrated into the electronic health record and creates a real-time rounding queue that updates nurses and family members on medical team rounding time and allows families to join in person or remotely via phone. A previous observational study showed that the implementation of Q-rounds in a neonatal intensive care unit (NICU) led to increased nurse and family presence.

Objective: This study aimed to understand clinicians' perceptions of the use of Q-rounds on NICU rounding practices, such as the impact on rounding efficiency and clinician satisfaction, as well as facilitators and barriers in its implementation.

Methods: Q-rounds was implemented in the NICU at M Health Fairview Masonic Children's Hospital in May 2023. In this survey study, surveys were distributed to physicians, advanced practice providers, and nurses 6 weeks before implementation and 6 weeks afterward to collect data on the impact of Q-rounds on family-centered rounds. Data were analyzed both quantitatively and qualitatively.

Results: There were 118 respondents in the preimplementation phase and 110 in the postimplementation phase. After implementation of Q-rounds, clinicians perceived an increase in nurse presence ("most" or "almost all of the time" n/N= 48/105, 46% to n/N=24/36, 75%; *P*<.001) and family presence (at least "sometimes" n/N=45/106, 46% to n/N=35/36, 97%; *P*<.001) on rounds. Respondents perceived rounds as more efficient (n/N=56/105, 53% to n/N=27/36, 75%; *P*=.006), and more respondents indicated being satisfied with rounds (n/N=59/105, 46% to n/N=62/84, 74%; *P*=.003). There was no perceived difference in rounding duration. These findings were supported by thematic analysis of open-ended responses.

Conclusions: A novel virtual rounding queue software that notifies families and nurses of when to expect the rounding team was associated with increased clinician perceptions of efficiency, participation in rounds by nurses and families, and satisfaction with rounds.

(JMIR Pediatr Parent 2026;9:e78547) doi:10.2196/78547

KEYWORDS

electronic health records; neonatal intensive care unit; standard of care; surveys and questionnaires; software

Introduction

Study Background

The practice of multidisciplinary family-centered rounds (FCRs) is considered standard practice by the American Academy of Pediatrics [1,2]. FCR entails the care team, including physicians, trainees, bedside nurses, and other staff (eg, dieticians, respiratory therapists, and interpreters where needed), along with the family or caregivers, working together to set the daily plan of care. Ample evidence supports the benefits of FCR, with

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previous studies showing improvements in health care team communication [1,3-6], increased participation and decision-making of patients and families [7,8], increased family confidence in the health care team [7], improved patient safety [1,5], improved perception of teaching [5], and improved rounding efficiency [1]. Furthermore, FCR in the pediatric setting has been found to increase "humanistic outcomes" in trainees, including empathy, partnership, and respect [6].

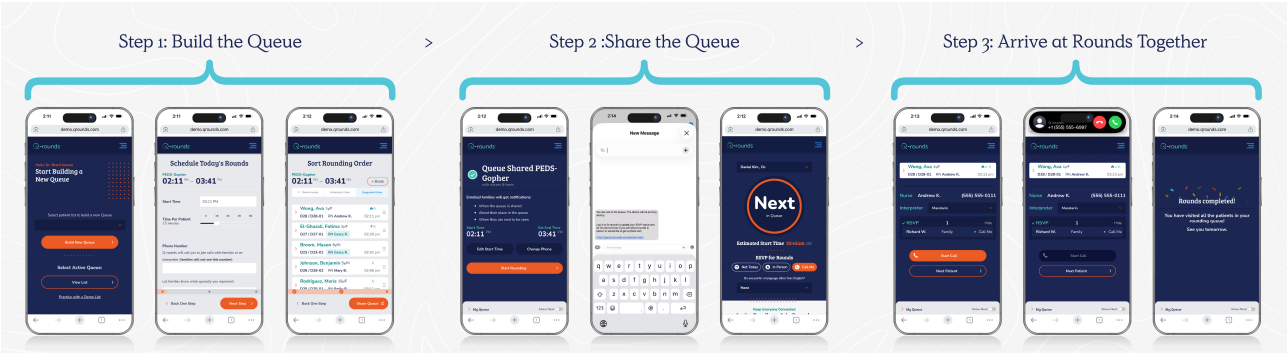
Despite these known benefits to FCR, there are many barriers to implementation. Practically speaking, no matter how impactful FCR is, the improved outcomes can only be realized if the nurse and family are able to be present for rounds. In a scoping review on FCR's implementation, the study by Knighton and Bass [2] reports that the "scheduling challenges for nurses, families, and others that want to attend rounds but may not have the flexibility needed because of important competing demands" is a significant barrier to implementation. Without knowing when to expect the team to arrive for a given patient, nurses are unable to plan for attendance or may be asked to drop what they are doing to join. Families often must choose between work or other obligations or sitting at the bedside for hours waiting their turn for rounds [9]. Additional barriers exist for families who communicate in languages other than English [2], which often has its own scheduling and logistics challenges [2,9]. Additionally, some medical teams are hesitant to implement FCR because of concerns regarding FCR taking more time than traditional rounds and potentially negatively affecting trainee teaching.

Other institutions have implemented static interventions to address scheduling barriers to FCR with some success, although they have their limitations. For instance, the study by Bekmezian et al [3] described implementing a rounding coordinator to complete the schedule and communication regarding rounding appointments and reported that this approach increased nurse attendance on rounds and resulted in positive feedback from patients and families. Other groups have implemented a rounding checklist to increase family participation [10] or have found providing a fixed rounding schedule before rounds began to be beneficial for increasing nurse and family presence [11,12]. Only 1 study addressed interpreter attendance [3], while many studies do not include patients or families who speak a language other than English. While it is promising that the barriers to FCR could be overcome, many of these strategies are prohibitively labor-intensive. Additionally, the use of a fixed rounding schedule also does not address the unpredictability of rounds, with often changing schedules as acute medical issues come up that need to be addressed.

Preliminary Studies

This software was first implemented in our medical center's neonatal intensive care unit (NICU). In an observational study comparing preimplementation and postimplementation of Q-rounds software (Figure 1), nurse and family attendance significantly increased without affecting the duration of rounds, with parent attendance increasing by over 100% [13]. However, this previous observational study did not address feedback from important members of the medical team, such as nurses, and the impact of the software on their experience with FCR. As the software was implemented, outcomes (eg, attendance of rounds by the key personnel, round planning, and efficiency) were incorporated in the deployment of the tool to capture the intervention's impact and sustainability [14].

Figure 1. Overview of the workflow of the Q-rounds software.



The physician or advanced practice provider starts by building a rounding queue based on anticipated clinical needs. They first estimate the rounding time for each patient. Next, the health care professional shares the rounding queue with the electronic health record (EHR) for other team members to view. The program calls nurses and texts the patients' families to provide their patient's spots in the rounding queue. When the rounding time for the patient arrives, the care team members and families are reminded to join. A phone call is automatically started if families reply requesting a phone call.

The purpose of this study was to understand and compare clinicians' (including physicians, nurses, and advanced practice providers) perspectives and experiences (such as the impact on rounding efficiency, clinician satisfaction, trainee teaching, as well as facilitators and barriers in its implementation) about rounding before and after implementing Q-rounds to better facilitate multidisciplinary FCR. We hypothesized that providing real-time notification of care team members and families about the expected rounding times would lead to improved experiences and efficiency, without affecting the availability of teaching time for learners.

Methods

This was a single-center survey study. We used a research design using quantitative analysis of survey results, supported by qualitative analysis of open-ended survey questions.

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Ethical Considerations

This study was reviewed and approved by the University of Minnesota Institutional Review Board (IRB-STUDY 00017619), and the IRB determined that this study involves no greater than minimal risk. Researchers who developed the software (MBP and JS) had conflict of interest policies managed by the University and were not allowed to access raw data.

Settings

The study took place in the M Health Fairview Masonic Children's Hospital 68-bed level IV NICU. Surveys were distributed in two 6-week phases: preimplementation (February 6, 2023-March 20, 2023) and postimplementation (June 14, 2023-July 27, 2023).

Rounds occur each morning and involve the clinical teams (attending, fellow, and resident physicians or advanced practice providers) working from a conference room. In addition to the attending physician and residents or advanced practice providers, the teams typically include a pharmacist, a dietitian, and sometimes a neonatology fellow. Before Q-rounds implementation, 1 team member would find or call the nurse for a patient when they were ready to round, and the nurse would bring the family with them if they were present in the room. This summoning to the conference room rounding approach is used in this setting for privacy, as there are shared patient rooms, preventing discussions at the bedside.

Study Design

We developed a Research Electronic Data Capture (REDCap; Vanderbilt University) survey to elicit perceptions of nurse and family member presence on rounds, rounding length of time and efficiency, clinician communication, and trainee teaching experience, as well as participants' demographics and roles. We had a mix of question styles including closed-ended multiple-choice questions, 5-point Likert-style questions, and open-ended questions. Likert scale questions included anchors of agreement (1 "strongly disagree" to 5 "strongly agree"), satisfaction (1 "very dissatisfied" to 5 "very satisfied"), or temporal assessment (1 "almost never" to 5 "almost always") depending on the prompt. The survey used branching logic to present relevant questions to physicians, advanced practice providers, and nurses, with several common questions being asked from both groups. The number of questions ranged between 15 to 25 depending on the branching logic used. Each question asked the respondent to reflect over the last week when providing an answer. In the postimplementation survey, there were additional open-ended questions asking about perceptions of the implementation of the Q-rounds software. We expected that it would take approximately 10 to 15 minutes to complete the survey.

Participants

All nurses, advanced practice providers, attending physicians, and trainee physicians (resident and fellow physicians) who work in the NICU were eligible to participate in the study. Participation was voluntary and anonymous, with no link to their email or other identifying information. In the instructions for the survey, people were instructed to take it only once, that is, 1 survey per 2-week period *within each phase* of the study.

Intervention or Exposure

The intervention being evaluated in this study was the implementation of the Q-rounds software described in detail in the background section above. When a patient was admitted to the NICU, the nurse asked the family if they wished to receive SMS text message updates about when to expect the medical team for rounds. If they indicated yes, the nurse would indicate so in a flowsheet in the EHR, which would enroll the family in Q-rounds and they would subsequently receive notifications about rounding time and the ability to RSVP to join in person or remotely. Regardless of whether or not the family opted in to enroll, nurses would still receive notifications of rounding time. The electronic survey was created using REDCap tools hosted at the University of Minnesota [15,16].

Data Collection

The surveys were sent to 180 potential participants on a rolling basis via email. For the trainee physicians, attending physicians, and advanced practice providers, they received 1 email if they had been on service in the prior 2 weeks, and 1 reminder email. For the nurses, the complexity and inconsistency of their schedules required sending the survey to the listserv of all nurses who work in the NICU and limiting responses via branching logic in the survey to only those who had worked in the study period. All nurses received 1 email each week during the study. All participants were asked to complete 1 survey per 2-week period in each study phase. All data were securely stored within Box [17] and REDCap [15,16].

Data Analysis

Quantitative Analysis

Descriptive statistics (counts and percentages) were used to summarize survey questions for the preimplementation and postimplementation periods. Wilcoxon rank sum tests were used to compare the question responses between the periods. *P* values <.05 were considered statistically significant. SAS (version 9.4; SAS Institute) was used for the analysis.

Qualitative Analysis

The open-ended survey responses were analyzed using the rapid template analysis approach [18,19]. Template analysis is a structured approach in which researchers identify major domains covered in a data collection and provide summaries of participant responses for each domain. They then place each summary in a matrix to identify recurring themes under each domain. Coding was done by 2 coauthors (RFR and ESJ). The whole process was iterative until coders came to an agreement. We analyzed 59 and 60 open-ended survey responses, respectively, to each question, "What was most useful about using Q-rounds?" and "What would you suggest changing about Q-rounds to make it more useful?"

Results

Q-rounds was successfully implemented during the crossover period of the study to notify nurses and families of when they were expected for rounds and to allow families to join remotely. The software was used for rounds daily during the intervention period.

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A summary of survey respondents by role is provided in Table 1. There were 118 respondents in the preimplementation phase and 110 in the postimplementation phase. Nurses comprised most respondents in both phases: (n=66, 55.9% preimplementation and n=71, 64.5% postimplementation).

Table . Summary of clinical role by survey period.

	Preimplementation (n=118), n (%)	Postimplementation (n=110), n (%)
Attending physician	15 (12.7)	6 (5.5)
Advanced practice provider	24 (20.3)	24 (21.8)
Resident physician	9 (7.6)	5 (4.5)
Fellow physician	4 (3.4)	2 (1.8)
Nurse	66 (55.9)	71 (64.5)
Other	0 (0)	2 (1.8)

The analysis of the quantitative survey data is summarized in Table S1 in Multimedia Appendix 1. The additional questions in our survey, although results not discussed here, are included in Table S2 in Multimedia Appendix 1 for review.

The quantitative findings were supported by our qualitative analysis of the open-ended survey results of physicians, advanced practice providers, and nurses. Of the 110 participants of the postimplementation survey, 66 responded to at least one of the 2 open-ended questions that were thematically analyzed.

The most common coded response regarding usefulness of the software was for improved planning for rounds (n=20, 55%), followed by improved efficiency (n=6, 17%), parent attendance (n=6, 17%), and finally, nurse attendance (n=4, 11%). The most common coded response for suggestions for improvement was for improving the notification system (n=11, 37%), adding additional team members to be notified for rounds (n=10, 33%), improving the timing accuracy of the notifications (n=6, 20%), and lastly, improving education for team members and families regarding Q-rounds (n=3, 10%).

Improved Perceived Attendance by Key Personnel

In the postimplementation period, there was an increase in the perception of nurse presence for the entirety of rounds, with the perception of the nurse being present “most” or “all the time” increasing from 48/105 (46%) to 24/36 (75%; *P*<.001). Similarly, there was an increase in the perception of the family being present for rounds, with clinicians indicating that family was present “at least sometimes” increasing from 45/106 (42%) to 36/36 (97%; *P*<.001). There was no significant difference in time spent waiting for nurses to arrive for FCR (*P*=.47) or the ability to provide daily family updates (*P*=.55). There was no difference in the perception of time waiting for nurses.

The above findings were further supported by the following quotes from the clinicians about their perception of significantly improved attendance:

> *More opportunity for me to be part of family updates, whether listening in and showing/stating agreement with the resident, providing coaching for the resident during family update, or being able to direct/deliver the update.* [Attending physician 115]

> *Simply clicking a button to get the next patient’s nurse and family was so much easier than making calls.* [Attending physician 2]

> *Increased availability for RNs and Parents to join rounds; Improved expectations regarding rounds (i.e.: RN can see an estimated time for rounds and knows when to expect rounds to happen).* [Nurse practitioner 38]

> *Facilitating nurse communication/participation in a timely way.* [Attending physician 23]

While there was an increased perceived opportunity for parents to join, survey participants cited the need for increased family education regarding the software and improvement in the timing of notifications for nurses and families:

> *It was difficult to help families navigate how to add additional parent to Q-rounds.* [Attending MD 2]

> *[We need] better education to parents on how it works to encourage more involvement.* [Nurse practitioner 11]

> *[Would like] allowing for updated time calls when they decide to push rounds back or another patient rounds take really low.* [Nurse 88]

> *[Would be useful to have] calls for updates in expected time changes for rounds if more than 10 minutes different than originally anticipated.* [Nurse 57]

A highly suggested improvement was also to add notifications for other team members:

> *Notifying respiratory therapy would also be useful.* [Fellow MD 1]

> *Include other allied health staff.* [Attending MD 45]

Perceived Enhanced Rounding Efficiency and Planning

There was no change in perceived rounding length (*P*=.40), or the time spent discussing each patient (*P*=.54), which was also supported by the previous observational study [14]. Despite these findings, after implementing Q-rounds, there was an increase in clinicians’ perception of rounding efficiency with the percentage of clinicians who agreed with the statement that rounding was efficient, increasing from 56/105 (53%) to 62/84 (75%; *P*=.006). Similarly, more clinicians indicated they were

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satisfied with rounds after implementation of Q-rounds (62/84, 74%) compared to before implementation (59/105, 56%; *P*=.003). Importantly, there was no significant change in satisfaction with trainee teaching time (*P*=.82).

This was supported by a qualitative analysis theme identified highlighting the improved efficiency of the rounding process after the intervention:

> *This decreases the amount of time spent updating families after rounds. It is a huge benefit in regard to workflow and time management.* [Nurse practitioner 71]
>
> *Q-rounds coordinates and calls the nurses and families for us leaving me more time to open charts and notes and prepare. This helps minimize time between patients.* [Nurse practitioner 44]

Furthermore, there was improved perceived ability to have a plan for rounds, including having a rounding order and rough timeline of rounds. Examples of quotes supporting this theme include the following:

> *Knowing a general timeline helped me not be in the thick of a time-consuming treatment/bath/educational moment so I could attend rounds.* [Nurse 86]
>
> *Organization of the rounding structure and personnel, keeping the team on focus.* [Nurse practitioner 36]

Discussion

Principal Findings

This study surveyed clinicians and nurses on their perceptions of rounding practices before and after the implementation of novel rounding software. We found that the respondents had improved perceptions of rounding efficiency and satisfaction with rounding. We also found a perceived improvement in nurse and parent attendance. While there were suggestions for improving the software, they were mainly related to providing education, fine-tuning the notification timing, and including additional team members in the notifications. Both our quantitative analysis and coding of open-ended survey responses supported findings from our previous observational study, which showed that Q-rounds improved nurse and parent attendance [13]. Direct quotes from the clinicians further endorsed the value Q-rounds adds in terms of improving perceived efficiency of rounding practices and overall patient care delivery.

This approach directly addresses barriers to FCRs, such as giving nurses advanced notice of rounding timing and accommodating family schedules, not only by giving advance notice but also by allowing them to join via telephone [8,9]. Our results align with previous studies, showing that schedule-based FCR increases clinician satisfaction [12], and novel nursing contact strategies increase nurse attendance [20]. As with others, we found that families are highly interested in knowing when to expect the medical team for rounds [21], and explicit invitations help to increase caregiver participation [22]. Our intervention is novel, however, in that previous interventions typically focused on approaches at either getting more families or nurses to rounds, but not both [23]. Thus, Q-rounds was broadly regarded as an innovative mechanism for implementing FCR within the NICU, reinforcing prior evidence that FCR enhances the engagement and participation of patients and their families [7]. Our approach is novel in its ability to be seamlessly integrated into the EHR, directly contact parents via technology such as phone app updates, and allow for either in-person or phone family participation. By meeting families where they are, we hope to improve care participation across all socioeconomic backgrounds. We are planning future studies to look more deeply at demographic and social determinants of health factors that may point to this approach, allowing families to participate in FCR who are often unable to attend in the hospital. Future studies will also assess other potential benefits of the increase in multidisciplinary FCR afforded by this approach, including impacts on length of stay and patient satisfaction.

Beyond increasing the presence of key personnel during rounding and making rounds more effective and efficient, the primary goal of FCR is, as the name suggests, to engage families and ensure their presence in the decision-making process. Prior research has demonstrated that when families are more present during rounds and actively involved in shared decision-making, their satisfaction with both the care provided and with the physicians increases [7,8]. Although the referenced study was conducted in an urban midsized city setting, we can see a strong role for virtual or “Q-rounds” in rural environments as well as larger, high-stress, fast-paced cities with commuting delays. Especially in rural settings, various sociodemographic factors such as competing family responsibilities, time limitations, and transportation challenges can make in-person participation difficult. Virtual rounds allow patients and families to engage remotely, ensuring they remain involved in care despite these constraints. Additionally, virtual rounds are valuable in situations where exposure to patients must be minimized, for example, during pandemics, outbreaks of contagious conditions, or when caring for immunocompromised patients. Using a virtual rounding platform reduces infection risk while still maintaining a family-centered approach, regardless of whether the family can be physically present at the bedside.

In a follow-up observational study conducted 2 years after initial implementation, we evaluated whether the early benefits associated with the virtual rounding queue software were sustained over time [24]. We also examined its performance across 2 distinct rounding models: table rounds and walking rounds [24]. When comparing family attendance across the 2 rounding cohorts, overall family presence was similar; however, the walk rounding cohort showed a significantly higher rate of in-person attendance and a greater proportion of nurses present for the entirety of rounds [24]. Rounding duration did not significantly change across any of the table rounding cohorts over time, helping address persistent concerns that FCR reduces efficiency [24]. An important consideration for broader implementation is the feasibility of updating the virtual queue during walk rounds, where the team is physically moving from 1 bedside to the next. Centers that rely heavily on walk-around workflows may require modest adaptations, such as designating a specific team member to update the queue, using hands-free or voice-activated features, or some shortcut functionalities.

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There are limitations to this study. This was an initial implementation, limited to rounding teams of the same unit in a single medical center. Future studies will aim to expand to additional units, teams, and medical centers to more fully understand the effect of Q-rounds. While our results found no significant difference in satisfaction regarding time to teach trainees, findings are constrained by the low number of resident physicians who completed the surveys. Further studies focusing on trainees, including medical students, residents, and fellows, are needed to better understand their educational benefits from Q-rounds. Our study did not incorporate family feedback, which will be obtained in a future study. The fact that we were unable to individually target nurses to participate and had to use a large listserv of the entire NICU staff, including those who only work night shifts, prohibited us from being able to calculate a true response rate. We also had a lower response rate (66/110, 60%) for clinicians who answered the open-ended qualitative questions as compared to the quantitative survey questions, which may have limited our thematic analysis. It is worth noting that the clinicians asked to continue to use this approach for rounding in the NICU after the study was complete, and it has since become the standard for rounding across all 4 teams in the 68-bed NICU as well as other units in the same hospital.

At the time of this study, Q-rounds was an internally developed, grant-supported research tool implemented within a single health system, and there were no direct institutional costs associated with its use. Since completion of this pilot, the technology has undergone commercialization and is now available for use at other institutions. Generalizability may therefore be influenced by local resource considerations. For example, at the time of this study, Q-rounds was only able to integrate with Epic's EHR. Institutions seeking to replicate this approach would need to either develop a comparable internal tool or adopt an existing solution, both of which carry financial and operational implications.

Conclusions

Q-rounds provides an innovative approach that addresses multiple previously identified hurdles to FCR, including real-time updated scheduling and the ability to work with families' schedules by creating an option that allows families to confirm attendance by phone or in person. Clinicians perceived having a technical solution that provides real-time updates to nurses and families about the timing of rounds, with the ability for families to join remotely or in person, as an effective way to facilitate multidisciplinary FCR. While previously shown to improve nurses' participation, here we showed that Q-rounds was associated with improved clinician perceptions of efficiency, increased nurse and family participation in rounds, and increased satisfaction with rounds. Future evaluation of Q-rounds integrated into other EHRs and the development of additional features to support multidisciplinary FCR, including virtual family participation by video, enhanced interpreter coordination, and options for families to submit questions in advance of rounds represent potential directions for broader implementation.

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Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request.

Conflicts of Interest

MBP and JS are cofounders with an ownership stake in Q-rounds Inc, which holds an exclusive license to the intellectual property evaluated in this project. This interest has been reviewed and managed by the University of Minnesota in accordance with its conflict of interest policies. MBP and JS were not allowed access to the raw data collected in this study. RFR is an associate editor for *JMIR Medical Informatics*. No other authors have conflicts of interest to report.

Multimedia Appendix 1
Summary of pre- and postsurvey clinician responses and additional survey questions.
[DOCX File, 23 KB - pediatrics_v9i1e78547_app1.docx]

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Abbreviations

EHR: electronic health record
FCR: family-centered round
NICU: neonatal intensive care unit
REDCap: Research Electronic Data Capture

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Assessing Caregiver Comfort With Linking the Health Care System and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC)

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Abstract

This study assessed families' comfort levels with information-sharing between health care providers and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) using a survey-based approach.

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KEYWORDS

WIC; food insecurity; electronic health records; Special Supplemental Nutrition Program for Women, Infants, and Children; data sharing

Introduction

The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) is an evidence-based federal nutrition program that provides nutrition education, breastfeeding support, health care referrals, and access to healthy foods for low-income families [1]. Studies demonstrate that WIC participation is associated with improved birth outcomes, reduced infant mortality, and better overall child nutrition [2]. Given the benefits of WIC and underenrollment among eligible children, there is increasing interest in strengthening partnerships between health care settings and WIC to facilitate family enrollment and engagement [3].

Although health care systems and WIC care for a shared population, they exist in information silos, utilizing different electronic systems. While states allow sharing of specific data between health care settings and WIC, a form must be completed and faxed, creating barriers. Integrating WIC referrals within clinical care may improve WIC uptake, data sharing, and nutrition/health outcomes, but little research has explored family perspectives about information exchange between health care providers and WIC regarding their child's health [4]. Better understanding family perceptions of information exchange could facilitate improvements in the design of effective, family-centered referral pathways. This study aims to assess families' comfort levels with information-sharing between health care providers and WIC using a survey-based approach.

Methods

Study Design and Intervention

This cross-sectional study was part of a mixed methods study that implemented an innovative electronic health record (EHR)–based WIC screening and referral tool [5,6]. Briefly, WIC staff in three counties were granted secure, online, read-only access to the health system's EHR [7], allowing review of medical charts, sending and receiving secure messages with health care teams, and receiving WIC referrals. This intervention was permissible under a memorandum of understanding that allowed data sharing between the health care system and county health departments. Participants gave verbal permission to have their information shared with WIC, which was documented in the EHR.

Data Collection and Analysis

To understand parent/caregiver perceptions of information-sharing, a telephone-based survey was developed based on a review of the literature [8]. The survey was pilot-tested for face validity with resulting minor changes in sentence structure or word choice. The survey had four sections: (1) WIC participation history, (2) WIC benefit usage, (3) communication between health care team and WIC, and (4) self-reported demographics, including race/ethnicity (Hispanic vs non-Hispanic and Asian, Black, White, or Other [specify]) and food insecurity status using the Hunger Vital Sign [9].

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Race/ethnicity were included as variables since WIC participation rates vary by race/ethnicity. Caregivers were eligible to participate if their child was ≤5 years old and attended one of eight participating clinics, received WIC benefits within the past year, underwent WIC EHR screening, and spoke English/Spanish. Eligible participants were purposively sampled via weekly EHR extractions of WIC screening results and were recruited via telephone, consented, and verbally administered the survey by trained research staff (AP, BO-S) in the participant's preferred language. The staff member conducting the survey in Spanish was certified bilingual. Recruitment occurred from March to July 2022. Results were entered into Research Electronic Data Capture. Participants received a US $25 gift card as renumeration.

Results were analyzed using descriptive statistics. Bivariate comparisons between participant groups based upon demographic and other characteristics were made using χ^2 testing or *t* testing (SAS, version 9.4; SAS Institute).

Ethical Considerations

The Wake Forest University School of Medicine Institutional Review Board approved this study (IRB00078127).

Results

Of 100 survey respondents, 93% were mothers. Respondents had a mean age of 29.9 years; 33% were Black, 19% White, and 53% Hispanic; 53% had completed high school (Table 1).

Table . Participant demographics (N=100).

Participant demographics	Values
Caregiver relationship, n (%)	
Mother	93 (93)
Father	4 (4)
Nonrelated caregiver	3 (3)
Caregiver age, mean (SD)	29.9 (6.1)
Caregiver race, n (%)	
White	19 (19)
Black	33 (33)
Other	48 (48)
Caregiver ethnicity, n (%)	
Hispanic	53 (53)
Non-Hispanic	45 (45)
Missing	2 (2)
Child age, mean (SD)	3.5 (0.98)

[a]Other race/ethnicity included: Costa Rican, Hispanic, Mexican, Mayan, multiracial, Puerto Rican, and Salvadorian. These answers were provided via an open-ended text box after "Other" was chosen.

One third (35%) reported food insecurity (FI); 90% reported receiving WIC benefits for ≥1 year (see Multimedia Appendix 1 for full survey results). Overall, 79% were comfortable and 17% were uncomfortable about their child's doctor communicating directly with WIC. Ninety-one percent were very or somewhat comfortable with WIC accessing their child's EHR and 6% were uncomfortable; 95% were very or somewhat comfortable with secure messaging between their child's doctor and WIC. Caregiver race/ethnicity and age were not associated with reported comfort levels (Table 2).

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Table . Bivariate comparison between demographics and comfort levels with different activities involving the Special Supplemental Nutrition Program for Women, Infants, and Children's (WIC's) access to electronic health record (EHR) data.

Demographic	Comfortable with doctor communication with WIC[a]	*P* value	Comfortable with WIC staff having access to child's EHR[a]	*P* value	Comfortable with doctors and WIC using the EHR to send secure messages[a]	*P* value
Caregiver race, %						
White	79.0	.84[b]	89.5	.96[b]	89.5	.21[b]
Black	78.8		90.9		100	
Other	83.3		91.7		93.8	
Caregiver ethnicity, %						
Hispanic (n=53)	84.9	.52[b]	92.5	.81[b]	94.3	.39[b]
Non-Hispanic (n=45)	80.0		91.1		97.8	
Comparing mean (SD) age (years) across comfortable versus uncomfortable caregivers						
Comfortable[a] caregivers	29.7 (6.3)	.57[c]	30.0 (6.1)	.60[c]	29.9 (6.2)	.79[c]
Uncomfortable caregivers	30.6 (5.3)		28.9 (6.6)		30.6 (4.0)	

[a]For the "Doctor Communication" question, "comfortable" designation combines individuals with "comfortable" and "neither comfortable nor uncomfortable" survey responses, and for the EHR questions, the "comfortable" designation combines individuals with "very comfortable" and "somewhat comfortable" survey responses in Multimedia Appendix 1.

[b]For comparing rates of "comfortable" responses across categorical groups (eg, race, ethnicity), *P* values are for χ^2 tests.

[c]To compare the mean ages of caregivers who were comfortable versus not for each task, *t* tests were used.

Discussion

While pediatricians, WIC nutritionists, and caregivers alike have identified data security and confidentiality as potential barriers to implementing integrated care models [4], WIC participants in this study were overwhelmingly comfortable with information sharing and integrated communication between health care providers and WIC. These comfort levels did not significantly vary by caregiver age, race, or ethnicity, signifying broad acceptability across demographic groups. Over one-third of caregivers reported FI, and almost all received WIC benefits for a year or longer.

These findings highlight an opportunity—caregivers were largely open to enhanced communication between health care systems and WIC. A prior study showed the majority of health care providers and WIC staff in favor of an EHR-based referral intervention [5]. Given the high prevalence of FI and the favorable attitudes toward EHR-based information sharing, health care systems may be uniquely positioned to bridge service gaps through continued thoughtful collaboration with community-based nutrition programs like WIC. Increasing the uptake of WIC and enhancing communication between the two systems have public health relevance, such as strengthening prevention/early intervention efforts on FI and obesity and reducing inconsistent messaging [10].

Although the American Academy of Pediatrics and the National WIC Association recommend health care referrals to WIC [11,12], practical and policy barriers prevent uptake of this recommendation. Chief among these policy barriers is that, without specialized legal data sharing agreements, bidirectional data sharing between health care systems and WIC is prevented by the Health Insurance Portability and Accountability Act [13]. Modifying such policies to allow for easier bidirectional data sharing could support direct referrals to/from health care practitioners and WIC, improve care coordination, and increase communication between the two entities, which often share populations but are siloed. To support such policies, more research is needed to determine whether WIC accessing the EHR improves efficiency of care and decreases costs and care duplication.

This study had several limitations. While modest, the sample size was limited by funding. Results are from one institution, which may limit generalizability of findings. Social desirability and selection biases may have influenced participant responses; all surveyed caregivers had consented to information sharing/referral, which may have prejudiced their comfort levels with bidirectional communication. Future studies should explore the impact of such information sharing on FI outcomes, parent/caregiver trust, and health care utilization and outcomes over time.

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Data Availability

Deidentified individual participant data (including data dictionaries) will be made available upon reasonable request from the corresponding author. Data are available on request due to privacy/ethical restrictions.

Authors' Contributions

KAS drafted the initial manuscript and critically reviewed and revised the manuscript for important intellectual content.
BO-S and AP collected data and critically reviewed and revised the manuscript for important intellectual content.
KHL conceptualized and designed the study, designed data collection instruments, carried out the initial analysis, and critically reviewed and revised the manuscript for important intellectual content.
KM conceptualized and designed the study, designed data collection instruments, drafted portions of the initial manuscript, and critically reviewed and revised the manuscript for important intellectual content.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey responses.
[DOCX File, 18 KB - pediatrics_v9i1e89731_app1.docx]

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Abbreviations:

EHR: electronic health record
FI: food insecurity
WIC: Special Supplemental Nutrition Program for Women, Infants, and Children

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Clinician Perspectives on Commonly Used Online Sexual and Reproductive Health Resources for Adolescents: Qualitative Analysis

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Abstract

In this interview study with 24 adolescent-serving clinicians, participants described current online sexual and reproductive health resources they share with adolescents and highlighted areas of improvement to better meet the developmental needs of this age group.

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KEYWORDS

adolescent; sexual and reproductive health; digital literacy; social media; health literacy

Introduction

Adolescents frequently search for and encounter information about sexual and reproductive health (SRH) online [1,2]. While some of this information may be high-quality, patients also access misleading, inaccurate information that can negatively impact health outcomes, with long-term implications [3,4].

Clinicians depend on reliable, accessible online resources to support effective patient education and engagement; however, they may be unfamiliar with peer-recommended websites. The objective of this paper was to identify commonly used online SRH resources, examine expert-identified key considerations for adolescent populations, and assess potential gaps in existing materials to inform the development of improved resources.

Methods

Overview

These findings are part of a broader qualitative study focused on improving clinician-adolescent communication about online information [5]. Self-identified adolescent SRH experts providing clinical care in the United States were recruited through national listserves (Society for Adolescent Health and Medicine, Society of Family Planning) to participate in audio-recorded semistructured interviews over videoconferencing. Clinicians were asked the following questions embedded within a larger interview guide: “Are there any online resources that you provide adolescent patients about SRH? What are resources that you wish you had?”

Transcripts were audited for accuracy, and data were analyzed via the matrix method through rapid qualitative analysis [6] by two team members, with careful review by three additional team members. Participants were provided an opportunity to review and provide feedback on the synthesized findings.

Ethical Considerations

This study was designated exempt by the University of North Carolina at Chapel Hill Institutional Review Board (#24 - 2060). All participants provided informed consent through an electronic survey prior to participation. Data were stored in password-protected files accessible only to the research team. Participants were compensated with a US $50 gift card for their time.

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Results

Participant Characteristics

Overall, 24 clinicians participated in our study, representing all US regions. Most were White (n=18, 75%), cisgender women (n=19, 79%), and physicians (n=20, 83%) who were trained in pediatrics (n=17, 71%) and practiced in academic settings (n=20, 83%; Multimedia Appendix 1).

Common Resources

Clinicians described using 10 online sources for high-quality patient-facing information, with various considerations shared for each (Table 1). Many clinicians described being comfortable using 1 to 2 specific resources, and some discussed finding it challenging to keep up with new options. The most recommended patient-facing websites were Bedsider and the Center for Young Women's/Men's Health from Boston Children's Hospital, although several participants cautioned that Bedsider may be most appropriate for older adolescents and young adults.

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Table . Clinician-recommended sexual and reproductive health (SRH) information sources with considerations for adolescent populations.

Resource name, description, and social media handle (if applicable)	Reasons to recommend the resource	Limitations or specific patient considerations
Amaze: Provides an overview of developmentally appropriate SRH topics through animated videos (@amazeorg)	• Patient-friendly content that may be especially appropriate for younger adolescents • Corresponding parent content • Available in many languages	• May be less relevant for older adolescent populations
Bedsider: An online resource focused on contraception, abortion, relationships, and health sexuality (@bedsider)	• Patient stories • Interactive tools • Consistent social media presence	• May be more focused on sex positivity versus medical management • Parents may find content inappropriate for younger adolescents
Centers for Disease Control and Prevention: Overview of information about contraception and STIs[a], including options like pre-exposure prophylaxis	• Up-to-date materials across SRH topics • Familiar to most clinicians • Standardized recommendations and guidelines	• Some clinicians concerned about current accuracy and availability of SRH information due to administrative changes
Go Ask Alice: Interactive website with question-and-answer format, offered through Columbia University	• Interactive and provides direct answers to specific questions	• Not described beyond concerns related to the responsibility of clinicians to provide accurate information and being concerned about offline complications after following online advice
Individual clinician social media content creators (eg, @drjenniferlincoln, @drjengunter)	• Allows adolescents to access information on the platforms they already use • Informal education and more engaging content formats • May be targeted to specific demographic or cultural groups	• Hard for clinicians to verify content and may not feel comfortable recommending content that they have not seen • May prefer recommending institutional or organizational social media content
Individual institutional resources: Format varies by institution (eg, websites, brochures/pamphlets, social media accounts)	• May be perceived as more trustworthy depending on patient/family relationship with the institution • Can offer local service recommendations	• May be redundant if other institutions are providing similar resources • More upkeep • Institutional social media often more focused on parents
Planned Parenthood: Provides local clinical services and online educational content (@plannedparenthood)	• Site covers a variety of sexual and reproductive health topics (eg, contraception, STIs) • Can provide local recommendations for how to access care	• Political baggage and may be concerning to parents (ie, assumed connection to abortion)
Reproductive Health Access Project: Online patient-friendly guides for different forms of contraception and abortion care (@reproductiveaccess)	• Nongendered user guides and fact sheets • Based on patient-centered values (ie, not just efficacy)	• Not described
Scarleteen: Sexual education site focused on queer identities (@scarleteenorg)	• Interactivity • LGBTQ+[b] friendly information • Engagement on social media	• Not described
Young Women's and Young Men's Health: Online health resource pages managed by Boston Children's Hospital (@bch_cywh for Young Women's Health)	• High-quality, comprehensive health information across a variety of topics (including beyond SRH) • Available in Spanish	• Gendered name may make site feel less applicable to gender minority youth • Fewer interactive features (ie, more reading)

[a]STI: sexually transmitted infection.

[b]LGBTQ+: lesbian, gay, bisexual, transgender, queer/questioning, plus (others).

Considerations When Sharing Resources

Clinicians stressed the importance of matching resources to the developmental stage of patients, their general literacy skills, and cultural background (Table 2). A few explained that they did not want to overload patients by sharing too many options. Clinicians also discussed the importance of considering the role of parents when administering resources, describing three common scenarios. First, some described providing joint educational resources for adolescents and parents to review together (eg, if a patient was considering contraception to manage heavy menstrual bleeding). Second, some clinicians

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provided direct parent-facing resources to help support the child's pubertal development and discussion of common SRH topics. Finally, some clinicians described being cautious in situations where parents may be monitoring adolescents' internet use without their child's knowledge (eg, through search histories), prompting potential concerns about certain content recommended to adolescents (eg, political baggage with Planned Parenthood).

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Table . Current and future considerations when recommending sexual and reproductive health (SRH) resources to adolescent patients.

Themes and subthemes	Illustrative quotations
Considerations when recommending online SRH resources	
Developmental stage	• "For things like Bedsider, it was really designed for 21- to 29-year-olds. It's very sex positive, like the Frisky Friday emails and things that are for people who are very comfortable with their sexuality and concepts around sexual health. I think it resonates a lot less with people who are earlier in their journey, or are in cultural communities for which sex positivity isn't the way that this is framed... So I want I want it to be somewhat values-aligned." (Participant 8)
Cultural relevance	• "But there's another [clinician influencer that I recommend] that talks a lot about PCOS and sexual health. And she is actually Muslim. And it's a nice perspective to see that from a Muslim healthcare provider [since I care for] a large Muslim population with my patients." (Participant 15)
Literacy skills and accessibility of information	• "But a lot of my patients don't really like to read, or they don't have good reading skills, or they don't read well in English, and they'd rather watch something. They'd rather listen to something and watch something at the same time, or they prefer to be presented in like a case vignette style of a story or in shorter clips or shorter amounts of information... They can watch, listen, interact, get feedback." (Participant 18) • "We give Bedsider and Young Women's Health to every single person with a uterus that comes in a clinic because they're accessible and have such good information." (Participant 11)
Parental supervision or content directed to parents	• "I hear from patients not uncommonly that they can't look at websites like Planned Parenthood, because if their parents saw a Planned Parenthood in a search engine history or on a web browser, they would freak out because of the historical baggage that comes with the name Planned Parenthood. I don't ever talk about it in [state name]." (Participant 4) • "Amaze, literally at the top, has a whole parent section, and so I think that they acknowledge that parents will be on the website. They expect it, and they're not trying to hide anything. And so that's why I really like that." (Participant 4)
Desired qualities in future online resources	
Adolescent codevelopment and guidance	• "I think that it is important to have adolescents and young adults involved... I think that it's very clear to me that I'm no longer an adolescent, and so like I don't know where the spaces are that this information will be accessed, where [are] the most relevant places people are going and how people are searching. We can hypothesize all we want, but I think that if we really want to create resources and put them in places, the adolescents are on the internet and social media. We need to engage that traffic in those decisions. Maybe I would Google my institution and that's how I would get to the resource, but that might not be how an adolescent is doing it." (Participant 24) • "Yeah, I think something that engaged patients to create it and not healthcare providers. I mean, we could be involved. But we really need patients and young people to explain how to explain this to their peers... So, for example, for the birth control sheets that we came up with like in [state name] we engaged young people, and it turned out talking about menstrual cycles was horrible. They were like, 'What...is a menstrual cycle?' and we were like, 'Oh, it's your period.' And even the word contraception was hard. They were like, 'Can you just say birth control?'" (Participant 4)
Availability in languages other than English	• "I think one of the downfalls of a lot of resources, especially for my patients, is that are that they're not available in languages really other than Spanish and so it doesn't matter if I'm pointing to the best information in the world...[if] they can't access it or read it." (Participant 25)

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Themes and subthemes	Illustrative quotations
Established organizations putting content on social media	• "We have a resource sheet and I remember putting it together and being like, 'Would I really use this in clinic?'... When I stopped to think about it from more of a research perspective, I was like, 'I don't think people are going to use this.' And I didn't want it to just be a thing that nobody used. I think that's what made me think about like, maybe Bedsider is a good example. They have an Instagram page, they have a TikTok handle, so why am I giving them the website when they're not going to go to a website?" (Participant 22)
Knowledge about individual creators making high-quality content	• "I know that there are a number of great OB/Gyns, for example, that do a lot of reproductive health. That can be great. I know a lot of institutions now are trying to have representatives send out information in different contexts with a little bit more scientific rigor ideally... I know there are definitely a ton of other providers out there who are making good evidence-based content. But I think the question is can we take part of that, and then combine it with other sources?" (Participant 3) • "I just started doing a dive...on some of the information available on social media related to abortion. And so I haven't yet incorporated giving Instagram accounts or TikTok accounts to patients, but I'm thinking about that, as we did in a deep dive, and what might be coming up for folks, and so wondering if there's room to say, 'Oh, this is an account I suggest you follow, or something like that, and something to consider.'" (Participant 24) • "If I were more of an active social media user and I knew the content creators out there that I think are like really nailing this like I would definitely recommend specific people." (Participant 8)
Engaging, interactive format versus static, text-based resources	• "People really don't like static resources anymore. And this is subjective, but from doing trainings and hearing from people and then dealing with students, something that's like, 'Here's a website that lays out a bunch of text and tells you about stuff,' I don't think it speaks to people anymore. So I think...videos and interactives, and it's real people, and it's not necessarily like an explanation of something, but it's storytelling, I think, is helpful for people. Interactives where people can enter—like decision aids kinds of things, like 'These are the side effects that would bother me,' people are able to interact with and personalize things. That trend toward personalization is very widespread people want things that are tailored to them." (Participant 13)
Patient/family-facing centralized location	• "I think having a more centralized website available. There's bits and pieces of every website that I can pick from knowing what the complaint is, and I can do that as a physician. But I think for patients and parents to be able to go to is the biggest bang. I don't think those are readily available." (Participant 25)

Improvements for Future Resources

Participants expressed a desire for more resources to be available in languages other than English (Table 2). Some described challenges with information on social media being more engaging and accessible than resources created by health care institutions, making it less likely that patients would visit recommended websites than use social media resources. Accordingly, clinicians often wished for specific social media content to recommend, although a few described concerns about this type of resource recommendation since they did not feel that they were able to vet all information from individual creators. Social media accounts from health care institutions were sometimes seen as a good way to combine these goals, although clinicians often described these as currently being aimed at parents as opposed to adolescents.

In general, participants recommended that future resources be created or revised in partnership with adolescents who can help ensure that the resources are developmentally appropriate and engaging, and use patient-friendly language. They also recommended posting these resources in a centralized location that can be updated regularly by experts, which they described would be especially helpful for general pediatricians who may be less familiar with adolescent SRH, as well as for adolescents and parents.

Discussion

Clinicians recommended a variety of online SRH resources to refer adolescents to outside of the clinical encounter. Resources had pros and cons, with certain sources being more appropriate for different developmental stages. Importantly, this study was

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not exclusively focused on generating a list of online resources—thus, this may not be an exhaustive list of adolescent-focused SRH online resources—nor does it comprehensively cover all factors that may impact individualized resource provision. Other limitations include a relatively small and homogeneous clinician sample and data collection embedded in a larger study, both of which may reduce the diversity of resources discussed.

Future work is needed for adolescent-engaged content development [7], resources available in languages other than English [8], and integration of high-quality medical content into commonly used platforms (eg, social media) to more effectively reach patient populations who often encounter health information on social networking sites [9]. Additionally, while the Society for Adolescent Health and Medicine currently has a website where many of these resources are compiled, it does not include some of the considerations mentioned by participants (eg, parental concerns) that may impact individualized resource provision [10]. Creating an up-to-date, detailed resource database that is easily accessible to patients, families, and clinicians—potentially supplemented by a list of recommended social media accounts to follow—is one way to help bridge this gap.

These findings can be used to improve identification of developmentally relevant and accurate online SRH content—as well as creation of new resources—that can improve adolescent well-being amid a complex digital information environment.

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Data Availability

Anonymized qualitative data from participants relevant to this analysis is available upon request to the corresponding author.

Authors' Contributions

Conceptualization: CS, SR, EP, LF, BAA
Data curation: CS, SR
Formal analysis: CS, SR, LF, BAA
Funding acquisition: CS, LF, BAA
Investigation: CS
Methodology: CS, LF, BAA
Project administration: CS
Validation: CS, SR, EP, LF, BAA
Visualization: CS, SR, EP, LF, BAA
Writing – original draft: CS
Writing – review & editing: CS, SR, EP, LF, BAA
Supervision: LF, BAA

Conflicts of Interest

None declared.

Multimedia Appendix 1
Participant characteristics of 24 adolescent-serving clinicians.
[DOCX File, 21 KB - pediatrics_v9i1e89643_app1.docx]

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Abbreviations

SRH: sexual and reproductive health

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The Role of Japan's "Hello Baby" Home Visit Program: Secondary Analysis of Municipal Evaluation Data

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Abstract

Given growing concern about maternal loneliness in Japan, this secondary analysis of municipal evaluation data suggests that the nationwide Universal Home Visit Program for Families with Infants ("Hello Baby") may serve as an initial point of contact and an entry point for expanding parenting support networks, with most mothers receiving a visit and reporting encouragement to talk with someone afterward.

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KEYWORDS

parenting; loneliness; home visit; social networking; infant; Japan

Introduction

Under Japan's national policy for child health and development, established in February 2021, the proportion of parents who wish to raise their children in their local community is used as a performance indicator. The policy aims to foster communities that collectively nurture and safeguard children's healthy development. Maternal loneliness and isolation are key concerns, and support systems are needed to help mothers build local connections [1,2]. Loneliness scales have been applied to parents raising children [3], and social prescribing has been proposed as a policy response to connect mothers with supportive people and resources in their communities [4]. Universal, early-contact programs that reach almost all families may therefore play an important role.

The home visit program for families with infants, known as the Konnichiwa Akachan (Hello Baby) home visit program, was established under the Child Welfare Act in 2009 and has since been implemented nationwide by municipalities. The program visits households with infants up to 4 months of age to listen to parents' concerns, provide parenting information, assess family needs, and connect families to appropriate services. In Fukushima City, public health nurses and community volunteers each conduct one home visit per infant, and the program is evaluated annually [5]. In this report, we analyze the most recent program evaluation data to examine parents' willingness to share what they learned from Hello Baby home visits with others as a form of proactive networking.

Methods

Study Design

The Hello Baby program evaluation data were obtained from an anonymous survey conducted by Fukushima City in February 2024. The survey targeted households in Fukushima City with children born between April 1 and July 31, 2023. Invitations to participate were mailed to eligible households, and responses were collected through an online system.

Survey Items

The main survey items were whether respondents received a visit from a health care professional (yes/no); whether they received a visit from a community support volunteer (yes/no); the appropriateness of the timing of the visit (too early, too late, or just right); the degree to which they obtained information about the local area (5-point Likert scale); the degree to which the materials provided were useful (5-point Likert scale); whether the visit prompted them to talk with someone about parenting (yes/no); and whom they spoke with (multiple responses permitted). To assess feelings about receiving the visit, respondents were asked to rate their agreement with each of the following 4 statements: "I felt listened to by the visitor," "My anxiety was reduced," "I gained confidence in parenting," and "I would welcome being approached by a community support volunteer in my local area." Likert scale responses ("strongly agree," "agree," "neither agree nor disagree," "disagree," and "strongly disagree") were dichotomized by combining the first two categories as "Agree" and the remaining three categories as "Do not agree."

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Statistical Analysis

We first conducted a descriptive analysis of whether the home visit prompted respondents to talk with someone and with whom as our major outcome proxy indicator of proactive networking. Then, we examined the associations between the main outcome indicator and their feelings about receiving the visit by using the χ^2 test. Statistical analyses were conducted using SPSS (version 28), and a *P* value of <.01 was considered statistically significant.

Ethical Considerations

This study involved a secondary analysis of anonymized data, and it did not fall under the Japanese Ethical Guidelines for Medical Research Involving Human Subjects [6]. Ethical review by Fukushima Medical University was therefore not required.

Results

Of the 449 households eligible for the program, responses were obtained from 173 (response rate: 38.5%). A total of 94.2% of respondents received a visit from a health care professional, and 91.9% received a visit from a community support volunteer. Overall, 69.6% of respondents reported that the visit prompted them to talk with someone (Table 1). The most common conversation partners were their husband (68.2%), their mother (38.2%), and their friend(s) (17.9%).

Reporting that the visit prompted them to talk with someone was significantly associated with perceiving the timing of the visit as appropriate, finding the materials provided to be useful, and obtaining information about the local area. Regarding respondents' feelings about the visit, feeling listened to by the visitor, experiencing reduced parenting anxiety, gaining confidence in parenting, and welcoming being approached by a known community support volunteer in the local area were all significantly associated with talking with someone as a result of the visit (Table 2).

Table . Summary of Hello Baby home visit characteristics (N=173).

	Participants, n	Percentage
Visit from a health care professional		
Received	163	94.2
Not received	10	5.8
Visit from a community support volunteer		
Received	159	91.9
Not received (telephone contact only)	14	8.1
Timing of visit		
Too late	1	0.6
Just right	151	87.3
Too early	18	10.6
Did the visit prompt you to talk with someone?		
Yes	119	69.6
No	52	30.4

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Table . Factors associated with being prompted to talk with someone by the Hello Baby home visit.

	Did the visit prompt you to talk with someone?				
	Yes (N=119)		No (N=52)		*P* value[a]
	Number	Percentage	Number	Percentage	
Timing of the visit					
Too early or too late	9	40.9	13	59.1	.002
Just right	110	73.8	39	26.2	
The materials provided were useful					
Do not agree	7	20.6	27	79.4	<.001
Agree	112	81.8	25	18.2	
I felt listened to by the visitor					
Do not agree	11	42.3	15	57.7	.001
Agree	108	74.5	37	25.5	
I obtained information about the local area					
Do not agree	8	34.8	15	65.2	<.001
Agree	111	75	37	25	
My anxiety was reduced					
Do not agree	17	35.4	31	64.6	<.001
Agree	102	82.9	21	17.1	
I gained confidence in parenting					
Do not agree	23	41.1	33	58.9	<.001
Agree	96	83.5	19	16.5	
I would welcome being approached by a community support volunteer in my local area					
Do not agree	5	23.8	16	76.2	<.001
Agree	114	76	36	24	

[a]The χ^2 test was used.

Discussion

Our findings suggest that Japan's Hello Baby home visit program might serve as an opportunity for parents of infants to engage with others in their community. Similar effects of home visiting have been reported in international reviews [7]. Expanding social networks is a core need for mothers, and it is crucial that they realize they do not have to undertake child-rearing entirely on their own [8]. Beginning to talk with others about parenting can be considered a positive sign of recognizing the existing social network. Maternal loneliness is known to be exacerbated by a lack of social support and to increase parenting stress [9]. Even when parents find it difficult to build relationships on their own, face-to-face contact with visitors can help prevent social isolation by facilitating connections with neighbors and the local community. As home visit programs provide opportunities to identify parents' circumstances, including loneliness [10], and link them with social support, their role is likely to become increasingly important [2].

This study has several limitations. First, because existing program evaluation data were used, detailed participant characteristics could not be assessed, and in-depth analyses were not possible. Second, the analysis relied on single-year survey data from one municipality, with a response rate below 40%, which limits generalizability. Respondents might have been somewhat more engaged with the program than nonrespondents, which could have influenced the overall pattern of responses. Further epidemiological studies in Japan are needed to examine the impact of home visit programs on parents' social connectedness [11].

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Data Availability

The data that support the findings of this study are available from the Fukushima City office upon reasonable request.

Authors' Contributions

Conceptualization: TA, AG
Data and funding acquisition: AG
Data curating: TA
Formal analysis: TA
Methodology: AG
Writing – original draft: TA, AG
Writing – review and editing: TA, AG

Conflicts of Interest

None declared.

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Feasibility and Acceptability of a Digital Indoor Air Quality Monitor Among Children with Asthma

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Abstract

This pilot study examined the feasibility and acceptability of implementing a digital in-home air quality monitor among families with children with asthma (N=20). Interview and survey data indicated that the use of this tool was both feasible and acceptable, while highlighting affordability as an important concern for use in future clinical practice for asthma management.

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KEYWORDS

air quality monitor; pediatric asthma; feasibility; acceptability; implementation; digital monitoring

Introduction

Approximately 6 million US children have asthma, and between school and home, they spend 80%-90% of the day indoors [1]. There is evidence that indoor air exposure significantly affects asthma severity. Studies emphasize that the indoor environment and housing quality are crucial determinants of asthma outcomes, yet self-reported assessments are subject to recall bias and misclassification of exposures [2]. The emergence of digital indoor air quality monitors offers a possible scalable and sustainable approach to indoor air data collection that could aid in tailored recommendations for the home environment [3,4]. However, studies utilizing these monitors are still limited in clinical care, and concerns remain about equitable deployment of these tools [3]. The aims of this study are (1) to assess the feasibility and acceptability of using digital in-home air quality monitors in the homes of children with asthma and (2) evaluate the feasibility of providing a WiFi hotspot to overcome internet connectivity barriers.

Methods

Study Design

This was a pilot feasibility study with 20 participants recruited from a pediatric pulmonary clinic from December 2023 to March 2024. Eligibility criteria included (1) children aged 4-17 years old, (2) the *ICD-10* (*International Classification of Diseases, Tenth Revision*) code for persistent asthma in the past 12 months, (3) sleeping in the same room of the same house for 4 or more nights a week (ie, the child's bedroom), and (4) English-speaking caregivers.

The study intervention included an air quality monitor (uHoo Smart Air Monitor) that was placed in the child's bedroom for 3 months, a pre-paid WiFi hotspot (Simple Mobile Moxee Wi-Fi Hotspot), and a summary review with a pediatric allergist at the end of the study. Relative to commercial grade monitors, the uHoo air quality monitor is marketed directly to consumers and may be a more affordable option for some households (US $300). It uses sensors with auto-calibration algorithms to obtain measurements of 8 air quality parameters: carbon monoxide, carbon dioxide, nitrogen dioxide, ozone, particulate matter 2.5, relative humidity, total volatile organic compounds, and

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temperature [5]. This device was chosen because of its cost and its acceptable stability and calibration, measured in a laboratory [5]. The WiFi hotspot was paired with the air quality monitor for internet connectivity to upload the data to the uHoo web portal. Participants did not have access to the uHoo app or portal that displayed real-time data and were informed at enrollment that aggregated data would only be reviewed at the completion of the study.

Baseline surveys at enrollment inquired about demographics, home environment, asthma control, digital literacy (ranging from 0-12, with higher scores indicating higher literacy) [6], and asthma self-management (ranging from 0-5, with higher scores indicating higher self-efficacy) [7]. Exit surveys, completed 3 months from enrollment, assessed asthma control, feasibility, acceptability, and usability with the System Usability Scale (SUS) [8]. Feasibility was defined a priori as 1 week of continuous data collection by monitors. Acceptability was assessed through the brief exit semistructured interview and survey. SUS scores range from 1-100, with 70 indicating an "acceptable" level of usability. After the exit survey, a semistructured interview was completed by televideo, and before the interview, the pediatric allergist reviewed the summary air quality findings from the monitor, the child's asthma control scores, and home practices to improve air quality.

Descriptive statistics included frequencies, proportions, and median and IQRs for sample characteristics and survey responses. Interviews were audio-recorded and transcribed, and a deductive approach was used for qualitative analysis (coders: LS, KB, OO, KK) regarding feasibility and acceptability. A convergent mixed methods approach was used to connect interview responses with the survey data.

Ethical Considerations

The Ann & Robert H. Lurie Children's Hospital of Chicago Institutional Review Board (IRB 2023 - 6409) approved this study. The institutional review board determined that this study involves no greater than minimal risk.

Results

The study sample was mostly composed of mothers (n=17, 85%), those living in an apartment/duplex (n=13, 65%), and those with a high school diploma or less (n=12, 60%) (Table 1). Baseline digital health literacy and asthma management self-efficacy were high.

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Table . Sample characteristics (N=20).

	Value
Caregiver age, median (IQR)	39.5 (34.75-43.25)
Caregiver sex, n (%)	
Female	18 (90)
Male	2 (10)
Other	0 (0)
Caregiver race/ethnicity, n (%)	
Hispanic/Latino	7 (35)
Black/African American	7 (35)
White	5 (25)
Asian	1 (5)
Caregiver relationship to child, n (%)	
Parent (mother or father)	19 (95)
Grandparent	1 (5)
Caregiver education, n (%)	
High school diploma or less	12 (60)
More than a high school diploma	8 (40)
Household income (US $), n (%)	
Less than 30,000	9 (45)
30,000-74,999	6 (30)
75,000 and above	5 (25)
Home type, n (%)	
Apartment/duplex	13 (65)
Single family	5 (25)
Condominium/townhouse	1 (5)
Other	1 (5)
Child age, median (IQR)	7 (5.5-11)
Child sex, n (%)	
Female	7 (35)
Male	13 (65)
Other	0 (0)
Child race/ethnicity, n (%)	
Hispanic/Latino	8 (40)
Black/African American	7 (35)
White	4 (20)
Asian	1 (5)
Baseline DHLQ[a], median (IQR)	12 (10.75-12)
Baseline PAMSES[b], median (IQR)	
Attack prevention self-efficacy	4.8 (4.3-5)
Exacerbation management self-efficacy	4.6 (4.25-5)
ACT/c-ACT[c], median (IQR)	
Baseline	19 (18-21)

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	Value
Final (3-month survey)	20 (17.5-21.5)

[a]DHLQ: Digital Health Literacy Questionnaire.

[b]PAMSES: Parental Asthma Management and Self-Efficacy Scale.

[c]Asthma Control Test (ACT) and Child Asthma Control Test (c-ACT) were combined due to small sample size.

Feasibility

Nineteen of 20 enrolled participants successfully collected continuous indoor air quality data for at least 1 week and averaged 81 (SD 19) out of 90 days. One participant never completed set-up of the device at home. Indoor air data collected an average of 72% (SD 16%) of the available hours for each participant, ranging from 34% to 97%, and 74% of available days had at least 12 hours of data collection. Feasibility measures were rated highly (Table 2 and Multimedia Appendix 1).

Table . Feasibility and acceptability of using a digital indoor air quality monitor.[a]

	Value, n (%)
Feasibility survey questions (n=15)	
How often did the child sleep in the same room as the air quality monitor?	
Everyday	15 (100)
>50% of days in a week (4 or more)	0 (0)
<50% of days in a week (3 or less)	0 (0)
How would you rate the set-up of the air quality monitor (uHoo- the white device) at home?[b]	
Easy/very easy	15 (100)
How would you rate the set-up of the Wi-Fi hotspot at home (the black device?)[b]	
Easy/very easy	15 (100)
Acceptability survey questions (n=15)	
How likely are you to use the air quality monitor in the future if this device was provided to you in clinic?[c]	
Neutral	2 (13)
Very likely/likely	13 (87)
How likely are you to recommend this technology to a family caring for a child with asthma?[c]	
Neutral	2 (13)
Very likely/likely	13 (87)
Would you have joined the study if the WiFi hotspot was not provided?	
Yes	11 (73)
No	1 (7)
Not sure	3 (20)

[a]All participants who completed the exit interview (n=13) had corresponding exit survey data.

[b]Other item responses included very difficult and difficult or neutral.

[c]Other item responses included very unlikely and unlikely.

Acceptability

Fifteen of 20 enrolled participants completed exit surveys and 13 completed exit interviews. Most participants rated acceptability questions highly (Table 2). While most participants reported they would have joined the study if the WiFi hotspot was not provided, only half interviewed (n=7) stated that they would use the monitors if they had to pay for it. Participants described that the “price may be prohibitive” and “insurance probably should cover” it. On the SUS, participants rated the intervention with a median of 67.5 (IQR 56.3 - 81.3).

Discussion

This study demonstrated that data collection with digital indoor air quality was feasible and acceptable to a socioeconomically varied sample of families with children with asthma.

The high feasibility may be due to the pre-pairing of monitors with WiFi hotspots so that participants only had to plug in each device at home with no additional set-up. The air monitor intervention’s usability score, despite scoring similarly to other air pollution monitors (SUS: 50-66), fell slightly below the

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threshold for acceptable usability, suggesting further inquiry is needed to understand how usability can be improved. Nevertheless, this rating was similar to how the public rated using cellphones in past evaluations (SUS: 66.5) [8]. Nevertheless, over a quarter of participants were unsure if they would have joined without the WiFi hotspot. Proponents of health equity have highlighted that neighborhood broadband access and perceived digital self-efficacy can limit access and use of digital health tools [9].

For acceptability, most participants reported a future interest in using a digital air monitor if provided by the clinic, and the data reviewed with the pediatric allergist were well-received. This finding fits with those from other digital health studies, that is, that closed-loop communication by the health care team about patient-generated health data is crucial to enhance chronic disease self-management [10]. However, this study's aggregated data report, short enrollment period, and device limitations prohibited more tailored recommendations for improving asthma control.

Despite interest in the monitors, half of the participants also identified that they could not afford the cost of the monitor themselves. A recent Centers for Medicare & Medicaid Services (CMS) policy will address this cost barrier to digital health adoption by reimbursing technology-supported health care, including wearable devices and health coaching apps, for Medicare-insured patients with certain chronic conditions [11]. While this CMS model may alleviate costs for some, this will not address affordability for pediatric populations, and expanded access models for technology-supported pediatric health care should be considered.

Study limitations included (1) participants' lack of real-time air quality data during the study, which affected their ability to make at-home modifications, (2) the inability of this type of air monitor to detect indoor environmental allergens (eg, mold, dander), and (3) the short enrollment period and small sample size, which limited inferences about sustained engagement with the air monitors and impact on asthma control, respectively.

Though the feasibility and acceptability of the digital air quality monitoring intervention were promising in this study, affordability was highlighted by participants as a key barrier to the use of these tools in clinical care. Future studies should also incorporate real-time feedback and associated clinical management with air quality monitoring year-round.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey questions and interview findings of the feasibility and acceptability of using a digital indoor air quality monitor.
[DOCX File, 20 KB - pediatrics_v9i1e92070_app1.docx]

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Abbreviations

CMS: Centers for Medicare & Medicaid Services
***ICD-10*:** *International Classification of Diseases, Tenth Revision*
SUS: System Usability Scale

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Perceptions of Dietary mHealth Apps Among Adolescents: Scoping Review

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Abstract

Background: Adolescents' high engagement with smartphones creates opportunities for mobile health (mHealth) apps targeting dietary behaviors. However, despite the availability of diverse dietary mHealth apps, user engagement remains low. Existing quantitative literature has identified barriers and facilitators to app effectiveness in youth (aged 10-19 years) but has not fully captured the nuanced perceptions of adolescents (aged 12-19 years), who represent a unique life stage. Synthesizing similarities and differences in adolescents' perceptions of what they value in dietary mHealth apps from qualitative studies may provide a more comprehensive understanding of app engagement and future app design.

Objective: We aimed to synthesize adolescents' perceptions of using diverse dietary mHealth apps.

Methods: A scoping review was conducted according to the 5-stage framework by Arksey and O'Malley. Eligible studies were published in English and reported on adolescents (aged 12-19 years) with perceptions of dietary mHealth apps using qualitative methods. Apps that were not specific to diet, relied only on SMS text messaging, were delivered as part of a school-based intervention or telemedicine service, or were housed on a website or social media platform were excluded. Five evidence sources (PsycINFO, Embase, Medline, Web of Science, and CINAHL) were searched. Extracted data were charted by 1 researcher following a pilot test. Similarities and differences in adolescents' perceptions were synthesized across studies using thematic analysis.

Results: Of the 1195 search results, 1.2% (n=14) met the eligibility criteria. We identified six themes that represented adolescents' perceptions of using dietary mHealth apps: (1) functionality and design, (2) content and depth, (3) social connection and support, (4) entertainment and gamification, (5) goal setting and motivation, and (6) perceived effectiveness. Overall, adolescents favorably perceived apps that were easy to navigate, fostered social connections, were personalizable, and were gamified. Apps that were felt to increase awareness of personal eating habits, often through tracking calories and foods consumed, and foster awareness of personal well-being were especially discussed in relation to perceived app effectiveness.

Conclusions: The findings of this review provide an innovative synthesis of adolescents' perceptions of diverse dietary mHealth apps, using qualitative data. Notably, dietary mHealth apps that were perceived as easy to navigate, tailored (eg, in terms of content), and gamified and those that included social engagement were perceived favorably, regardless of their dietary target and features. Apps that were perceived to improve adolescents' current dietary awareness were particularly valued. Inclusion of these elements in dietary mHealth apps may promote greater engagement. App developers should work with adolescents to establish how specific apps can incorporate these elements into their design, including how best to track dietary habits and integrate AI into app features.

Trial Registration: OSF Registries osf.io/vw4pq; https://osf.io/vw4pq

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KEYWORDS

adolescents; mobile health; mHealth; mobile apps; diet; nutrition; scoping review

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Introduction

Adolescence is a critical period marked by rapid physical growth and cognitive development [1,2]. There is broad consensus across disciplines that promoting health-protective behaviors during this life stage, including adequate consumption of fruits and vegetables, can help reduce the risk of chronic disease in adulthood [1,2]. Despite this, evidence from around the world indicates that adolescents' dietary behaviors often do not align with established recommendations [3-5]. For example, the literature from Canada and the United States reports that adolescents tend to consume diets high in sugar, fat, and sodium and frequently skip breakfast [3,4]. These patterns are consistent with findings from Europe and Oceania [6]. In contrast, current dietary guidelines emphasize the importance of consuming fruits and vegetables, whole grains, and protein-rich foods, while limiting foods that have added sodium, sugars, or saturated fats [7,8].

Similar misalignment between dietary recommendations and apparent fruit and vegetable consumption, fast food intake, and sugary carbonated beverage consumption has been observed in Thailand, Suriname, and Nepal [5]. Collectively, this body of evidence highlights that improving adolescents' dietary habits remains an ongoing global public health priority [3-6].

In high-income countries, smartphones may offer a promising avenue to address the gap between adolescents' dietary habits and expert dietary recommendations, given their widespread use within this population, with ownership rates frequently exceeding 90% [9,10]. Dietary interventions delivered through a mobile health (mHealth) platform (eg, apps) have shown significant improvements in dietary habits [11,12]. These interventions may facilitate behavior change by being highly accessible to adolescents [13-15] and often anonymous, thereby reducing barriers such as stigma and cost associated with accessing in-person support [15,16].

General mHealth app use has been associated with significant reductions in sugar-sweetened beverages [11,12,17] and energy-dense snacks [11,12]. Additionally, a systematic review of 14 digital interventions, including 9 targeting dietary outcomes among youth (aged 9-18 years), found improvements in fruit and vegetable intake in 3 studies [17]. However, excessive smartphone use (including use of apps) has also been associated with poorer dietary habits, including reduced fruit and vegetable intake and higher intake of fast food and sugar-sweetened beverages [18]. This dual potential highlights the importance of understanding variations in adolescents' app experiences to identify those most likely to benefit from dietary mHealth interventions [11].

Literature evaluating mHealth app experiences has predominantly focused on identifying barriers and facilitators to app use and effectiveness [11]. A 2023 systematic review of 14 studies outlining youths' (aged 10-19 years) experiences with 13 mHealth apps, 7 of which focused exclusively on diet, identified personalized messages and rewards as key facilitators of effectiveness [11]. Two additional systematic reviews published within the past 5 years, drawing on qualitative studies of youth (aged 4-18 years), reported similar findings, highlighting the value of personalization and rewards, along with simple interfaces, varied content, and inclusion of social support features [19,20].

However, these studies did not distinguish adolescents' perceptions and experiences from those of younger children. This limitation is important, as adolescence is characterized by rapid physical growth and pubertal changes that influence appetite [21] and nutritional needs [22]. It is also a period of identity formation, shifting dietary motivation, and increasing eating outside the home [23,24]. Consequently, findings that aggregate broad age ranges may obscure adolescent-specific experiences with mHealth apps. More recent systematic reviews have not addressed this gap and instead focus on specific outcomes such as sustainable dietary habits (eg, reduction in meat consumption) [25,26]. Consequently, there remains limited understanding of adolescents' perceptions of mHealth apps aimed at general healthy eating.

Poorer app experiences contribute to app disengagement, which may compromise intervention fidelity regardless of app quality [27]. Adolescents who do not fully engage with an app or discontinue use early are likely to be exposed to fewer of its key components and content, limiting its potential to influence dietary behaviors [27]. Given that low engagement is a persistent concern in mHealth research [11,18,28], with many users disengaging within the first month, a more nuanced understanding of adolescents' perceptions of mHealth apps is needed. Such insights could inform app design and improve engagement, thereby enhancing the likelihood of meaningful dietary changes [29]. Existing evidence syntheses have largely focused on barriers and facilitators to app use and effectiveness, often emphasizing the inclusion or exclusion of features [11,19,20] and intervention components [25,26]. However, these approaches may overlook broader experiential factors that shape engagement. This study aimed to build on existing reviews by synthesizing adolescents' perspectives on mHealth app use, identifying both similarities and differences in experiences.

Methods

Overview

We conducted a scoping review following Arksey and O'Malley's [30] methodological framework. Details of our methods and the subsequent results are reported according to the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) guidelines [31]. The PRISMA-ScR checklist can be found in Checklist 1.

Protocol and Registration

The review protocol was created by the research team and uploaded to the OSF prior to the initiation of the search [32].

Eligibility Criteria

To be eligible for this review, studies had to be published in English and report on adolescents (aged 12-19 years) and their engagement with an mHealth app related to diet and nutrition. This included studies that explored user perceptions of using these apps. We included qualitative and mixed methods studies

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that captured perceptions but only analyzed their qualitative data to increase our understanding of the nuances in reported adolescent perceptions that are not typically captured with quantitative data [33]. We excluded studies that reported on adults aged >19 years and children aged <12 years, as they do not experience the same behavioral, social, and biological changes that adolescents face [34]. Furthermore, literature reviews, scoping reviews, systematic reviews, and meta-analyses were not eligible for inclusion. Studies that reported on a school-based intervention, telemedicine services, online platforms, social media, and SMS text messaging systems were excluded to ensure that smartphone apps were the primary focus. Theses, dissertations, conference papers, protocols, and methodology papers were also excluded. There were no restrictions on the year of publication.

Information Sources

In consultation with the research team and 2 trained research librarians, PsycINFO, Embase (Ovid), Medline (Ovid), Web of Science, and CINAHL (EBSCO) were selected as appropriate sources of information.

Search

The search strategy was created in consultation with the university research librarian in 3 stages. First, the search terms were determined using the population, concept, and context framework [35]. Second, the research team identified 3 core papers that had recently been published and were considered critical to answering the research question based on the team's field expertise in dietary behavior change. Finally, with the research librarian, a research assistant developed and tested search syntaxes in all of the identified sources of evidence until all core papers were captured in the searches. The final searches that captured those core papers were considered robust and used. The search strategy and syntax can be found in Table 1.

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Table . Search strategy and example of syntax used.

Domains and inclusion	Exclusion	Example syntax[a]
Population		
Adolescents aged 12-19 years	Youth aged <12 years and >19 years	(MH "Adolescence") or (adolescen* or teen* or youth or youths)
Concept		
Perceptions (barriers, facilitators, and experiences)	Telemedicine apps, website-based platforms, SMS text messaging and chat systems, and apps delivered through a social media platform (eg, Facebook) instead of their own unique platform	(MH "Health services accessibility") or (experience* or view* or outlook* or barrier* or facilitator* or challenge* or opportunit* or access* or needs or concern* or perception* or perspectiv*)
Mobile health app	Telemedicine apps, website-based platforms, SMS text messaging and chat systems, and apps delivered through a social media platform (eg, Facebook) instead of their own unique platform	(MH "Mobile Applications") or ((mobile or tele* or virtual or digital or mhealth or m-health or smartphone or cellular) N2 app*)
Dietary behaviors and/or nutrition	Telemedicine apps, website-based platforms, SMS text messaging and chat systems, and apps delivered through a social media platform (eg, Facebook) instead of their own unique platform	(MH "Eating behavior+" or (MH "Diet+" or (MH "Eating") or (diet* or eat or eating or nutrition)
Context		
Apps available to the general adolescent public.	Apps delivered as part of a school-based intervention	No limits applied to avoid prematurely missing an article. Instead, criteria were applied during abstract screening.
Study design		
Report on adolescents' perceptions using qualitative methods	Literature reviews, scoping reviews, systematic reviews, meta-analyses, dissertations, conference papers, protocols, and methodology papers	No limits applied to avoid prematurely missing an article. Instead, criteria were applied during abstract screening.
Language		
English	Non-English	No limits applied to avoid prematurely missing an article. Instead, criteria were applied during abstract screening.

[a]Example syntax shown for the Cumulative Index to Nursing and Allied Health Literature (CINAHL) database. All search syntax components (population and concept) were combined with the Boolean operator AND. Truncation (*), exploding the search to include the main heading and all narrower related terms (+), adjacency operators (N2; within 2 words), and controlled database vocabulary (MH: Medical Heading) were tailored to each respective database. The search syntax included terms related to nutrition apps that were delivered as part of a medical intervention (eg, MH "health services accessibility"). After the search, the research team amended the original inclusion criteria to exclude all nutrition apps delivered as part of a medical intervention (eg, telemedicine) to avoid capturing perceptions that were related to medical support and not the app itself (eg, a clinical care team). The decision was made prior to any abstract screening and applied across all originally returned articles.

Selection of Sources of Evidence

All returned articles from the 5 searched databases were exported into Covidence (Veritas Health Innovation), a web-based reference management software system [36]. Duplicate records were automatically removed by Covidence software. Two research students then independently screened all titles and abstracts for eligible studies. Following this, full texts were reviewed by the same 2 research students. All screening (abstracts and full texts) was done individually, with discrepancies discussed and resolved with the project's senior authors (ASA and TRC).

Data Charting Process

A third research student who was not involved in screening (MBM) completed data extraction independently. MBM used Microsoft Excel (version 2408; Microsoft Corp) to manage the extracted data. Extracted data items were tentatively created prior to the data extraction phase based on previous reviews the research team had conducted. The final list was refined during a pilot extraction using 10% (n=3) of included studies.

Data Items

Extracted data items from the 3 piloted studies encompassed publication information (year, journal, and author names), study

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information (location; delivery setting; design; research questions; hypotheses; methods of data collection, analysis, and recruitment; inclusion and exclusion criteria; study length; and stated limitations), participant characteristics (age and/or grade; total sample size; attrition rate; sex and/or gender; prevalence of clinical conditions; and ethnic, racial, and/or cultural background), app details (length of use, app description, stage of development, app name, targeted behaviors, measured outcomes, and app development framework), and app perceptions (barriers, facilitators, attitudes, beliefs, motivators, and suggestions for improvement). After initial extraction, the research team identified the most relevant data items based on the eligible studies. For example, studies did not test the efficacy or effectiveness of a specific dietary intervention; thus, data items such as “length of intervention” were not relevant.

Critical Appraisal of Individual Sources of Evidence

We did not perform a critical appraisal of the included individual sources of evidence, as per the standard protocol of a scoping review [31].

Synthesis of Results

We conducted a thematic analysis [37] to synthesize the extracted data on adolescent perceptions of using dietary mHealth apps. A research student (MBM) first extracted stated app perceptions from the 14 studies using the predetermined categories from the extraction template (eg, barriers). Next, MBM inductively coded similarities and differences in extracted data within a category regarding app perceptions across eligible studies to develop a codebook. Codes were added during the review of each subsequent study. Added codes were then compared with codes from previously reviewed studies in an iterative fashion. Codes were grouped together to inform subthemes based on similarities and differences in underlying meaning. Subthemes were then mapped to inform broader overarching themes. The development of the codebook and the mapping of the themes occurred through discussion among the broader research team (ALD, TCB, and ASA). A summary of all themes and their subthemes is presented in Table 2.

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Table . Summary of identified themes and subthemes exploring adolescents' perceptions of dietary mobile health (mHealth) apps.

Themes and subthemes	Sample quotes[a]
Functionality and design (app performance, display, and access)	
Accessibility	"…participants had problems using a type of mobile phone that they were not accustomed to [Android]." [38]
Ease of use	"Participants did not want to spend too long figuring out how to use the app." [39]
Tracking	"Entering information on food consumed was difficult at times." [40]
Visual appeal	"…wanted a brighter color theme." [41]
Concept and depth (quality, depth, and delivery of nutritional information)	
Trusted feedback	"[Adolescents] appreciated getting feedback about their dietary intake in the…app." [38]
Multicomponent	"Features that were suggested by adolescents included information about emotions, mood, and their impact on motivation." [42]
Social connection and support (role of social features in influencing app use)	
Peer connection	"Peers…influenced young people to use apps and device through promoting understandings that they were 'cool,' 'in trend,' and/or 'popular'." [43]
Family interaction	"If you know people who always use it, you can ask them about it, they always recommend apps you should use." [43]
Entertainment and gamification (importance of making apps fun via gamification)	
Tells a story	"They liked the storyline of the game and its mountains climbing theme." [44]
Captures my attention	"I loved this video because of how lively it was! And I accept the mindful eating challenge!" [45]
Rewards	"High levels of enjoyment, especially earning points in the game, were reported." [44]
Goal setting and motivation (emphasis on goal-setting as a way to motivate app use)	
Personalized	"[Participants] liked the idea of being able to set progressive challenges and their own goals." [40]
Hold accountable	"If you accomplished all three goals very well, you'll get a gold badge…If you didn't accomplish any goals, you will not get a badge." [46]
Perceived effectiveness (perceptions of what contribute to app effectiveness)	
Tracking eating habits	"I sometimes did not eat things because then I would have to record them." [38]
Increased knowledge	"Importance of an app that provides them with educational information and manages individualized patient information." [47]
Mind-body connection	"I tried eating my dinner last night mindfully. When I did, I was surprised at how much better my food tasted and how I ate less than [normal]." [45]

[a]Quotes were extracted from the respective article's text or supplemental materials.

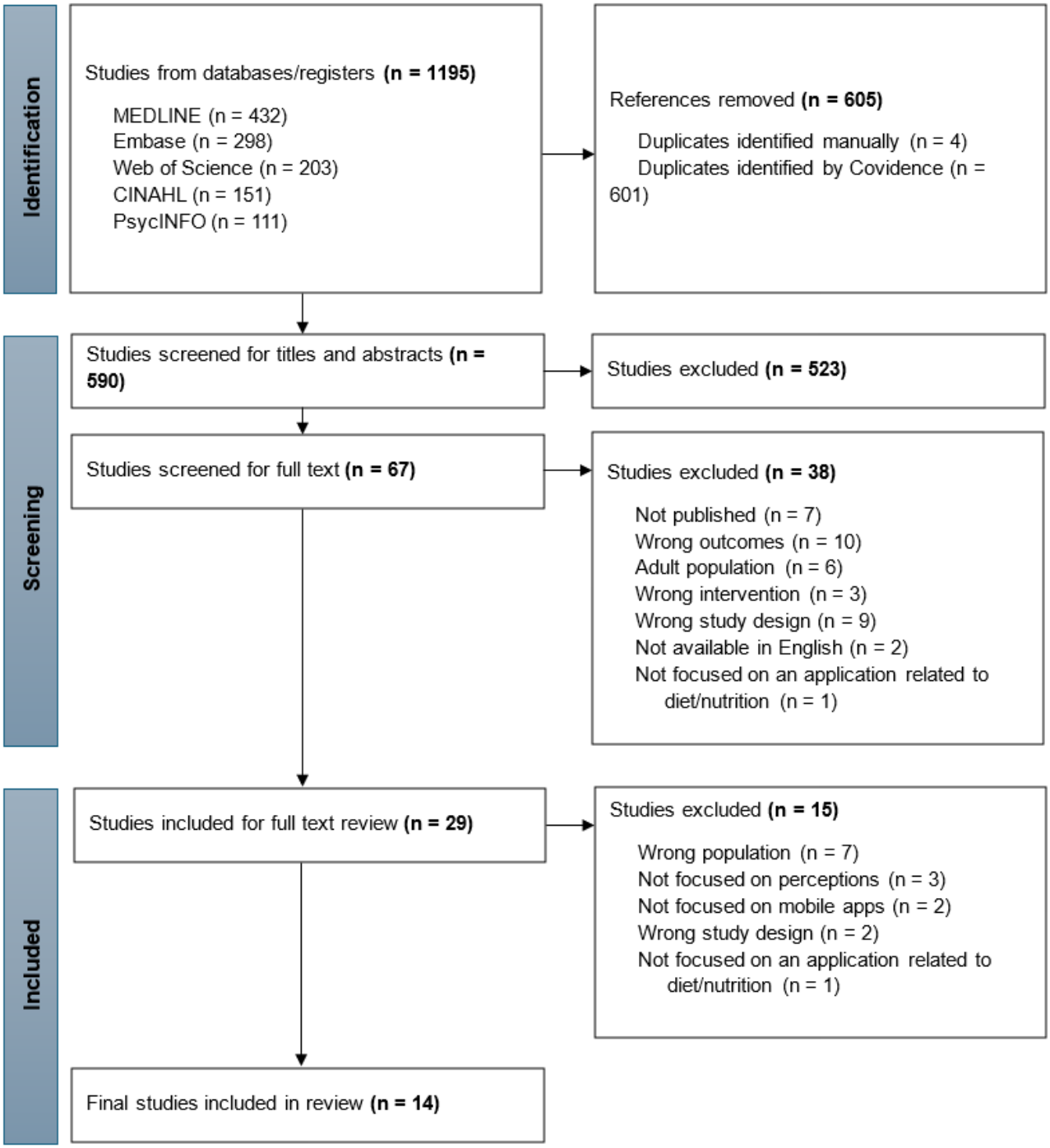
Results

Selection of Sources of Evidence

Initially, 1195 studies were identified from the databases. A total of 605 (51%) duplicate studies were removed by Covidence, and 590 (49%) were screened for eligibility. Of the screened studies, 1% (n=14) met the stated criteria. The flow diagram with a complete justification for exclusion can be found in Figure 1.

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Figure 1. PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) flowchart.



Characteristics of Sources of Evidence

A summary of extracted study characteristics is provided in Multimedia Appendix 1. Most studies were conducted in high-income countries in North America (4/14, 29%) [39,42,44,45] and Europe (n=6, 43%) [38,40,41,43,48,49], with 4 (29%) conducted outside of these regions, in the Dominican Republic, Indonesia, Korea, and Vietnam [46,47,50,51]. A total of 8 (57%) studies recruited adolescents from schools [38,40,41,43,46,49-51], 4 (29%) from clinical settings (eg, hospitals) [39,42,44,48], and 2 (14%) from community organizations [45,47]. Sample sizes ranged from 5 to 245 adolescents. Participants were between the ages of 12 and 19 years, with female subgroups ranging from 3 to 149 participants and male subgroups ranging from 0 to 106 participants. Only 6 (43%) papers were published before 2020 [38,42,43,45,48,50]. A total of 9 (64%) studies used mixed methods [38,40,41,43-45,48-50], whereas 5 (36%) used qualitative methods only [39,42,46,47,51].

Of the 14 described apps, 6 (43%) focused on diet and nutrition [38,40,41,46,50,51], while 4 (29%) other apps involved additional health behaviors such as physical activity [43-45,49]. Only 2 (14%) studies explored perceptions of adolescents living with a clinical condition (type 1 diabetes) [47,48], and 2 (14%) focused on weight management [39,42]. A total of 6 (43%) apps were in the pilot-testing stage [38,41,45,48-50], 3 (21%) were in development [40,44,46], 3 (21%) were available for download

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on the market [39,43,51], and 2 (14%) were described as a concept [42,47].

When it came to the use of behavioral theory to guide development, 1 (7%) study mentioned the use of integrated social cognitive theory, self-determination theory, and narrative transportation theory [44]. One other study used development frameworks such as the integrate, design, assess, and share framework (1/14, 7%) [40].

Critical Appraisal Within Sources of Evidence

We did not perform a critical appraisal within sources of evidence of the included studies, as per the standard protocol of a scoping review [31].

Synthesis of Results

We identified 6 themes to describe adolescents' perceptions of using dietary mHealth apps that are outlined in the following sections. A summary of all identified themes with examples of the text extracted can be found in Table 2.

Theme 1: Functionality and Design

This theme addresses adolescents' experiences with the technical performance and usability of dietary mHealth apps. Four subthemes captured adolescents' perceptions of what hindered and supported their use of dietary mHealth apps (accessibility, ease of use, visual appeal, and tracking).

Adolescents spoke about the important role of creating apps that were accessible regardless of their device and personal context. In particular, this included the need for apps that could be used across software platforms and were accessible on their personal devices, not just those provided by a research team [48]:

> *…downloading [the app] to their own phones, they would continue to use the applications.*

Additionally, adolescents expressed a need for apps that could evolve with their personal content, including having the ability to log diverse foods that they consumed and having access to food lists that were continually updated [51]:

> *…highlighted the importance of updating the list of beverages and drinks, as some kinds of drinks were not included in the database.*

Motivation to use an app was discussed relative to its perceived ease of use and visual appeal. Adolescents spoke about the value of apps that were simple, responsive, readable, and similar to apps they already integrated into their everyday lives [39]:

> *[Participants] used popular apps such as Facebook, Instagram, and Snapchat and specifically reported that they preferred certain weight management apps because it reminded them of those popular app.*

Esthetic components of apps, including design choices about color, font size, and display layout, were also highlighted as important characteristics [51]:

> *I don't think it captures the user's interest much [without images].*

Most apps explored in the 14 studies included some form of dietary tracking (eg, calorie counting). Importantly, adolescents often valued having such features within an app, but recognized nuances associated with these features that influenced having a positive app experience. For some, tracking dietary data led to concerns about privacy, was burdensome, and created confusion when errors appeared [38]:

> *[Participants'] views that the recording of dietary intake was burdensome.*

Theme 2: Content and Depth

This theme reflected adolescents' views on the quality, depth, and delivery of nutritional information and was reflected in 2 subthemes (trusted feedback and multicomponent apps).

Adolescents valued apps that they felt provided accurate and trusted dietary and nutrition information. This included helping with reading food labels [39], understanding their personal nutrition needs, and providing space to receive feedback from experts:

> *[Adolescents] liked taking pictures of barcodes on food items with their telephone so that they could identify the nutritional information regarding foods that they were considering eating.*

In addition to receiving trusted dietary and nutrition advice, adolescents also emphasized how apps that delivered content related to other behaviors, such as physical activity [47] and mental health, were desirable:

> *Participants suggested the possibility of having an exercise section in the app.*

Theme 3: Social Connection and Support

This theme emphasizes the role of social features in influencing adolescents' engagement with dietary mHealth apps. Two subthemes (peer connection and family interaction) were identified.

Adolescents spoke about the value of having spaces within the dietary mHealth apps to communicate with their peers. This was valued as a tool to discuss behavior change strategies, gain encouragement when goals were achieved [42], and socialize irrespective of the topic:

> *Encouragement and coping support were also discussed as potential benefits to a social support feature, which would allow for adolescents to share encouraging messages with peers and to seek out or offer advice.*

Adolescents valued apps that included options to compete or play in-app games with peers [40], and adolescents recognized the added motivational value that could come from having an app and its messaging seem more desirable when their peers also used it:

> *Participants suggested that they could be more engaged with the game if they could interact with other players.*

Family support was also recognized as a way to promote app use through normalization of its use. In contrast to peer-based

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support, adolescents spoke about how dietary mHealth app use could contribute to disruption of family routines, depending on what an app asked an adolescent to do [46]:

> *Inconvenience for family members in waiting for the process of taking pictures completely before starting to eat their meals.*

Theme 4: Entertainment and Gamification

This theme captured adolescents' perceptions of the importance of making apps fun via gamification aspects and specifically was broken down into 3 subthemes (tell me a story, capture my attention, and rewards).

Adolescents appreciated apps that used a storyline to deliver relevant dietary information and/or behavior change strategies [40]:

> *Positive about the main idea of the game, mainly because of the novelty of the topic and the setting of the game.*

Use of flashy and attention-grabbing digital content such as videos and images was also desired [49]:

> *Perhaps it would be good to have images? I don't think it captures the user's interest much [without images].*

Finally, the use of rewards helped make engagement fun [40]:

> *Being rewarded with medals that were visible to friends would be seen in a positive way as being motivating to them.*

Theme 5: Goal Setting and Motivation

This theme reflects adolescents' perspectives that goal setting could act as a powerful feature to motivate app use and is separated into 2 subthemes (personalized and hold accountable).

Being able to set and monitor personal dietary goals was expressed positively by adolescents across the studies [46]:

> *Enjoyed seeing daily statistics for individual dietary goals.*

Use of goal setting as a feature to motivate dietary behavior change was also talked about in conjunction with the use of reminders [39] and rewards for completing a goal:

> *Self-monitoring features, such as having reminders, alerts, or notifications to keep them on track with their healthy behavioral goals was a highly preferred feature.*

Theme 6: Perceived Effectiveness

This theme summarizes adolescents' perceptions of specific app components that they attributed to the effectiveness of a dietary mHealth app in altering their behaviors. Specifically, tracking eating habits, increased knowledge, and mind-body awareness were 3 identified subthemes.

Tracking eating habits was favorably viewed as helping adolescents self-monitor their habits and shift their behaviors. This was discussed through the act of recording nutrients and meals consumed, as well as by tracking what was eaten in relation to other aspects of health and well-being outcomes such as monitoring diabetes [47]:

> *The new app could assist them in managing their disease [such as] assistance with carbohydrate counting and food identification, better decisions on food choices using a list of glycemic indexes, and assistance with daily management of the disease.*

Perceptions of increased knowledge, whether related to nutrient needs or to related aspects of health, were further attributed to increased desire to make dietary changes [45]:

> *Better visual understanding of the cornerstones of diabetes self-management: food intake,....*

Finally, observing changes in feelings of well-being [45] further helped adolescents feel that using a dietary mHealth app was valuable:

> *[Adolescents who perceived] the app to be very helpful and enjoyable and reported feeling more relaxed, focused, and peaceful.*

Discussion

Summary of Evidence

This scoping review synthesized evidence on adolescents' perceptions of dietary mHealth apps across 14 studies. Importantly, we focused on adolescents aged 12 to 19 years, in contrast to the broader age ranges of prior reviews that also focused on youth (aged 10-19 years) [11,19,20]. From the evidence synthesis, six themes were identified that captured adolescents' perspectives: (1) functionality and design, (2) content and depth, (3) social connection and support, (4) entertainment and gamification, (5) goal setting and motivation, and (6) perceived effectiveness. Our findings build upon prior reviews that have focused on presenting barriers and facilitators of app features [11,19,20,25,26] to provide a more nuanced perspective that can be used across diverse dietary mHealth apps.

Overall, adolescents value dietary mHealth apps that are simple, fun, and raise awareness of their current habits. Technical ease [19,20], esthetic appeal [19,20], gamification [11,19,20], avenues of social support [20,25], and use of goal setting [19,20,25,26] have all been reported in prior literature as essential facilitators to dietary mHealth app engagement, matching key themes that arose in this scoping review. Importantly, apps that were perceived to be more effective by adolescents specifically included dietary tracking and increased knowledge that moved beyond just nutrition facts, opening up novel avenues for research to consider.

Calorie Counting, Dietary Tracking, and Behavior Change Promotion

Tracking eating habits emerged as a critical subtheme influencing adolescents' perceived dietary changes. This included approaches such as calorie counting and tracking different types of foods consumed. Such dietary self-monitoring is a common feature of many dietary mHealth apps [52]; a 2021 systematic review found that 20 out of 28 included nutrition apps incorporated calorie counters [52]. The review identified

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goal setting, personalization, and dietary self-monitoring [52] as key facilitators of app engagement.

Within behavioral medicine, calorie counting is categorized as a behavior change technique (BCT), reflecting dietary self-monitoring [53]. Evidence supports its effectiveness: a meta-regression of 122 diet and physical activity interventions in adults found that self-monitoring accounted for the greatest variability in outcomes, with stronger effects observed when combined with other techniques [54]. These findings align with the present results, suggesting that dietary self-monitoring through strategies such as calorie counting may support behavior change. However, recent literature has raised concerns about calorie counting as a dietary strategy. It can be burdensome, requires a high degree of nutrition literacy [55], and may promote an overemphasis on numerical targets rather than internal cues of hunger and satiety (eg, intuitive eating) [56].

Many countries have adapted national dietary guidelines that use plate-based eating (eg, MyPlate) [56]. These approaches guide intake using proportions of macronutrients (eg, protein) and broader food groups (eg, grains), offering a more visual and intuitive framework for food choices. A Canadian study examining the perspectives of registered dietitians (n=44) and the general public (n=52) found that plate-based approaches were valued for promoting dietary self-awareness through simple visual representations of foods on a plate [55]. Despite this, few mHealth apps have adopted plate-based approaches.

Given that adolescents in this scoping review, as well as prior studies [19,20], report valuing simple and visually engaging app content, plate-based eating may represent a promising dietary self-monitoring strategy in digital content. Beyond simplicity, this approach connects how they feel with what they eat by shifting focus away from numerical targets. This aligns with principles of intuitive eating that emphasize internal cues such as hunger and satiety [56] and are associated with lower odds of poor mental well-being (eg, high depressive symptoms and low self-esteem), body dissatisfaction, and negative weight control behaviors (eg, skipping meals) among adolescents in longitudinal research (n=1491) [57]. Participants in this scoping review also expressed interest in app content linking mental health and dietary behaviors (eg, mind-body awareness subtheme). Taken together, these findings suggest that incorporating plate-based eating into mHealth apps warrants further exploration as a developmentally appropriate and potentially supportive dietary self-monitoring strategy.

Peers and Family Systems as Enactors of Social Support

In this scoping review, social interaction emerged as a key component of valued dietary mHealth apps, consistent with previous reviews [20,25,52]. Importantly, peers and the family unit were identified as particularly important sources of social support. In contrast to prior research, our findings did not highlight a perceived need for the involvement of clinical professionals, suggesting that adolescents may prioritize informal support networks over formal health care input in the context of app use.

A 2023 scoping review of 43 studies evaluating dietary mHealth apps among individuals living with chronic disease (n=256,430; eg, cancer) found that social features connecting users with clinicians or health coaches were key to sustaining behavior change [58]. In contrast, interactions with health professionals were not a central focus for adolescents included in our scoping review. This divergence may reflect differences in health status; adolescents managing complex or chronic conditions may face a greater burden, increasing the perceived value of clinical support.

This interpretation is consistent with findings from studies included in our review, where adolescents valued app content that linked dietary behaviors to disease management (eg, effects on insulin levels in diabetes). As such, these findings suggest that preferences for social support features may vary depending on the health context. Future research is needed to better understand when and for whom different forms of support, such as health coaches or clinical professionals, are most relevant and effective for adolescents using mHealth apps.

In the growing world of AI, it is also important to clarify adolescents' perspectives on AI as a social support feature (eg, a chatbot). A scoping review that explored youths' (aged 10-19 years) acceptability of chatbots in nutrition and physical activity apps found that, in 2 of the 5 reviewed studies, adolescents expressed satisfaction with a chatbot [59]. Interestingly, when the authors discussed the findings on chatbots with a youth advisory panel, youth brought forward additional concerns surrounding the possibility of spreading misinformation through chatbots and data privacy [59]. Although adolescents in our scoping review did not explicitly discuss chatbots, they did highlight privacy concerns with sharing data in an app. This highlights the need to further explore the role of AI within dietary mHealth apps as a source of information or dietary consultant and to understand how adolescents perceive the use of AI within dietary apps as a potential social support feature in greater depth.

Multicomponent Apps

In this scoping review, adolescents expressed an interest in the inclusion of physical activity and mental health support. Previous literature has replicated this finding, with many apps integrating both behaviors alongside each other [11,19,59]. Importantly, our findings highlighted adolescents' perceptions that mental health information and features that foster reflection on emotions and mood were valuable. Although numerous apps exist that target aspects of mental health and well-being [60], such apps are often stand-alone apps that do not encompass dietary aspects or are developed for individuals living with eating disorders [61]. This raises questions as to the extent to which mHealth apps should target more holistic approaches to health as a facet of physical and mental well-being in 1 place, and if such an approach would have benefits for adolescents' behavioral outcomes.

Limitations

Most included studies in this review were conducted in North America and Europe, which limits the generalizability of our findings to diverse cultural contexts and countries where

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smartphone use is lower. As recent literature has reported lower smartphone use among adolescents from low- to middle-income countries, especially among female adolescents [62], our findings may not be relevant to all adolescents. We further did not evaluate any objective measures of app efficacy and effectiveness. This means that we are not able to draw conclusions about associations between changes in behaviors and our findings. Furthermore, data charting and synthesis were conducted by a single reviewer, which may have introduced bias in study selection and interpretation. To help mitigate this risk, the research team collaboratively developed the data extraction form and resolved ambiguities through consensus. We also did not have the ability to probe for more specific perceptions of app use across unique devices and contexts. It is possible that the type of device a user owns (eg, Android vs iOS) or context (eg, delivered through a school vs clinical site) may impact adolescents' perceptions of the apps, and these nuances are not captured here. Finally, given the rapid evolution of adolescent smartphone use and mHealth app development, our findings may not reflect the most recent innovations that are on the market today. Future reviews should consider using living methods to allow continual updating of information as it becomes available.

Conclusions

This scoping review provides comprehensive and novel insights into adolescents' perceptions of dietary mHealth apps across a range of dietary mHealth apps—a group whose perceptions have not been explored in depth. Adolescents expressed an interest in apps that are easy to navigate, foster social connections, can be personalized, and have gamified elements. In particular, apps that were perceived to improve awareness of one's dietary habits through tracking and connections to aspects of well-being were desired. Future work is needed to explore how dietary tracking can be best facilitated and the extent to which AI has a role within adolescent-focused dietary mHealth apps.

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Authors' Contributions

Conceptualization: TCB, ASA, TRC
Formal analysis: MBM
Funding acquisition: ASA, TRC
Investigation: MBM
Methodology: MBM, ALD, TCB, ASA, TRC
Project administration: TCB
Resources: TRC
Supervision: ALD, ASA, TRC
Validation: ALD, TCB, ASA
Writing – original draft: MBM
Writing – review & editing: ALD, TCB, ASA, TRC

Conflicts of Interest

ASA has received speaker fees from Boehringer Ingelheim and consulting and speaker fees from Obesity Canada (unrelated to this work). All other authors declare no other conflicts of interest.

Multimedia Appendix 1
Characteristics of sources.
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Checklist 1
PRISMA-ScR checklist.

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[DOCX File, 89 KB - pediatrics_v9i1e91650_app2.docx]

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Abbreviations

BCT: behavior change technique
mHealth: mobile health
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews

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Global Prevalence and Associated Factors of Medication Errors in Hospitalized Pediatric Patients: Systematic Review and Meta-Analysis

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Abstract

Background: Medication errors represent a major patient safety concern among hospitalized children due to developmental variability, weight-based dosing, and limited communication capacity. However, the global burden and determinants of pediatric inpatient medication errors remain insufficiently characterized.

Objective: This study aims to estimate the worldwide prevalence of medication errors in hospitalized pediatric patients and to identify factors associated with their occurrence.

Methods: A systematic review and meta-analysis was conducted using Embase, MEDLINE, Web of Science, PubMed, and the Cochrane Library from database inception to June 2025. Observational studies involving pediatric inpatients younger than 18 years were included. The review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement. Data were pooled using a DerSimonian-Laird random-effects model, with subgroup and sensitivity analyses performed to explore heterogeneity.

Results: A total of 61 studies from 29 countries or regions were included. The pooled prescribing error rate was 28%, the pooled administration error rate was 32%, and 54% of the hospitalized pediatric patients experienced at least one medication error. Prescribing error rates were higher in lower-middle–income countries (44%), intensive care units (34%), antibiotic prescriptions (30%), and studies conducted between 2013 and 2025 (32%). The proportion of patients experiencing medication errors was the highest in upper-middle–income countries (64%), whereas administration error rates were the highest in low-income countries (71%), although these subgroup findings should be interpreted cautiously because of limited numbers of studies and wide CIs. Factors associated with medication errors included intravenous administration (odds ratio [OR] 6.86, 95% CI 3.17 - 14.83), hospital stay longer than 5 days (OR 1.94, 95% CI 1.33 - 2.81), and prescription of 3 or more medications (OR 2.12, 95% CI 1.66 - 2.70).

Conclusions: Medication errors are highly prevalent among hospitalized children worldwide, with substantial variation by region, income level, care setting, and time period. Errors are closely associated with treatment-related factors, underscoring the need for targeted system-level strategies to improve pediatric medication safety.

(JMIR Pediatr Parent 2026;9:e100070) doi:10.2196/100070

KEYWORDS

medication errors; pediatric patients; hospitalized children; meta-analysis; prevalence; associated factors; systematic review

Introduction

Medication errors have become a major public health issue threatening patient safety worldwide [1] and are particularly prominent in pediatric health care settings [2]. Children and neonates are reported to be up to 3 times more likely to experience medication errors than adults [3,4]. Due to the limited availability of pediatric-specific formulations, adult medications often require dose calculations, manipulation, or reconstitution to meet individualized pediatric treatment needs [5,6]. In

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addition, factors such as complex dose calculations [7], age-related differences in drug metabolism [8], the use of unlicensed or off-label medications [8], and children's limited ability to communicate symptoms and treatment-related concerns [9] may further increase the risk of medication errors. These errors may lead to adverse drug events, prolonged hospitalization, increased health care costs, and even irreversible harm or death [10]. Medication errors impose a substantial burden on health care systems worldwide. In the United States, medication errors are associated with annual costs exceeding US $29 billion, including an estimated additional US $28 million in hospital costs each year [11,12]. In the United Kingdom, medication errors result in economic losses of £9,846,258 annually for the National Health Service and consume a considerable number of bed-days [13]. The World Health Organization has estimated that medication errors cost approximately US $42 billion globally each year [14].

The National Coordinating Council for Medication Error Reporting and Prevention (NCC MERP) [15] defines a medication error as any preventable event that may cause or lead to inappropriate medication use or patient harm while the medication is in the control of a health care professional, patient, or consumer. These events may be related to professional practice, health care products, procedures, or systems and may involve prescribing, order communication, product labeling, packaging, nomenclature, compounding, dispensing, administration, education, monitoring, and use. Medication errors thus span multiple stages of the medication-use process. Prior studies [16] suggest that most medication errors in children occur during the prescription, dispensing, and administration stages. Among them, prescription errors account for 3% to 37% of children's medication errors, dispensing errors account for 5% to 58%, and administration errors account for 72% to 75% of children's medication errors [17].

Although numerous studies in recent years have examined the epidemiology of pediatric medication errors [18-20], substantial methodological heterogeneity persists. Inconsistencies in the operational definitions of medication errors, variation in data collection methods, diversity of study settings, and differences in denominators have resulted in wide variability in reported prevalence, limiting comparability across studies. Gates et al [21] stratified pooled estimates of medication error prevalence in hospitalized children by ward type and use of health information technology, but their work focused solely on quantitative synthesis of prevalence without systematically addressing associated factors. This lack of root cause analysis limits the ability to develop efficient and targeted prevention strategies in clinical practice.

To address these gaps, we conducted a systematic review and meta-analysis with two primary objectives: (1) to evaluate the occurrence of medication errors among hospitalized pediatric patients worldwide and (2) to identify factors associated with medication errors in hospitalized children. By consolidating epidemiological evidence, our study aims to support the development of more precise and evidence-based strategies for the prevention of pediatric inpatient medication errors.

Methods

Search Strategy and Study Selection

The systematic review and meta-analysis was conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement (Checklist 1). A comprehensive search was conducted in Embase, Web of Science, the Cochrane Library, MEDLINE, and PubMed from database inception to June 2025. A combination of MeSH terms and free-text terms was used, including "children," "hospitalized," and "medication errors." Detailed search strategies for each database are provided in Multimedia Appendix 1. This study was registered with PROSPERO (registration number: CRD42024613159).

Inclusion criteria were (1) hospitalized pediatric patients aged less than 18 years, including those in general pediatric wards, pediatric intensive care units (PICUs), and neonatal intensive care units (NICUs); (2) studies reporting the prevalence of medication errors or investigating associated factors; and (3) observational studies (cross-sectional, cohort, or case-control).

Exclusion criteria were (1) studies focusing exclusively on specific patient populations (eg, oncology patients) or specific drug categories; (2) studies based solely on voluntary reporting systems, as these systems rely on active reporting by health care professionals and may underestimate the true prevalence of medication errors; however, studies that combined voluntary reporting with active surveillance methods, such as direct observation, medical record review, or other systematic detection approaches, were included; (3) non-English publications; and (4) conference abstracts, posters, studies with insufficient data, or studies for which the full text was unavailable.

Data Extraction and Quality Assessment

Two investigators independently extracted data using Microsoft Excel, including first author, publication year, country or region, study design, ward type, study period, age range or mean age (SD) of included children, data collection methods, source of medication error definition, prevalence of medication errors (%), and associated factors. Discrepancies were resolved by a third investigator. For overlapping datasets, the study with the larger sample size was prioritized.

Cohort and case-control studies were assessed using the Newcastle-Ottawa Scale (NOS), with scores of 0 to 3, 4 to 6, and 7 to 9 indicating low, moderate, and high quality, respectively [22]. Cross-sectional studies were evaluated using the Agency for Healthcare Research and Quality (AHRQ) criteria, with scores of 0 to 3, 4 to 7, and 8 to 11 indicating low, moderate, and high quality, respectively [23]. Studies of all quality levels were included to capture all available evidence in the field.

Outcome Definitions

This study initially planned to extract data on various types of medication errors, including prescribing errors, dispensing errors, and administration errors. However, because some error types were reported in only a limited number of studies and exhibited substantial variability in reporting methods,

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meta-analyses were conducted only for outcomes that met the criteria for quantitative synthesis, namely the proportion of patients experiencing medication errors, prescribing error rates, and administration error rates.

To avoid misinterpretation arising from differences in units of analysis, the outcome measures were defined as follows. The prescribing error rate was defined as the proportion of prescriptions containing at least one medication error among all prescriptions, reflecting the occurrence of medication errors during the prescribing process. The administration error rate was defined as the proportion of medication administrations involving at least 1 medication error among all medication administrations, reflecting the occurrence of medication errors during the medication administration process. The proportion of patients experiencing medication errors was defined as the proportion of patients who experienced at least one medication error during the observation period among all patients, reflecting the overall burden of medication errors among hospitalized pediatric patients. Because these outcomes were calculated using different units of analysis (prescriptions, medication administrations, and patients), their estimates represent different aspects of medication error occurrence and should not be directly compared.

Statistical Analysis

All statistical analyses were performed using Stata (version 17.0). Neither the Freeman-Tukey double arcsine transformation nor the logit transformation was applied to the original proportions. For the meta-analysis of medication error occurrence among hospitalized pediatric patients, the effect size was the medication error rate. For the meta-analysis of factors associated with medication errors, the effect size was expressed as the odds ratio (OR) with its corresponding 95% CI. Given the substantial heterogeneity among the included studies (I^2> 50% and P<.05), pooled estimates were calculated using the DerSimonian-Laird random-effects model. Subgroup analyses were conducted according to relevant study characteristics and associated factors to explore potential sources of heterogeneity. To assess the robustness of the findings, several sensitivity analyses were performed. A leave-one-out analysis was conducted to evaluate the influence of individual studies on the pooled estimates. In addition, restricted maximum likelihood (REML) estimation was applied within the random-effects framework to examine the impact of different τ^2 estimation methods on the pooled results. Publication bias was assessed using both Egger's test and visual inspection of funnel plot symmetry. All statistical tests were 2-sided, and P<.05 was considered statistically significant.

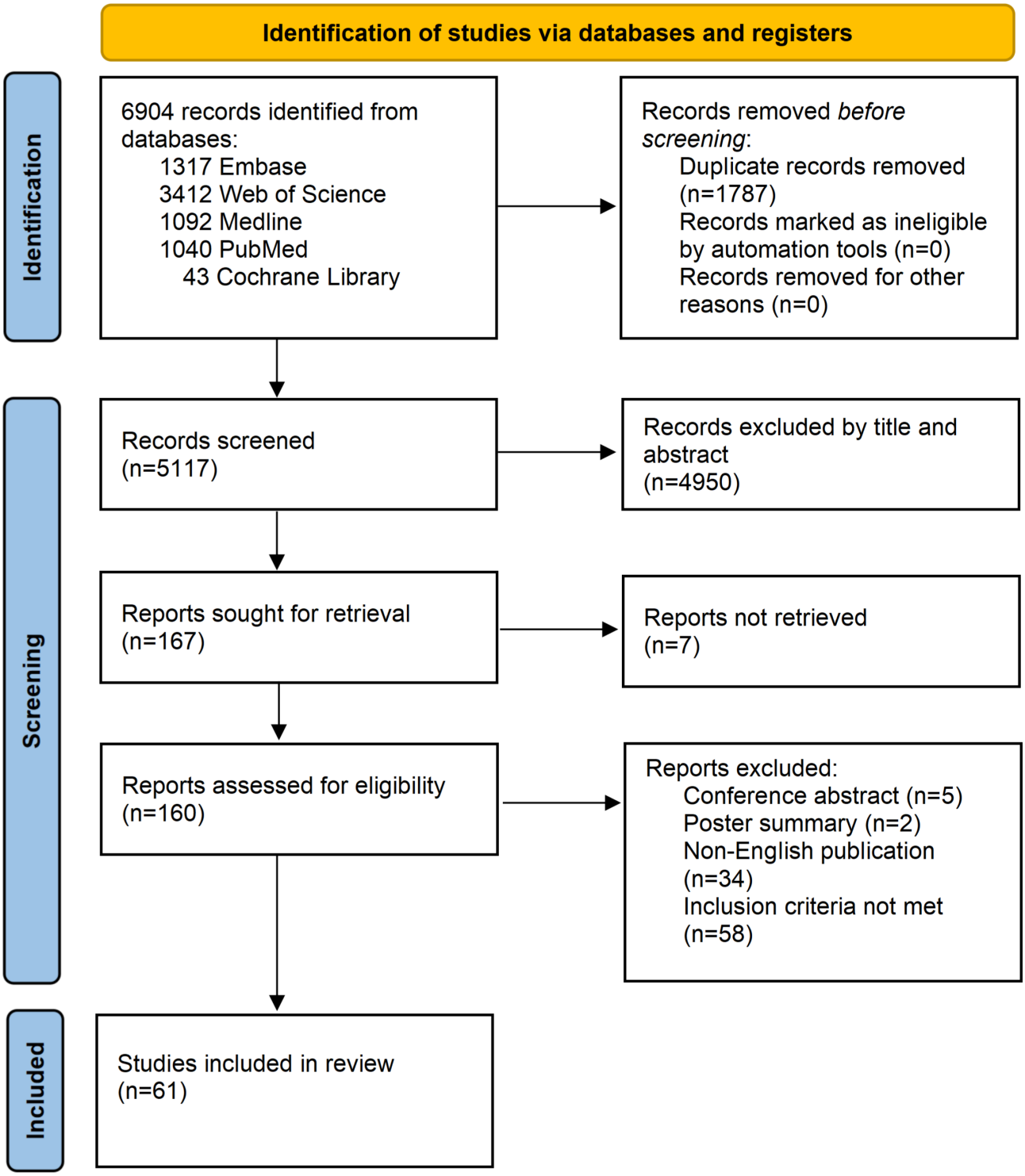
Results

Literature Search

A total of 6904 records were identified through searches of Embase, Web of Science, the Cochrane Library, MEDLINE, and PubMed. After removing 1787 duplicates, 4950 records were excluded based on titles and abstracts, and 7 reports were excluded because the full text was not available. Following full-text review, 99 articles were further excluded for not meeting the inclusion criteria, leaving 61 studies for analysis. The study selection process is summarized in Figure 1.

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Figure 1. Flow diagram of the study selection process.



Characteristics and Quality Assessment of the Included Studies

Details of the included studies are provided in Table 1, with sample sizes ranging from 20 to 8691 participants. The studies were conducted across 29 countries or regions, including 14 high-income, 8 upper-middle–income, 4 lower-middle–income, and 3 low-income countries. Ward types included general pediatric wards, PICUs, and NICUs. Among the included studies, 35 were cross-sectional, with AHRQ scores ranging from 4 to 7 (Table S1 in Multimedia Appendix 2), and 26 were cohort studies, with NOS scores ranging from 3 to 9 (Table S2 in Multimedia Appendix 2). To ensure that all available data were used to estimate medication error rates, no studies were excluded based on methodological quality; all original studies reporting medication errors were included.

The types of medication errors reported in the included studies included prescribing errors, administration errors, dispensing errors, and medication reconstitution errors. However, because only a limited number of studies reported on dispensing errors and medication reconstitution errors, and substantial variability existed in outcome definitions and reporting methods, reliable

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quantitative synthesis was not feasible for these error types. Therefore, meta-analyses were conducted only for the proportion of patients experiencing medication errors, prescribing error rates, and administration error rates among hospitalized pediatric patients.

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Table . Basic characteristics of included studies.

First author (year)	Country or region	Study design	Ward type	Study period	Age range or mean (SD)[a]	Data collection method	Source of medication error definition	Medication error rate	Associated factors
Canales-Siguero et al [24], 2025	Spain	Cross-sectional	NICU[b]	2021 - 2022	34 weeks (median, IQR 30 - 39)	Medical record review	Reference	Prescription errors: 3.3%	Birth weight, gestational age, ward occupancy
Henry Basil et al [25], 2025	Malaysia	Cohort	NICU	2022 - 2023	35 weeks (median, IQR 30 - 39)	Direct observation	Reference	Administration errors: 68.0%; proportion of patients experiencing medication errors: 92.4%	Medications administered intravenously, unavailability of a protocol, the number of prescribed medications, nursing experience, nonventilated neonates, and gestational age in weeks
Badgery-Parker et al [26], 2024	Australia	Cohort	Medical, surgical, and day-stay wards	2016 - 2020	0 - 18 years (range[c])	Direct observation; medical record review	NR[d]	Prescription errors: 18.6%; administration errors: 36.2%	Age
Westbrook et al [27], 2024	Australia	Cohort	General pediatric, medical, and surgical wards	22 weeks	0 - 16 years (range)	Direct observation; medical record review	Reference	Administration errors: 37.0%	Intravenous route, early morning and weekend administrations, patient age ≥11 years, oral medications requiring solvents or diluents, and eMM[e] use
Abiri et al [28], 2024	Sierra Leone	Cross-sectional	Pediatric ward	2021	0 - 18 years (range)	Medical record review	NCC MERP[f]	Proportion of patients experiencing medication errors: 56.1%	NR
Kwaku Wuni et al [29], 2024	Ghana	Cross-sectional	Pediatric and the newborn care units	2022	1.37 years (mean, SD 0.83)	Questionnaire survey	Reference	Proportion of patients experiencing medication errors: 65.9%	Ward type
Satir et al [30], 2023	Switzerland	Cohort	Pediatric ward	2018 - 2019	0 - 18 years (range)	Medical record review	Reference	Prescription errors: 49.55%	NR

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First author (year)	Country or region	Study design	Ward type	Study period	Age range or mean (SD)[a]	Data collection method	Source of medication error definition	Medication error rate	Associated factors
Bante et al [31], 2023	Ethiopia	Cross-sectional	Pediatric ward	2020 - 2021	≤28 days to ≥10 years (range)	Questionnaire survey	NCC MERP	Proportion of patients experiencing medication errors: 69.5%	Work environment, child weight, education level of medication provider, parental involvement, adherence to administration authority, length of hospital stay
Xavier et al [32], 2022	Mozambique	Cross-sectional	Pediatric ward	2020	0 - 10 years (range)	Medical record review	WHO[g], BNFC[h], NICE[i]	Prescription errors: 34.9%; proportion of patients experiencing medication errors: 36.5%	Number of prescribed medications, length of hospital stay
Akkawi et al [33], 2022	Malaysia	Cross-sectional	Pediatric ward	2019	0 - 12 years (range)	Medical record review	National Antibiotic Guideline	Proportion of patients experiencing medication errors: 57.9%; prescription errors: 27.9%	Infection type, number of antibiotics used
Garedow et al [34], 2022	Ethiopia	Cross-sectional	Pediatric ward	2021	0 - 18 years (range)	Medical record review	NR	Prescription errors: 19.29%	Length of hospital stay, number of prescribed medications, empirical therapy
Nasso et al [35], 2022	Italy	Cohort	Pediatrics, pediatric nephrology, and pediatric rheumatology	2019	0 - 18 years (range)	Medical record review	WHO	Prescription errors: 56.0%	Ward type
Alekaw et al [36], 2022	Ethiopia	Cross-sectional	Pediatric ward	2020 - 2021	1.96 years (mean, SD 3.48)	Medical record review	NR	Proportion of patients experiencing medication errors: 30.8%	Age, parental negligence, residence
Özdemir et al [37], 2021	Turkey	Cross-sectional	Pediatric ward	2016	1-226 months (range)	Database; medical record review	Reference	Proportion of patients experiencing medication errors: 40.4%	NR

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First author (year)	Country or region	Study design	Ward type	Study period	Age range or mean (SD)[a]	Data collection method	Source of medication error definition	Medication error rate	Associated factors
Abdel-Qader et al [38], 2021	Jordan	Cross-sectional	NICU, PICU, general pediatrics, surgical ICU, pediatric surgery	2019	2.1 years (mean)	Medical record review	NR	Prescription errors: 31.5%	Number of prescribed medications
Kadmon et al [39], 2021	Israel	Cohort	PICU[j]	2015 - 2016	6.5 years (mean)	Database	NR	Prescription errors: 1.6%	Age, disease severity
Yehualaw et al [40], 2021	Ethiopia	Cross-sectional	Pediatric ward	2018 - 2019	3.26 years (median, IQR 2 - 4)	Medical record review	NR	Proportion of patients experiencing medication errors: 28.3%	Age
Bharathi et al [41], 2020	India	Cohort	NICU	2016	NR	Voluntary reporting; interview; medical record review	Reference	Proportion of patients experiencing medication errors: 22%	Polypharmacy, length of hospital stay
Brennan-Bourdon et al [42], 2020	México	Cross-sectional	PEC[k], NICU, NIMCU, PICU	2017 - 2018	0 - 18 years (range)	Medical record review	NCC MERP	Prescription errors: 53.5%	NR
Howlett et al [43], 2020	Ireland	Cross-sectional	PICU	2017	0 - 16 years (range)	Bedside direct observation; electronic prescription system	NCC MERP	Administration errors: 13.0%	NR
McMullan et al [44], 2020	Australia	Cross-sectional	Pediatric ward	2014 - 2017	0 - 18 years (range)	Standardized online audit tool	NR	Prescription errors: 19.6%	Admission to nontertiary pediatric hospital, hospital location in nonmajor city
Bonafide et al [45], 2020	United States	Cohort	PICU	2016 - 2017	<6 months to ≥18 years (range)	Telecommunications and electronic health record data	Investigator-defined	Administration errors: 3.2%	Mobile phone interruptions, nursing experience, nurse-to-patient ratio, patient care level
Ramírez-Camacho et al [46], 2020	México	Cross-sectional	NICU	NR	NR	Direct observation	NCC MERP	Administration errors: 34.6%	NR
Eslami et al [47], 2019	Iran	Cross-sectional	NICU	2016	NR	Medical record review	NCC MERP	Proportion of patients experiencing medication errors: 74.8%; prescription errors: 42.0%	Gestational age, length of hospital stay

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First author (year)	Country or region	Study design	Ward type	Study period	Age range or mean (SD)[a]	Data collection method	Source of medication error definition	Medication error rate	Associated factors
Fekadu et al [48], 2019	Ethiopia	Cross-sectional	Pediatric ward	2017	1 month to 12 years (range)	Medical record and medication chart review	NR	Proportion of patients experiencing medication errors: 68.0%	Critical illness, administration route, number of prescribed medications
Palmero et al [49], 2019	Switzerland	Cross-sectional	NICU	2010-2012	33.4 weeks (mean)	Direct observation	NCC MERP	Patient-related errors: 84.8%	Number of prescribed medications, gestational age
Tang et al [50], 2018	Malaysia	Cross-sectional	Pediatric ward	NR	0.1-16.1 years (range)	Direct observation	ASHP[l]	Prescription errors: 1.5%; administration errors: 10.4%	Intravenous formulations, gastrointestinal medications
Kadam et al [51], 2018	India	Cross-sectional	NICU	2013	NR	Medical record review	ASHP	Prescription errors: 65.6%	NR
Ergül et al [52], 2018	Turkey	Cross-sectional	ICU, hematology, infectious diseases, pediatric ward	2017	10 - 80 months (range)	Medical record review	NR	Proportion of patients experiencing medication errors: 33.8%	NR
Baraki et al [53], 2018	Ethiopia	Cross-sectional	Pediatric ward, PICU and NICU	2016 - 2017	1 day to 14 years (range)	Structured questionnaire; observation	WHO and NCC MERP	Administration errors: 62.3%	Patient age, education level of administering health care provider, availability of pharmacy preparation room, number of prescribed medications, availability of medication administration guidelines
Rishoej et al [54], 2018	Denmark	Cross-sectional	NICU, PICU and pediatric ward	2016	0 - 16 years (range)	Unobtrusive direct observation; on-site recording	NCC MERP	Administration errors: 8.0%	NR
Truter et al [55], 2017	South Africa	Cross-sectional	Neonatal and pediatric ward	6 months	1 month to 19 years (range)	Direct observation; medical record and prescription review; medication error checklist	NCC MERP	Proportion of patients experiencing medication errors: 78.0%	NR

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First author (year)	Country or region	Study design	Ward type	Study period	Age range or mean (SD)[a]	Data collection method	Source of medication error definition	Medication error rate	Associated factors
Al-Ramahi et al [56], 2017	Palestine	Cohort	Pediatric ward	2014	1 - 182 months (range)	Medical record review	Drug information handbook	Prescription errors: 22.4%; proportion of patients experiencing medication errors: 40.0%	Age, weight, number of medications, length of hospital stay
Mekory et al [57], 2017	Israel	Cross-sectional	Pediatric ward	2013 - 2014	0 - 18 years (range)	Medical record review	ASHP	Prescription errors: 6.5%; administration errors: 11.3%	NR
Nikhithasri et al [58], 2017	India	Cross-sectional	PICU and NICU	6 months	0 - 18 years (range)	Records; direct communication	NCC MERP	Prescription errors: 56.1%	NR
Khoo et al [59], 2017	Malaysia	Cross-sectional	Pediatric ward, PICU and NICU	2015	0 - 18 years (range)	Drug chart review	NR	Prescription errors: 9.2%	NR
Ewig et al [60], 2017	China	Cohort	PICU	2015	3.2 years (mean, SD 3.2)	Medical record review	Institute of Medicine	310 errors per 100 admissions	NR
Tribble et al [61], 2020	United States	Cross-sectional	Medical, surgical, NICU and non-neonatal intensive care	2016 - 2017	0 - 17 years (range)	Electronic medical record review; standardized assessment form	NR	Proportion of patients experiencing medication errors: 25.7%; prescription errors: 21.0%	Prescription drug category, indication
Dedefo et al [62], 2016	Ethiopia	Cohort	Pediatric ward	2014	≤28 days to ≤14 years (range)	Medical record review	ASHP	Proportion of patients experiencing medication errors: 75.1%; prescription errors: 46.0%	Length of hospital stay, number of prescribed medications
Palmero et al [63], 2016	Switzerland	Cohort	NICU	8 months	33.1 weeks (mean)	Review of medical orders	Reference	Prescription errors: 28.9%	NR
Machado et al [64], 2015	Brazil	Cross-sectional	NICU	2011	NR	Medical record review	ASHP	Prescription errors: 43.5	Gestational age, weight
Glanzmann et al [65], 2015	Switzerland	Cohort	PICU	2010	NR	Medical record review	Reference	Prescription errors: 13.4%	NR
Stultz et al [66], 2014	United States	Cohort	General ward	2011	0 - 17.8 years (range)	Electronic medical record; pharmacy record review	Guidelines and formularies	Prescription errors: 0.54%	NR

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First author (year)	Country or region	Study design	Ward type	Study period	Age range or mean (SD)[a]	Data collection method	Source of medication error definition	Medication error rate	Associated factors
Sakuma et al [67], 2014	Japan	Cohort	Pediatric general ward, NICU, PICU, ICU, and emergent care unit	2009	2 years (median, IQR 0 - 7)	Medical record review	NR	69.5 errors per 100 admissions	NR
Chedoe et al [68], 2012	The Netherlands	Cohort	NICU	2006	≥25 weeks (range)	Direct observation	NR	Administration errors: 48.6%	NR
Booth et al [69], 2012	United Kingdom	Cohort	PICU	32 weeks	1.65 years (median, IQR 0.35 - 6.10)	Prescription review	Reference	892 errors per 1000 occupied bed-days	NR
Al-Jeraisy et al [70], 2011	Saudi Arabia	Cohort	PICU	5 weeks	0 - 14 years (range)	Medical record review	Reference	Prescription errors: 56.0%	NR
Kunac et al [71], 2010	New Zealand	Cohort	NICU, postnatal ward and pediatric ward	2002	NR	Medical record review; multidisciplinary meeting; parent interview; voluntary report	NCC MERP	NR	Length of hospital stay, number of prescribed medications, administration route
Feleke et al [72], 2010	Ethiopia	Cross-sectional	Pediatric ward	2009	0 - 15 years (range)	Direct observation	Reference	Administration errors: 89.9%	NR
Chua et al [73], 2010	Malaysia	Cross-sectional	General pediatric ward and pediatric oncology ward	2004 - 2005	0 - 16 years (range)	Direct observation	Reference	Administration errors: 11.7%	Ward type
Ghaleb et al [74], 2010	United Kingdom	Cross-sectional	Surgical, medical, intensive care (PICU or NICU), adolescent units	2004 - 2006	NR	Drug chart review; unobtrusive observation	Reference	Prescription errors: 13.2%; administration errors: 19.1%	NR
Ligi et al [75], 2008	France	Cohort	NICU	2005	NR	Anonymous voluntary reporting system; independent observer verification; standardized form recording	Reference	4.9 errors per 100 admissions	NR
Campino et al [76], 2008	Spain	Cohort	NICU	NR	NR	Medical record review	Reference	Prescription errors: 32.8%; transcription error rate: 20.5%	NR

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First author (year)	Country or region	Study design	Ward type	Study period	Age range or mean (SD)[a]	Data collection method	Source of medication error definition	Medication error rate	Associated factors
Parihar et al [77], 2008	India	Cohort	NICU, PICU, pediatric ward, and rooming-in labor ward	2005	28 weeks to 18 years (range)	Medical record review; interview	Reference	Prescription errors: 24.3%	NR
Otero et al [78], 2008	Argentina	Cross-sectional	NICU, PICU, pediatric ward	2002	0 - 18 years (range)	Medical record review	ASHP	Prescription errors: 11.4%	Night shift, age, year of resident or researcher, assistant administration
Buckley et al [79], 2007	United States	Cohort	PICU	2004	0 - 18 years (range)	Direct observation	Reference	Prescription errors: 14.6%	NR
Wang et al [80], 2007	United States	Cross-sectional	NICU, PICU, pediatric ward	2002	NR	Medical record review; voluntary reporting	Reference	Prescription errors: 5.1%	NR
Walsh et al [81], 2006	United States	Cohort	NICU, PICU, pediatric ward	2002 - 2003	NR	Medical record review; computer log analysis; standardized form recording	Reference	Prescription errors: 1.5%	NR
Prot et al [82], 2005	France	Cross-sectional	PICU, NICU, pediatric nephrology unit, and general pediatric unit	2002 - 2003	NR	Direct observation	ASHP	Administration errors: 31.3%	Drug category, administration route, nurse type, number of patient management protocols
Potts et al [83], 2004	United States	Cohort	Pediatric critical care unit	2001 - 2002	6.5 years (mean, SD 12.0)	Medical record review	Investigator-defined	Prescription errors: 39.1%	NR

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First author (year)	Country or region	Study design	Ward type	Study period	Age range or mean (SD)[a]	Data collection method	Source of medication error definition	Medication error rate	Associated factors
Kaushal et al [3], 2001	United States	Cohort	Pediatric general medical wards, general surgical wards, PICU, and NICU	1999	NR	Clinical staff reports and review of prescription sheets, medication administration records, and patient charts	Reference	Prescription errors: 5.7%	NR

[a]The age values are reported as range, mean (SD), or median (IQR) as available.

[b]NICU: neonatal intensive care unit.

[c]range: minimum-maximum.

[d]NR: not reported.

[e]eMM: electronic medication management system.

[f]NCC MERP: National Coordinating Council for Medication Error Reporting and Prevention.

[g]WHO: World Health Organization.

[h]BNFC: British National Formulary for Children.

[i]NICE: National Institute for Health and Care Excellence.

[j]PICU: pediatric intensive care unit.

[k]PEC: pediatric emergency care.

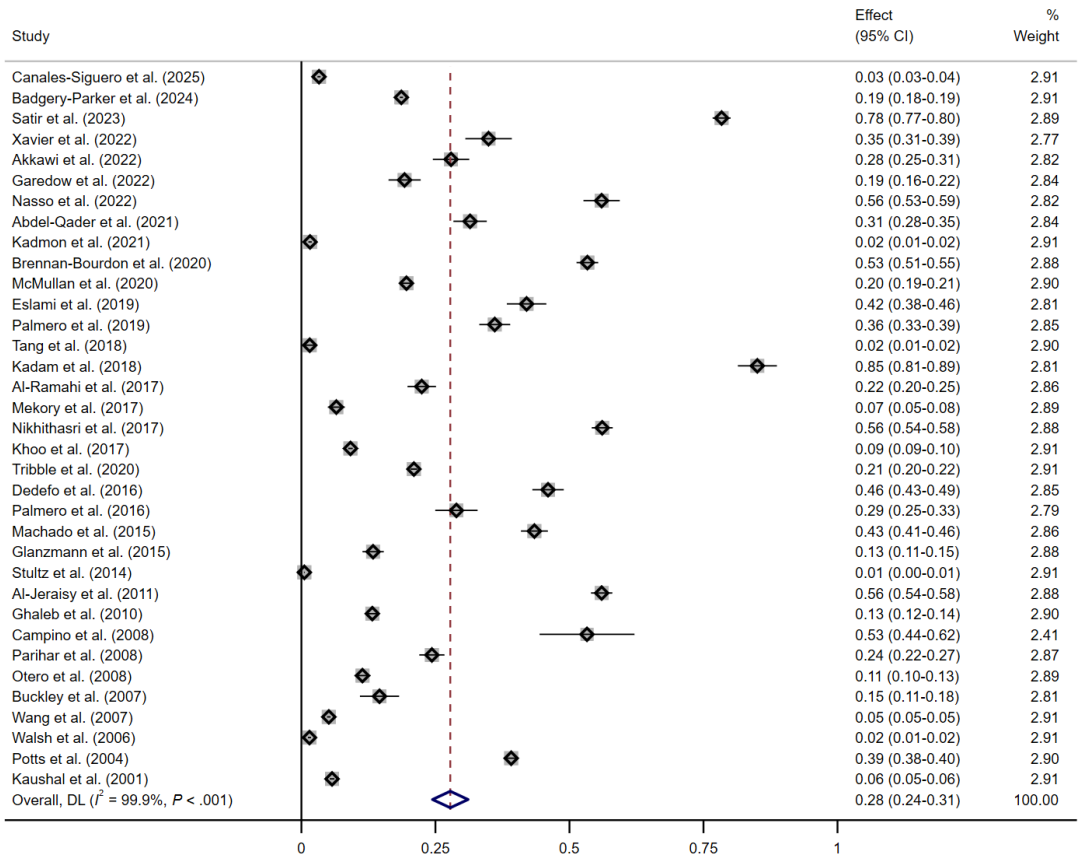
[l]ASHP: American Society of Health-System Pharmacists.

Meta-Analysis of Prescribing Errors in Hospitalized Pediatric Patients

Based on the denominators used in the included studies, we reported prescribing and administration error rates as well as the proportion of patients experiencing medication errors. Thirty-five studies [3,24,26,30,32-35,38,39,42,44,47,49-51,56-59,61-66,70,74,76-81,83] reported prescribing error rates in hospitalized children. Significant heterogeneity was observed among studies (I^2=99%; P<.001). Sensitivity analyses using a leave-one-out approach indicated that no single study significantly influenced the overall results. Therefore, a random-effects model was applied. The pooled prescribing error rate among hospitalized pediatric patients was 28% (95% CI 24% - 31%; Figure 2).

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Figure 2. Forest plot of prescribing error rates in hospitalized pediatric patients. Weights are from random effects model. DL: DerSimonian-Laird [3,24,26,30,32-35,38,39,42,44,47,49-51,56-59,61-66,70,74,76-81,83].



Subgroup Analysis of Prescribing Error Rates in Hospitalized Pediatric Patients

Subgroup analyses of prescribing error rates are presented in Table 2, with the number of included studies reported for each category. When stratified by study design, prescribing error rates were comparable between cohort studies (28%, 95% CI 23% - 34%) and cross-sectional studies (27%, 95% CI 22% - 32%). By country income level, prescribing error rates appeared higher in lower-middle–income countries (44%, 95% CI 24% - 64%) compared with low-income countries (33%, 95% CI 16% - 51%), although the number of studies in each subgroup was limited and CIs were wide. Regional subgroup analysis showed variability across geographic areas. The highest estimate was observed in Latin America and the Caribbean (36%, 95% CI 8% - 64%), whereas North America showed a lower estimate (12%, 95% CI 7% - 17%). However, these differences should be interpreted cautiously due to limited study numbers and substantial uncertainty. Regarding ward type, intensive care units showed higher prescribing error rates (34%, 95% CI 29% - 39%). For prescription types, antibiotic medications showed slightly higher error rates (30%, 95% CI 24% - 36%) compared with nonantibiotic medications (27%, 95% CI 24% - 31%). For temporal trends, studies conducted between 2013 and 2025 showed higher prescribing error rates (32%, 95% CI 26% - 38%) compared with those conducted between 2000 and 2012 (18%, 95% CI 14% - 22%). However, this finding should be interpreted cautiously given potential differences in study settings, definitions, and data collection methods across time periods.

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Table . Subgroup analysis of prescribing error rates in hospitalized pediatric patients.

Subgroup	Studies, n	Events, n	Total, n	Prevalence (95% CI)	*P* value	I^2 (%)
Study design						
Cross-sectional	19	13,398	89,380	0.27 (0.22-0.32)	<.001	99.85
Cohort	16	21,618	157,676	0.28 (0.23-0.34)	<.001	99.95
Country income level						
High income	20	27,301	206,580	0.23 (0.19-0.27)	<.001	99.95
Upper-middle income	7	4227	25,689	0.27 (0.16-0.38)	<.001	99.82
Lower-middle income	5	2489	5919	0.44 (0.24-0.64)	<.001	99.67
Low income	3	803	2244	0.33 (0.16-0.51)	NA[a]	NA
Study location						
Europe	8	3857	32,939	0.35 (0.15-0.55)	<.001	99.92
Asia	11	5897	28,962	0.31 (0.23-0.39)	<.001	99.89
Africa	3	803	2244	0.33 (0.16-0.51)	NA	NA
North America	7	8011	105,964	0.12 (0.07-0.17)	<.001	99.94
Latin America and the Caribbean	3	2101	5602	0.36 (0.08-0.64)	NA	NA
Australia and New Zealand	2	14,047	75,000	0.19 (0.18-0.19)	NA	NA
Special regions	1	213	949	0.22 (0.20-0.25)	NA	NA
Ward type						
Intensive care unit	17	10,070	89,161	0.34 (0.29-0.39)	<.001	99.91
General ward	11	17,588	83,764	0.30 (0.20-0.40)	<.001	99.87
Mixed wards	7	7358	74,131	0.10 (0.05-0.14)	<.001	99.84
Prescription type						
Antibiotic prescriptions	7	5971	26,589	0.30 (0.24-0.36)	<.001	98.81
Non-antibiotic prescriptions	28	29,045	220,467	0.27 (0.24-0.31)	<.001	99.94
Study period						
2000 - 2012	11	6027	87,882	0.18 (0.14-0.22)	<.001	99.87
2013 - 2025	18	25,435	142,088	0.32 (0.26-0.38)	<.001	99.92
NA	6	3554	17,086	0.33 (0.17-0.50)	<.001	99.90

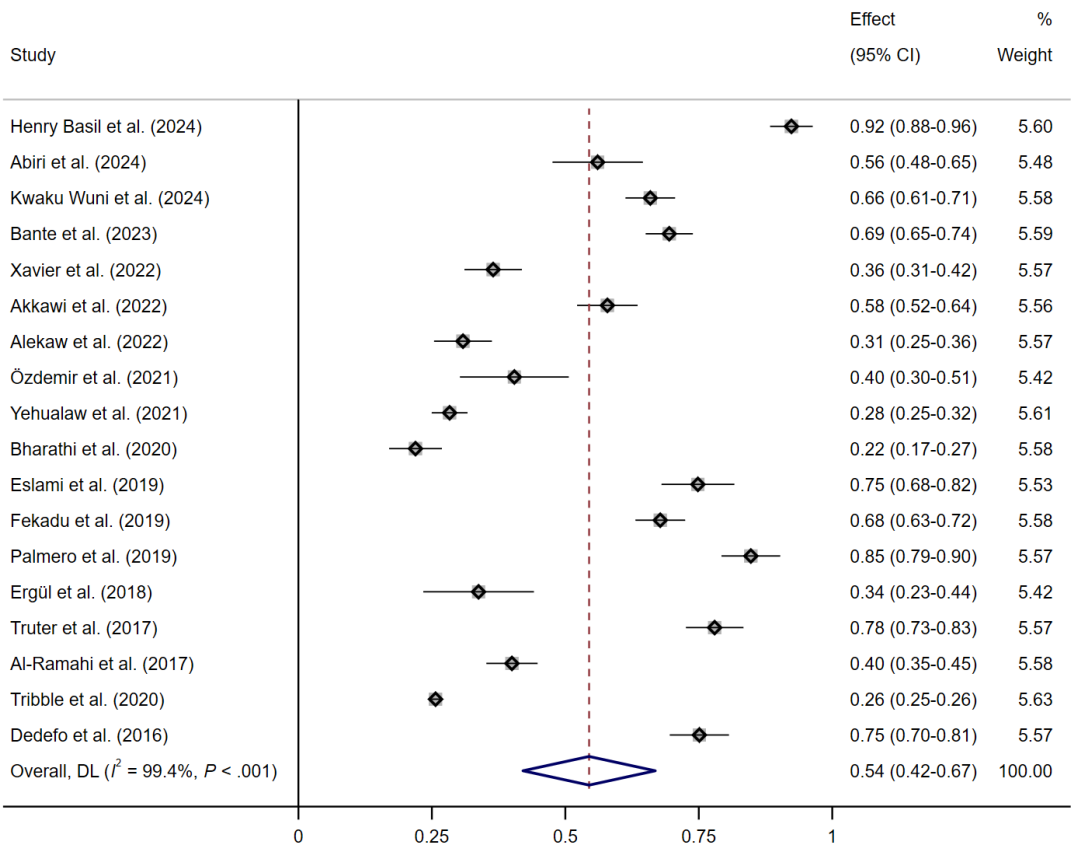
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Meta-Analysis of the Proportion of Patients Experiencing Medication Errors

Based on the denominators used in the included studies, we reported the proportion of patients experiencing medication errors, as well as prescribing and administration error rates. Eighteen studies [25,28,29,31-33,36,37,40,41,47,48,52,55,56,61-63] reported the proportion of patients with medication errors. The meta-analysis showed significant heterogeneity across studies (I^2=99%; P<.001). A sensitivity analysis using the leave-one-out method indicated that no single study had a substantial impact on the pooled results. Therefore, a random-effects model was applied. The analysis estimated that 54% of the hospitalized pediatric patients experienced at least 1 medication error (95% CI 42% - 67%), as shown in Figure 3.

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Figure 3. Forest plot of the proportion of hospitalized pediatric patients experiencing medication errors. Weights are from random effects model. DL: DerSimonian-Laird [25,28,29,31-33,36,37,40,41,47-49,52,55,56,61,62].



Subgroup Analysis of the Proportion of Patients Experiencing Medication Errors

The results of the subgroup analysis are presented in Table 3, with the number of studies reported for each subgroup. By study design, similar proportions were observed in cohort studies (57%, 95% CI 24% - 90%) and cross-sectional studies (54%, 95% CI 41% - 67%). By national income level, upper-middle–income countries showed a higher proportion (64%, 95% CI 50% - 77%) than other groups, but the number of studies was small. By region, estimates varied from 26% (95% CI 25% - 26%) to 85% (95% CI 78% - 90%). These results should be interpreted with caution due to limited studies and wide CIs. By prescription type, nonantibiotic prescriptions showed a higher proportion (66%, 95% CI 53% - 79%). By time period, the estimates were similar between 2018 and 2025 (55%, 95% CI 37% - 72%) and 2000 - 2017 (52%, 95% CI 34% - 69%).

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Table . Subgroup analysis of the proportion of hospitalized pediatric patients experiencing medication errors.

Subgroup	Studies, n	Events, n	Total, n	Prevalence (95% CI)	*P* value	I^2 (%)
Study design						
Cross-sectional	14	4972	15,401	0.54 (0.41-0.67)	<.001	99.30
Cohort	4	551	1072	0.57 (0.24-0.90)	<.001	99.48
Country income level						
High income	2	3166	11,948	0.27 (0.26-0.28)	NA[a]	NA
Upper-middle income	7	945	1412	0.64 (0.50-0.77)	<.001	97.32
Lower-middle income	2	219	669	0.31 (0.28-0.35)	NA	NA
Low income	7	1193	2444	0.52 (0.36-0.68)	<.001	98.64
Study location						
Europe	1	139	164	0.85 (0.78-0.90)	NA	NA
Asia	6	564	1055	0.54 (0.28-0.80)	<.001	99.07
Africa	9	1633	3070	0.56 (0.43-0.70)	<.001	98.60
North America	1	3027	11,784	0.26 (0.25-0.26)	NA	NA
Special regions	1	160	400	0.40 (0.35-0.45)	NA	NA
Prescription type						
Antibiotic prescriptions	7	3653	13,523	0.36 (0.28-0.44)	<.001	95.93
Nonantibiotic prescriptions	11	1870	2950	0.66 (0.53-0.79)	<.001	98.51
Study period						
2010 - 2017	9	4000	13,559	0.52 (0.34-0.69)	<.001	99.33
2018 - 2025	8	1346	2687	0.55 (0.37-0.72)	<.001	99.08
NA	1	177	227	0.78 (0.72-0.83)	NA	NA

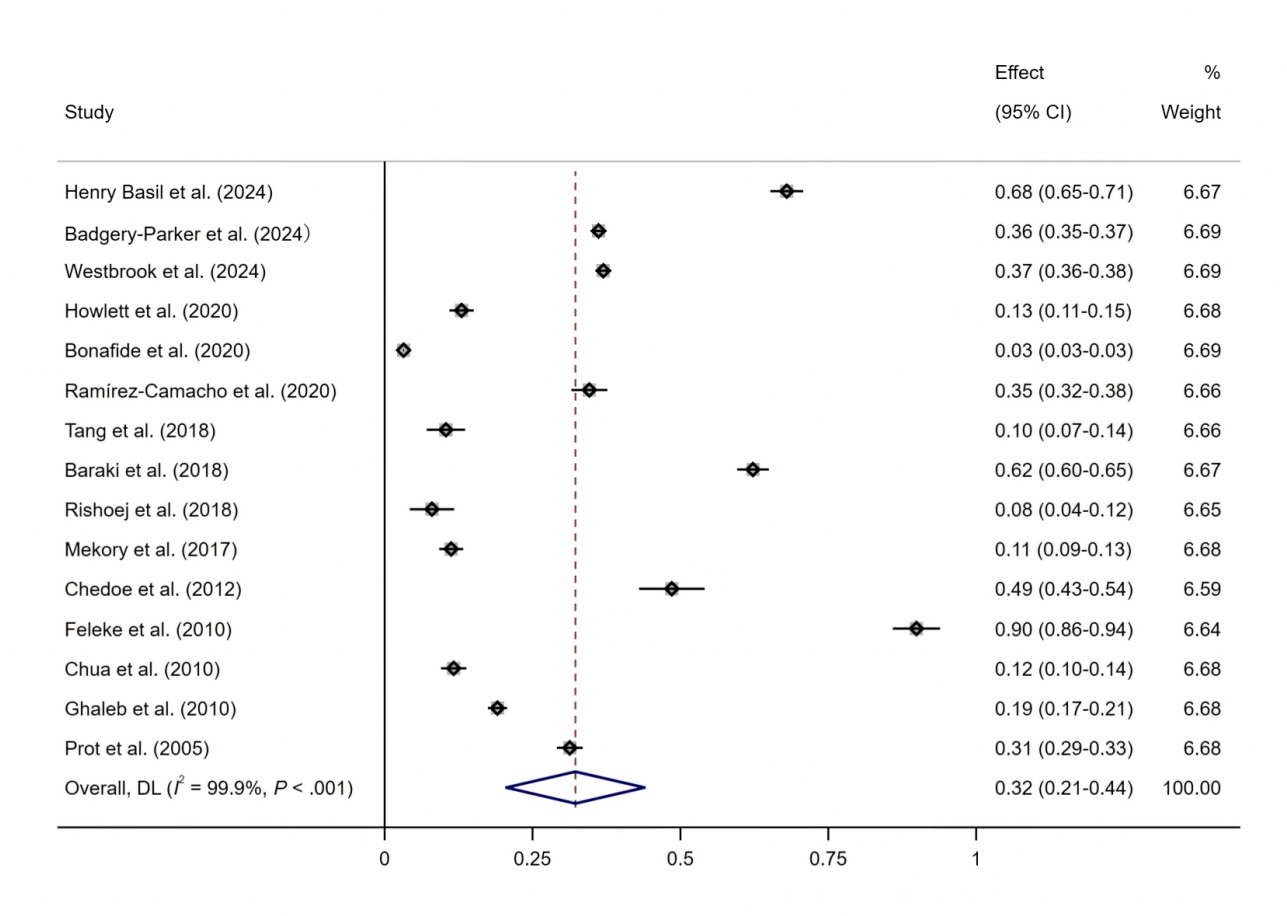
[a]NA: not applicable.

Meta-Analysis of Medication Administration Errors in Hospitalized Pediatric Patients

Fifteen studies [25-27,43,45,46,50,53,54,57,68,72-74,82] reported medication administration error rates in hospitalized pediatric patients. Meta-analysis revealed substantial heterogeneity among studies (I^2=99%; P<.001). Sensitivity analysis using the leave-one-out method indicated that no single study significantly influenced the overall estimate. Therefore, a random-effects model was applied, showing that the pooled rate of medication administration errors was 32% (95% CI 21% - 44%; Figure 4).

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Figure 4. Forest plot of medication administration error rates in hospitalized pediatric patients. Weights are from random effects model. DL: DerSimonian-Laird [25-27,43,45,46,50,53,54,57,68,72-74,82].



Subgroup Analysis of Medication Administration Error Rates in Hospitalized Pediatric Patients

The results of the subgroup analysis for administration error rates are presented in Table 4, with the number of studies reported for each subgroup. By study design, cohort studies showed higher estimates (39%, 95% CI 15% - 62%) than cross-sectional studies (29%, 95% CI 16% - 42%). By national income level, low-income countries showed a higher estimate (71%, 95% CI 69% - 73%) compared with other groups, but the number of studies was limited. By region, estimates varied across areas, ranging from 3% (95% CI 3% - 3%) to 71% (95% CI 69% - 73%). These differences should be interpreted cautiously due to limited data and uncertainty. By ward type, ICU (33%, 95% CI 10% - 57%) and general wards (33%, 95% CI 18% - 48%) showed similar estimates. By study period, estimates were 40% (95% CI 20% - 60%) and 29% (95% CI 11% - 47%), with overlapping CIs.

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Table . Subgroup analysis of medication administration error rates in hospitalized pediatric patients.

Subgroup	Studies, n	Events, n	Total, n	Prevalence (95% CI)	*P* value	I^2 (%)
Study design						
Cross-sectional	10	2655	9718	0.29 (0.16-0.42)	<.001	99.64
Cohort	5	12,284	250,218	0.39 (0.15-0.62)	<.001	99.94
Country income level						
High income	9	12,761	255,240	0.23 (0.11-0.35)	<.001	99.87
Upper-middle income	4	1203	3227	0.31 (0.04-0.58)	<.001	99.74
Low income	2	975	1469	0.71 (0.69-0.73)	NA[a]	NA
Study location						
Europe	5	1267	5502	0.24 (0.14-0.33)	<.001	98.61
Asia	4	882	2355	0.25 (−0.00-0.51)	<.001	99.77
Africa	2	975	1469	0.71 (0.69-0.73)	NA	NA
North America	1	7633	238,540	0.03 (0.03-0.03)	NA	NA
Latin America and the Caribbean	1	325	939	0.35 (0.32-0.38)	NA	NA
Australia and New Zealand	2	3757	10,274	0.37 (0.36-0.37)	NA	NA
Ward type						
Intensive care unit	5	8985	241,906	0.33 (0.10-0.57)	<.001	99.86
General ward	6	4192	12,611	0.33 (0.18-0.48)	<.001	99.72
Mixed wards	4	1762	5419	0.30 (0.10-0.50)	<.001	99.65
Study period						
2000 - 2012	5	1414	5354	0.40 (0.20-0.60)	<.001	99.69
2013 - 2025	7	11,266	248,168	0.29 (0.11-0.47)	<.001	99.91
NA	3	2259	6414	0.27 (0.12-0.42)	NA	NA

[a]NA: not applicable.

Meta-Analysis of Factors Associated With Medication Errors in Hospitalized Pediatric Patients

Intravenous administration, hospital stay longer than 5 days, and prescription of 3 or more medications were identified as factors associated with medication errors in hospitalized pediatric patients. Among these, intravenous administration was most strongly associated with medication errors (OR 6.86, 95% CI 3.17 - 14.83), followed by the prescription of 3 or more medications (OR 2.12, 95% CI 1.66 - 2.70) and a hospital stay longer than 5 days (OR 1.94, 95% CI 1.33 - 2.81; Table 5).

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Table . Meta-analysis of factors associated with medication errors in hospitalized pediatric patients.

Associated factors	Number of studies	Minimum OR[a]	Maximum OR	Pooled OR (95% CI)	I^2 (%)	*P* value for heterogeneity
Route of administration (intravenous vs oral)	4	3.36	21.18	6.86 (3.17-14.83）	89.4	<.001
Sex (male vs female)	3	0.82	1.09	1.00 (0.80-1.26）	0.0	.61
Hospital stay (>5 days vs <5 days)	5	1.34	3.46	1.94 (1.33-2.81）	63.1	.03
Number of prescribed medications (≥3 vs 1 - 2)	5	1.24	7.02	2.12 (1.66-2.70）	40.1	.15
Weight (>20 kg vs <10 kg)	2	1.13	1.7	1.28 (0.63-2.58)	0.0	.60
Night shift	2	0.81	3.06	1.52 (0.41-5.60)	94.9	<.001

[a]OR: odds ratio.

Sensitivity Analysis

Sensitivity analyses were conducted using a leave-one-out approach. Sequential exclusion of each study did not materially change the pooled estimates for prescribing errors, proportion of patients experiencing medication errors, or administration errors, indicating the robustness of the findings (Figures S1-S3 in Multimedia Appendix 3). To assess the robustness of the pooled estimates, the results obtained using the DerSimonian-Laird method were further validated using the REML method. The pooled effect estimates derived from the 2 methods were highly consistent, with substantial overlap in the corresponding 95% CIs, indicating good robustness of the study findings (Figures S4-S6 in Multimedia Appendix 3).

Publication Bias

Because fewer than 10 studies were included for each factor associated with medication errors, publication bias was only assessed for medication error rates. Multiple methods were used to evaluate publication bias. Funnel plots for prescribing errors, administration errors, and proportion of patients with medication errors showed asymmetry (Figures 7-9 in Multimedia Appendix 3). Egger tests indicated potential publication bias for prescribing errors and administration errors (z=9.39; P<.001 and z=2.25; P=.03). However, nonparametric trim-and-fill analyses (imputed studies=0) suggested that no additional studies were needed. Therefore, the observed asymmetry likely reflects true heterogeneity between studies rather than solely publication bias.

Discussion

Principal Findings

This systematic review and meta-analysis evaluated the overall medication error rates and associated factors in hospitalized pediatric patients. We found that 54% of the pediatric inpatients experienced a medication error, which is lower than the 69.5% reported by Bante et al [31]. The pooled prescribing error rate was 28%, comparable to the 28.9% reported by Palmero et al [63] but higher than the 17.5% reported by Koumpagioti et al [84]. The administration error rate was 32%, slightly lower than the 37% reported by Westbrook et al [27]. These discrepancies may be attributable to differences in the characteristics of the included populations, definitions of medication errors, and data collection methods. Furthermore, intravenous administration, hospital stay longer than 5 days, and prescription of 3 or more medications were identified as factors associated with medication errors, providing clinically relevant insights for error prevention strategies.

This systematic review and meta-analysis evaluated prescribing error rates, the proportion of patients experiencing medication errors, administration error rates, and associated factors among hospitalized pediatric patients. Notably, substantial heterogeneity was observed across all primary outcomes, and therefore the pooled estimates should be interpreted with caution. The observed heterogeneity may be attributable to methodological and clinical differences among the included studies [85]. Specifically, studies varied in their units of analysis, with some reporting errors per patient and others per prescription or medication administration. Variations were also identified in medication error detection methods, including direct observation, medical record review, and database-based data extraction, which may differ in their ability to identify errors. Furthermore, the included studies were conducted across diverse clinical settings, such as general pediatric wards, NICUs, and PICUs, where patient characteristics, medication-use processes, and risk profiles may differ substantially. In addition, definitions of medication errors were not uniform across studies. Collectively, these factors may have contributed to the high level of heterogeneity and may limit the generalizability of the pooled findings [86]. Therefore, the results of this review should be interpreted as reflecting the overall trends across the included studies rather than precise estimates applicable to all pediatric inpatient settings.

Subgroup analyses across prescription, patient, and administration dimensions highlight the complexity and heterogeneity of pediatric medication errors. Geographic and economic differences were observed, with higher estimates reported in Latin America and the Caribbean, Africa, and low-

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to middle-income countries. These findings may reflect differences in health care resources, reporting practices, and system development; however, they should be interpreted cautiously given the limited number of studies in several subgroups and substantial heterogeneity. Lower estimates observed in North America may be associated with more developed medication safety systems; however, this explanation remains speculative and was not directly examined in the included studies. Temporal trends showed higher prescribing error rates and a higher proportion of patients experiencing medication errors in more recent studies, which may reflect improved detection and reporting practices over time. In contrast, administration error rates appeared to decrease in recent years. PICUs consistently showed higher error rates, likely reflecting the complexity and high-risk nature of these clinical settings [87,88].

The findings of this study suggest that medication errors in hospitalized pediatric patients are closely associated with treatment-related factors, including intravenous administration, hospital stay longer than 5 days, and the prescription of 3 or more medications. However, as this study is based on observational data, the results reflect statistical associations rather than causal relationships, and residual confounding cannot be excluded.

Intravenous administration was associated with a higher likelihood of medication errors compared with oral administration (OR 6.86). This finding suggests that intravenous delivery may be an important factor associated with medication errors. Similar results have been reported by Westbrook et al [27], who observed 5137 medication administration events in hospitalized children and found that intravenous medications were associated with higher error rates, reaching 77.4% for injections and 64.7% for infusions. The complexity of intravenous medication processes, including dose calculation, dilution, preparation, and infusion rate adjustment, may contribute to the increased risk of errors. Pediatric dosing, which is often based on body weight or body surface area [62], further increases complexity. Rajakumar et al [89] also reported that such individualized dosing increases the risk of medication errors. In addition, pediatric doses are often substantially lower than adult doses, and even minor calculation or measurement errors may result in clinically significant dosing deviations, potentially leading to serious harm [74].

Patients with a hospital stay longer than 5 days were more likely to experience medication errors compared with those with a stay of 5 days or less (OR 1.94). This finding is consistent with the study by Bante et al [31], which also reported that longer hospital stays were associated with a higher risk of medication errors. Longer hospitalization may be associated with increased exposure to medications, resulting in a greater number of prescribing and administration processes, which in turn increases the opportunity for errors. However, any assumption that prolonged hospitalization directly leads to reduced adherence to verification procedures should be interpreted with caution, as this was not directly examined in the included studies.

Children receiving 3 or more prescribed medications had a higher likelihood of medication errors compared with those receiving fewer than 3 medications (OR 2.12). However, evidence regarding the underlying mechanisms of this association remains limited. This finding may be related to increased complexity in medication management as the number of prescriptions increases, including prescribing, verification, dispensing, and administration processes. It may also reflect greater exposure to medication-related procedures in patients receiving multiple drugs. In addition, patients receiving polypharmacy are often clinically more complex, which may contribute to higher observed error rates. Nevertheless, these explanations remain speculative, as the included studies did not provide sufficient information on drug classes, dosing frequency, or disease severity. Therefore, further research is needed to clarify the relationship between polypharmacy and medication errors and to explore potential underlying mechanisms.

Limitations

This study has several limitations. Although uniform inclusion criteria were applied, the definitions and classification systems for medication errors varied across the included studies. This may have led to misclassification bias, as certain error types may have been included in some studies but excluded in others. In addition, only studies published in English were included, which may have resulted in the omission of relevant evidence published in other languages, potentially limiting the global generalizability of the findings. Substantial heterogeneity was observed across the included studies, which may limit the interpretability and generalizability of the pooled estimates. Furthermore, only 3 outcomes were quantitatively synthesized, including the proportion of patients experiencing medication errors, prescription error rates, and administration error rates. Although some studies reported additional types of medication errors, such as dispensing errors and reconstitution errors, the limited number of studies and inconsistencies in reporting prevented meaningful meta-analysis of these outcomes. Therefore, the findings may not fully capture the overall burden of all types of medication errors in hospitalized pediatric patients. Future studies should adopt more standardized reporting frameworks for different types of medication errors to enable more comprehensive evidence synthesis.

Conclusions

The findings of this study indicate that medication errors remain a significant patient safety concern among hospitalized pediatric populations worldwide. Prescription errors and administration errors are the most frequently reported and relatively well-evidenced types of medication errors, and a substantial proportion of hospitalized pediatric patients experience at least 1 medication error. Intravenous administration, hospital stay longer than 5 days, and the prescription of 3 or more medications may be associated with an increased risk of medication errors, suggesting that treatment-related factors are closely linked to medication safety in pediatric inpatients. However, these findings should be interpreted as observational associations rather than causal relationships. These results highlight the importance of strengthening medication safety practices in pediatric inpatient settings to improve treatment quality and patient safety. Future research is needed to further investigate less-studied types of medication errors, such as dispensing and

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reconstitution errors, to provide a more comprehensive understanding of the overall burden and to support the development of targeted interventions.

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The authors declare that no generative AI or AI-assisted technologies were used in the writing, data analysis, or any other aspect of this manuscript. All content was produced solely by the authors.

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Authors' Contributions

XC, YM, and LY have made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data. XC, YM, XW, AL, JH, and LY were involved in drafting the manuscript or revising it critically for important intellectual content. XC, YM, XW, AL, JH, and LY gave final approval of the version to be published. XC, YM, XW, AL, JH, and LY agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.
XC and YM contributed equally to this work and share first authorship.

Conflicts of Interest

None declared.

Multimedia Appendix 1
The detailed search strategies for each database.
[DOC File, 90 KB - pediatrics_v9i1e100070_app1.doc]

Multimedia Appendix 2
Quality assessment of the included cross-sectional and cohort studies
[DOC File, 325 KB - pediatrics_v9i1e100070_app2.doc]

Multimedia Appendix 3
Sensitivity analyses, forest plots based on the restricted maximum likelihood random-effects model, and funnel plots for medication error outcomes.
[DOCX File, 991 KB - pediatrics_v9i1e100070_app3.docx]

Checklist 1
PRISMA 2020 checklist.
[PDF File, 170 KB - pediatrics_v9i1e100070_app4.pdf]

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Abbreviations

AHRQ: Agency for Healthcare Research and Quality
NCC MERP: National Coordinating Council for Medication Error Reporting and Prevention
NICU: neonatal intensive care unit
NOS: Newcastle-Ottawa Scale
OR: odds ratio
PICU: pediatric intensive care unit
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
REML: restricted maximum likelihood

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mHealth-Enabled Stroke Screening for Pediatric Sickle Cell Disease in Low-Resource Settings: Systematic Literature Review of Critical Barriers, Emerging Technologies, and AI-Driven Solutions

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Abstract

Background: Sickle cell disease (SCD) is a genetic blood disorder affecting millions globally, with life-threatening complications, and most patients live in sub-Saharan Africa. Particularly, children with SCD have a high risk of stroke. Although early screening for stroke could help prevent many cases, access to effective stroke screening remains limited in low-resource settings (LRS). Existing traditional approaches are highly operator-dependent, costly, resource-intensive, or difficult to deploy at scale in pediatric care. These limitations highlight the urgent need for accessible, scalable, and child-appropriate stroke screening and assessment tools suitable for low-resource health care contexts.

Objective: The aims of this systematic literature review are to (1) uncover system-level barriers affecting stroke screening accessibility for patients with pediatric sickle cell disease (PSCD) in LRS, including underserved contexts within high-income countries; (2) identify existing and emerging stroke screening and assessment technologies and their implementation characteristics, such as feasibility, scalability, portability, and training requirements; and (3) propose a user-centered mobile health (mHealth) framework for stroke screening that improves accessibility and feasibility in resource-constrained health care settings.

Methods: PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines were followed to organize the search process. A systematic search was conducted using an advanced query and defined eligibility criteria in the academic databases of PubMed, IEEE Xplore, Wiley Online Library, and Google Scholar. Studies published in English between January 1, 2021, and October 31, 2025, were selected. Collected data were arranged in a preformatted Microsoft Excel spreadsheet for analysis. Risk-of-bias assessment was performed using various risk-of-bias assessment tools because of the heterogeneity of the included studies. Narrative synthesis was used for data synthesis.

Results: The literature search initially identified 1465 studies, of which 28 (2%) were selected for analysis. Among the 28 studies, 10 (36%) focused on stroke screening accessibility for patients with PSCD in either low- and middle-income countries or other income-level countries for LRS, and 18 (64%) outlined key features and the feasibility of stroke screening technologies. Identified barriers were organized into 4 major categories (workforce and training constraints, health care system and infrastructure barriers, sociocultural and awareness factors, and economic and logistical constraints), emphasizing difficulties in accessing stroke screening in LRS. Additionally, existing and emerging stroke screening technologies were classified into 5 groups: nonimaging, imaging, light-based optical spectroscopy, biomarker-based, and artificial intelligence– and machine learning–based mHealth wearable approaches. Finally, a comprehensive mHealth app is proposed for an easy-to-use screening experience to address stroke screening challenges for patients with PSCD in LRS.

Conclusions: This study contributes to identifying major barriers to stroke screening in LRS and highlights key characteristics of stroke screening solutions that can be used in the future. It also contributes to the design of a holistic mHealth solution for implementing stroke screening clinical care for patients with PSCD in LRS.

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Trial Registration: PROSPERO 2025 CRD420251172487; https://tinyurl.com/3djampu6

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KEYWORDS

stroke screening; stroke prevention; low-resource setting; pediatric stroke; sickle cell disease; Preferred Reporting Items for Systematic Reviews and Meta-Analyses; PRISMA; mobile health; mHealth

Introduction

Background

Sickle cell disease (SCD) is a genetic blood disorder affecting millions of people globally, most of whom live in sub-Saharan Africa. About 75% of patients with SCD are from this region and experience high mortality rates, with an estimated 50% to 90% of affected children dying before the age of 5 years due to infections or life-threatening complications [1,2]. Children with SCD often experience severe complications. Studies indicate that about 11% of children with SCD in these regions experience stroke by the age of 20 years [3,4]. For instance, each year, at least 20,000 babies are born with SCD in Uganda, and up to 80% of these children do not survive beyond the age of 5 years because of complications and limited access to adequate health care [4,5]. Weak health care infrastructure, high costs, and limited availability of specialized medical personnel in these low-resource settings (LRS) further compound the challenges faced by these children. Particularly in rural regions, health care disparities present significant obstacles [5-7]. Despite ongoing efforts, mortality among children with SCD remains high because of inadequate and delayed stroke screening, emphasizing the urgent need for affordable and accessible solutions in LRS [5,8].

Several stroke screening tools exist for pediatric patients with SCD, differing in mechanism, accessibility, and clinical requirements. These stroke screening and assessment technologies include nonimaging techniques such as transcranial Doppler (TCD), the current gold standard; imaging methods such as magnetic resonance imaging (MRI) or magnetic resonance angiography (MRA); biomarker-based approaches; light-based optical spectroscopy techniques such as speckle contrast optical spectroscopy (SCOS), an emerging noninvasive technology; and artificial intelligence (AI)- and mobile health (mHealth)-enabled solutions for early stroke detection.

Traditional approaches, such as TCD ultrasonography, are the gold standard for stroke screening in pediatric sickle cell disease (PSCD) and can assess stroke risk in children with SCD aged 2 to 16 years [9]. Few centers in sub-Saharan Africa have the neuroradiology facilities needed to conduct TCD screenings. A clinical trial in Nigeria revealed that only around 3000 TCD assessments were performed out of 40,000 children needing screening, covering less than 8% [10]. Regular TCD detection of abnormal blood flow in the brain has proven effective in reducing stroke incidence in these children [11]. Studies have shown that consistent TCD screening can drastically lower stroke rates [3,12]. However, TCD has 2 major drawbacks: its operation is highly dependent on the expertise of operators, and although it is effective for assessing major brain arteries, it is not suitable for examining blood flow in smaller or specific parts of the brain [13]. For these reasons, despite its efficacy, TCD is still not widely implemented in resource-limited settings.

MRI or MRA is another crucial tool for stroke screening, delivering detailed images that reveal silent cerebral infarcts (SCI) and other cerebrovascular problems [14]. Research shows that MRI provides a broader view of cerebrovascular changes than TCD, leading to earlier interventions and better outcomes [15]. However, MRI is often unavailable in low-resource areas because of its high cost and lengthy availability procedures [16]. Moreover, the need for dye contrast and sedation in children adds complexity to its use. Hence, more affordable and less cumbersome imaging techniques are necessary as alternatives to MRI [14].

Recent advances in biomarker and genomic research now enable stroke risk assessment in patients with SCD [17]. Biomarker screening quantifies proteins and inflammatory markers, while genomic screening identifies genetic variations linked to susceptibility [18]. However, research on biomarkers and genomic screening for stroke prevention in SCD is ongoing [19].

Light-based SCOS solutions have shown promise in noninvasively assessing stroke risk [20]. Although this approach demonstrates significant potential for accessible and scalable stroke risk assessment, SCOS remains an emerging technology that requires further clinical validation for real-world use [21].

In addition, emerging technologies, such as wearable devices, have great potential for managing SCD because they allow continuous monitoring of vital parameters, such as oxygen saturation and heart rate [22,23]. These devices can alert both patients and health care professionals, enabling timely interventions before complications become life-threatening [24]. Although wearable devices vary in affordability, their continuous use may be impractical in resource-limited settings because of factors such as discomfort from wearing them all the time, the need for regular charging, and unreliable access to electricity [25].

mHealth technologies can significantly impact the management of SCD, especially in LRS [26]. For instance, mobile apps can monitor symptoms such as pain episodes [27,28], track disease progression, and enable timely interventions while also supporting patient engagement [29-31]. Overall, mHealth solutions have great potential in preventing chronic diseases because they can continuously track vital signs such as oxygen saturation and heart rate, providing real-time health information for improved disease management in critical situations [32].

Nevertheless, despite the great potential of mHealth solutions, significant gaps remain, particularly regarding their application to SCD [33,34]. Additionally, it is imperative to identify the

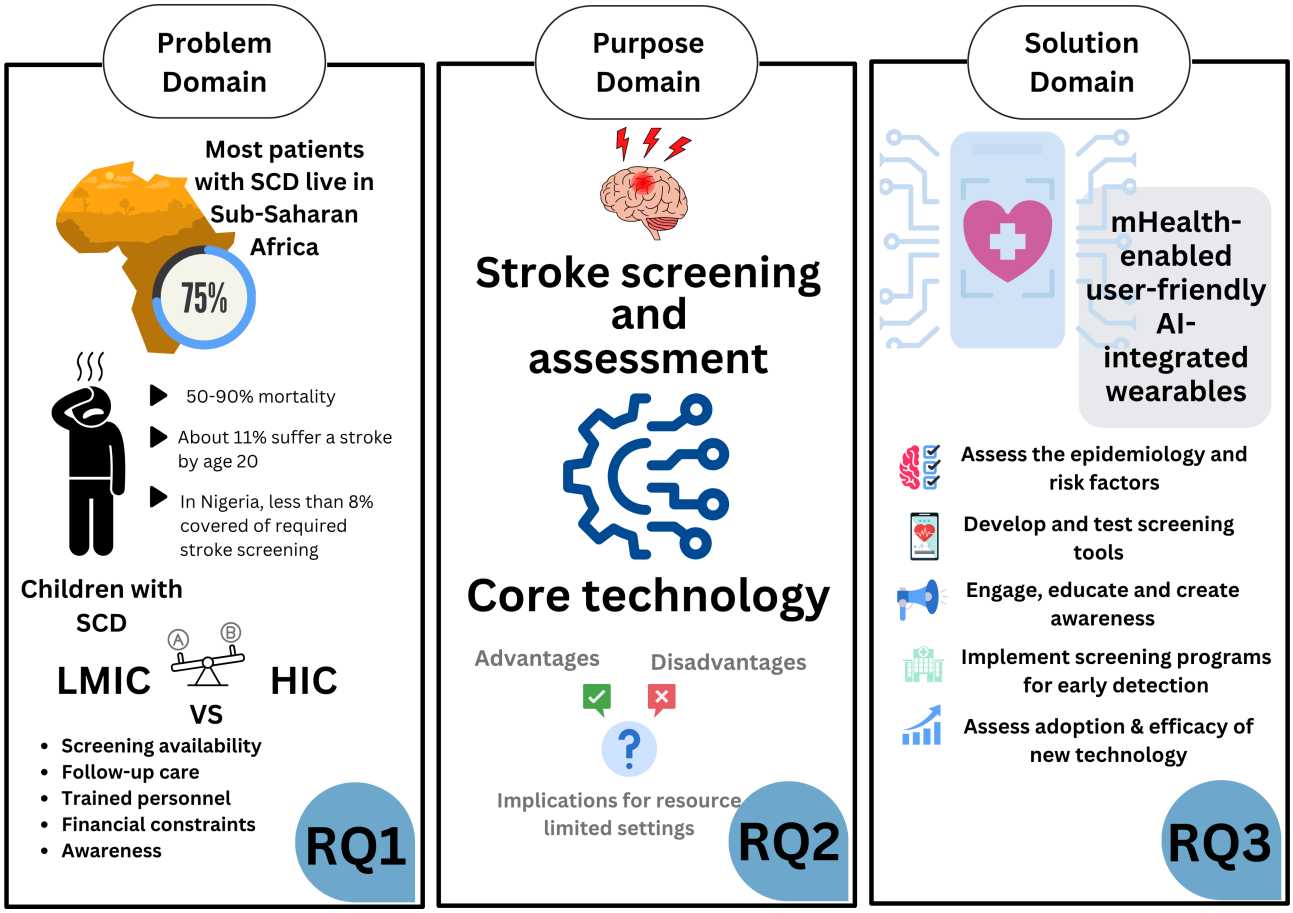
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barriers that impede the adoption of these mHealth solutions in LRS [35]. Furthermore, these mobile apps could foster better patient engagement in care by encouraging patients to actively participate in managing their condition [36-38].

Objective

Therefore, this study aims to explore the key barriers to stroke screening implementation for pediatric patients with SCD in LRS. We examine the feasibility of conventional and emerging practices for stroke screening assessment and investigate how a more modular, AI-enabled mHealth solution can promote early detection and management, support patient involvement, enhance monitoring, and improve overall health outcomes for pediatric patients with SCD. The findings of this systematic literature review are centered around the following 3 research questions, as illustrated in Figure 1.

Figure 1. Objective of this study and research question (RQ) generation, organized around the problem domain, purpose domain, and solution domain. AI: artificial intelligence; HIC: high-income country; LMIC: low- and middle-income country; mHealth: mobile health; SCD: sickle cell disease.



The study addressed the following research questions (RQs) as follows:

1. Problem domain (PSCD stroke): What are the key barriers influencing the implementation of stroke screening for patients with PSCD in LRS, including both low- and middle-income countries (LMICs) and resource-constrained contexts within other income-level countries?
2. Purpose domain (stroke screening and assessment): What existing and emerging stroke screening and assessment technologies have been evaluated in individuals with PSCD or broader populations with stroke, and what implementation characteristics (feasibility, scalability, portability, and training requirements) are relevant to their potential use in PSCD stroke screening?
3. Solution domain (addressing aims through mHealth solutions): How can an integrated, user-centered mHealth-based stroke screening framework be proposed to address accessibility barriers and support early stroke detection and follow-up care for patients with PSCD in LRS?

Methods

Overview

This systematic review was conducted according to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (Checklist 1). This review was registered with PROSPERO (CRD420251172487) and the full protocol can be accessed through the PROSPERO database. No amendments to the protocol were made following registration.

Eligibility Criteria

Studies were eligible for inclusion if they met the population, intervention, comparison, and outcome (PICO) criteria outlined in Table 1. Table 1 summarizes the inclusion and exclusion criteria based on the PICO framework, as described in Textbox 1.

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Table . Summary of inclusion and exclusion criteria.

Criteria	Inclusion criteria	Exclusion criteria
Population	• Pediatric patients (<18 y) at risk of stroke and diagnosed with SCD[a]. • Studies not exclusively focused on PSCD[b] were included only if they provided indirect, contextual, or technology-enabling evidence relevant to stroke screening implementation in PSCD or low-resource settings.	• Studies not focusing on stroke screening among patients with SCD. • Studies focusing exclusively on adult populations without relevance to pediatric or implementation contexts.

Intervention	• Any stroke screening or assessment method, including:
	  • Imaging: MRI[c] and MRA[d]
	  • Nonimaging: TCD[e]
	  • Laboratory biomarkers
	  • Optical spectroscopy or SCOS[f] tools
	  • Wearable devices
	  • mHealth[g] tools
	  • AI[h]- and ML[i]-based stroke assessment models
	• Studies not exclusive to PSCD were included only when they provided insights into implementation, scalability, or accessibility, offering possibilities for adaptation in stroke screening of PSCD in low-resource settings.
		• Studies unrelated to screening interventions (treatment-only studies).

Comparison	No comparator was required because the focus was on narrative and thematic synthesis.	• N/A[j]

Outcome	• Reports on at least one outcome related to:
	  • Screening feasibility or accessibility
	  • Accuracy or reliability
	  • Workflow or training requirements
	  • Implementation barriers or facilitators
	  • Portability, cost, or infrastructure needs
		• Studies not reporting any outcome related to screening implementation or feasibility.

Study design	• Quantitative, qualitative, mixed methods, or observational studies. • Retrospective cohort studies, cross-sectional studies, implementation studies, narrative reviews, systematic reviews, or technical feasibility studies. • Peer-reviewed journal articles or conference papers. Preprints were included only when they provided unique technology-enabling insights not yet available in peer-reviewed literature and were clearly labeled as preprints. • Published between January 1, 2021, and October 31, 2025.	• Editorials, interviews, comments, unstructured observations, and position papers.

[a] SCD: sickle cell disease.

[b]PSCD: pediatric sickle cell disease.

[c]MRI: magnetic resonance imaging.

[d]MRA: magnetic resonance angiography.

[e]TCD: transcranial Doppler.

[f]SCOS: speckle contrast optical spectroscopy.

[g]mHealth: mobile health.

[h]AI: artificial intelligence.

[i]ML: machine learning.

[j]N/A: not applicable.

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Textbox 1. Population, intervention, comparison, and outcome (PICO) framework for search query generation

Population

- Direct: pediatric patients (<18 y) who are at risk of stroke, particularly diagnosed with SCD.
- Indirect: Broader populations with stroke or neurological disorders were included only when studies provided indirect, technology-enabling, or contextual evidence relevant to stroke screening implementation in low-resource settings.

Intervention

- Studies examining stroke screening or assessment methods, including imaging (magnetic resonance imaging and magnetic resonance angiography), nonimaging approaches (transcranial Doppler), blood biomarkers, laboratory markers, wearable devices, mobile health tools, artificial intelligence–and machine learning–based technologies, or emerging screening modalities

Comparison

- No comparator was required because the focus was on narrative and thematic synthesis.

Outcome

- Studies reporting on screening feasibility, accessibility, accuracy, workflow processes, implementation challenges, barriers, facilitators, or overall effectiveness of stroke screening methods.

Definition of LRS

In this review, LRS was defined by the health care delivery context in which the essential capacity for routine stroke screening is hindered by a functional lack of medical infrastructure, specialized workforce, accessible funding for screening, or socioeconomic disparities [39]. This is a setting-level construct and may occur in both LMICs and underserved contexts within high-income countries (HICs) and other income-level countries. Country income status, such as LMIC, HIC, or other income-level countries, was recorded separately as a national-level descriptor.

Operationalization of Resource Setting

Although national income categories (LMIC or HIC) are frequently used as proxies for resource context, they do not capture the full range of constraints affecting health care delivery. Existing studies conceptualize that "LRS" consists of one or multiple interconnected domains of constraints, such as financial pressure, suboptimal health care service delivery, underdeveloped infrastructure, paucity of knowledge, research challenges and considerations, restricted social resources, geographical and environmental factors, human resource limitations, and the influence of beliefs and practices [39]. Using this concept, studies were classified as conducted in LRS if one or more system-level challenges hindered the routine delivery of stroke screening during the full-text screening and data extraction process. Although studies were initially tagged as conducted in LMICs or HICs using World Bank income classifications, the final classification was guided by this system-level conceptual framework rather than country income alone.

Database Selection and Search Strategy

The search was conducted in electronic databases including PubMed, Wiley Online Library, IEEE Xplore, and Google Scholar. A predefined search strategy, incorporating both Medical Subject Headings (MeSH) terms and free-text keywords, was used. The search terms were developed to capture literature related to stroke screening barriers, particularly those related to PSCD, stroke screening technologies, mHealth apps, and stroke screening challenges in LRS. Studies published in English between January 1, 2021, and October 31, 2025, were included. An advanced search string was built to search the databases. Search strategies were employed to align with the research questions, ensuring comprehensive coverage of the relevant literature.

The advanced search string used in this search was ((“stroke screening” OR “stroke risk assessment” OR “stroke prevention”) AND (“pediatric” OR “children” OR “child” OR “adolescent”) AND (“sickle cell disease” OR “SCD” OR “sickle cell anemia”) AND (“barriers” OR “enablers” OR “implementation” OR “training”)) OR ((“stroke screening” OR “stroke risk assessment” OR “stroke prevention”) AND (“TCD” OR “Transcranial Doppler” OR “mobile health” OR “mHealth” OR “wearable technology” OR “wearables” OR “wearable” OR “artificial intelligence” OR “AI” OR “MRA” OR “MRI” OR “Magnetic Resonance” OR “machine learning” OR “ML” OR “blood biomarkers” OR “biomarkers”)) (With filter in PubMed: Free full text filter, Wiley online library: Open Access Content).

Resource-setting terminology such as “low-resource,” “resource-limited,” “underserved,” or “resource-constrained” was not used as a mandatory search filter because these labels are not standardized and are applied inconsistently across disciplines and regions and are often absent from titles and abstracts. Instead, identification of LRS was prespecified as part of the full-text screening and data extraction process, using predefined system-level criteria described in the “Eligibility Criteria” section. This approach was used to avoid missing relevant studies while ensuring systematic and reproducible classification of the resource context.

Selection Process

The screening process was conducted according to the PRISMA framework [40]. Two reviewers (NJ and NA) independently conducted the literature screening process. During the identification step, we gathered our search results from the selected databases and exported them into the reference

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management tool Zotero (Corporation for Digital Scholarship) to remove duplicates [41]. During the screening and eligibility steps, a title-based screening was conducted using keywords derived from the advanced search queries. Following this, the screening was conducted based on an abstract review. Finally, studies meeting the initial criteria were subjected to full-text review based on the inclusion and exclusion criteria. Both reviewers performed these steps. Discrepancies were resolved through discussion or adjudication by a third reviewer (NS).

Risk-of-Bias Assessment

Risk-of-bias (RoB) assessment was conducted to evaluate the methodological quality of the included studies. Because the review comprised diverse study designs, including qualitative, quantitative, mixed methods, and technology-focused feasibility studies, the appropriate appraisal tools were applied accordingly. We used the Joanna Briggs Institute (JBI) Qualitative, JBI Analytical Cross-Sectional, JBI Text and Opinion, JBI Systematic Review and Research Syntheses, Newcastle-Ottawa Scale Cohort, Quality Assessment of Diagnostic Accuracy Studies–2 (QUADAS-2), Prediction Model Risk of Bias Assessment Tool (PROBAST), RoB 2.0, and Mixed Methods Appraisal Tool (MMAT; McGill University) for RoB assessment purposes (Multimedia Appendix 1). The assessment focused on key domains, including clarity of aims, methodological rigor, sampling, data collection, analytical transparency, and relevance to clinical or technological implementation. Studies were evaluated independently by 2 reviewers (NS and NA). Disagreements between the 2 reviewers were resolved through discussion.

Data Extraction

Data extraction was performed independently by 2 reviewers using a standardized Microsoft Excel form. The extracted data included study characteristics (author, year, country, study design, sample size, and population type; Multimedia Appendix 2). We also extracted study details and intervention details (resource settings, stroke screening accessibility challenges, barrier categories, tool type, tool characteristics, training requirements, outcomes, and challenges; (Multimedia Appendices 3 and 4). Extracted data were cross-checked for consistency and completeness. Due to the variation in methodologies across studies, conducting a meta-analysis was considered unsuitable. Instead, information was narratively synthesized. Data extraction was conducted manually from a total of 28 included studies (27 peer-reviewed studies and 1 preprint) following the identification and selection process outlined in the PRISMA framework.

Data Synthesis

For this systematic literature review, due to the heterogeneity in interventions, outcomes, and contexts, we employed narrative synthesis, as a meta-analysis was not feasible based on the reviewed studies. As this review did not involve statistical hypothesis testing or meta-analysis, no *P* values were reported. No statistical effect measures, such as risk ratios or mean differences, were used because the outcomes were qualitative and heterogeneous. We narratively synthesized qualitative data related to our research questions, applied thematic analysis to categorize different barriers to stroke screening accessibility, and used narrative synthesis to highlight the key characteristics and outcomes of technological solutions for stroke screening. We categorized included studies as direct evidence, which pertains to clinical stroke screening or assessment in populations with PSCD, and indirect evidence, which pertains to barriers or technology-enabling studies from broader populations with stroke or neurological disorders. Barriers were extracted, coded, and categorized into thematic domains (workforce and training challenges, health care and infrastructure, sociocultural and awareness, and logistical and economic factors). Studies focusing primarily on stroke screening technologies were included whether they involved pediatric patients with SCD or broader populations with stroke. We included them because they demonstrated scalability, feasibility, or potential applicability as future screening tools for PSCD and interpreted them in terms of implementation and accessibility characteristics rather than as direct clinical validation in populations with pediatric SCD. Finally, we grouped stroke screening technology domains into 5 higher-level categories (nonimaging, imaging-based, light-based tools, biomarkers, and AI- and ML-based mHealth solutions).

Certainty of Evidence

Certainty of evidence was not assessed using grading of recommendations assessment, development, and evaluation (GRADE) or similar frameworks because the included studies were highly heterogeneous. We included descriptive outcomes rather than quantitative effect measures. As recommended for narrative syntheses, we provide contextual interpretation of findings rather than formal certainty ratings.

Ethical Considerations

Institutional review board approval was not required because the study did not involve human participant research. Zotero was used for screening and managing large volumes of literature while considering transparency and accountability, bias and fairness, privacy and confidentiality, as well as validity and reliability through continuous monitoring and the application of human judgment at each step.

Applicability of CHERRIES Guidelines

This study did not involve online surveys or web-based data collection. All analyzed data were obtained from previously published peer-reviewed studies, and 1 clearly identified preprint study was found through database searches. Therefore, the CHERRIES (Checklist for Reporting Results of Internet E-Surveys) guidelines are not applicable to this review.

Results

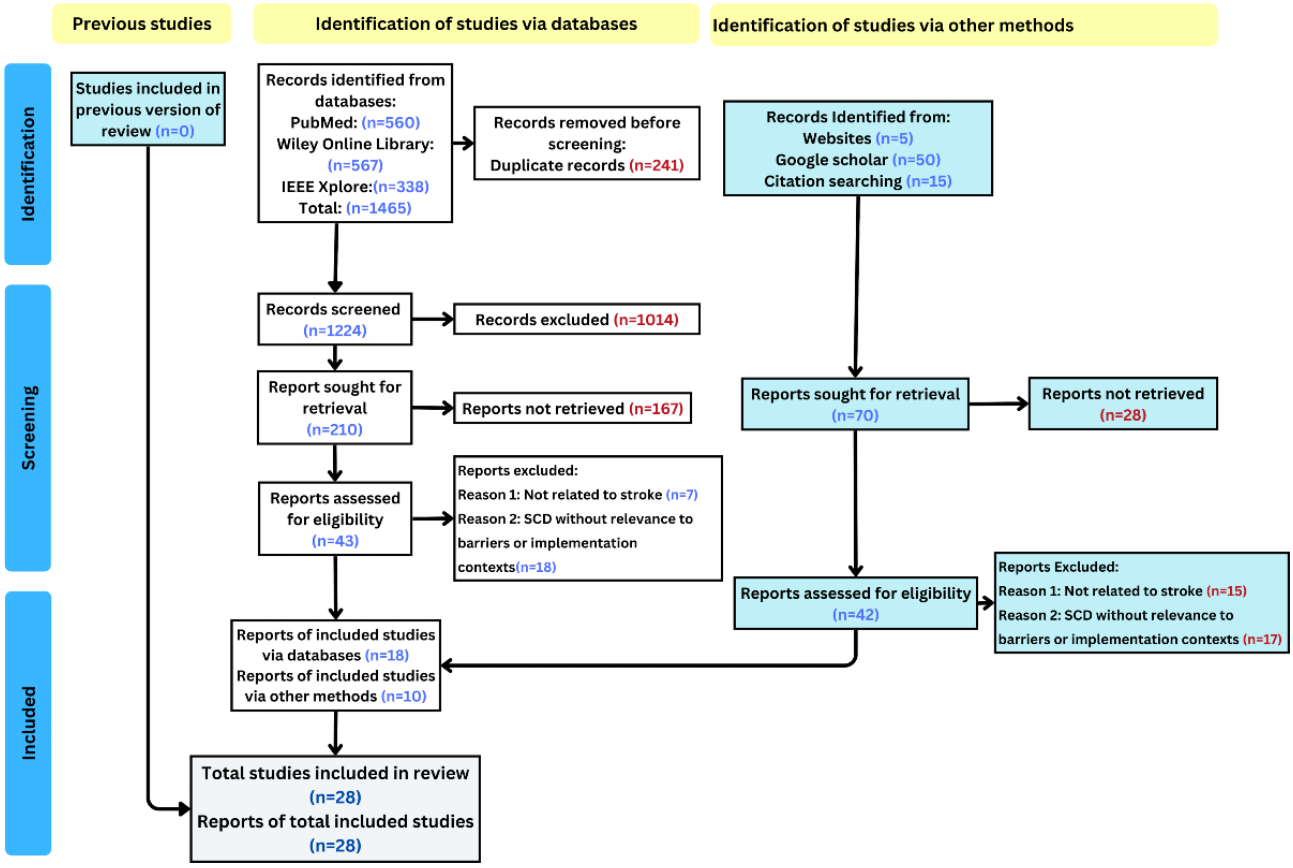
Overview

Initially, a total of 1465 studies were retrieved. After excluding 241 duplicates, 1224 studies remained. During the initial screening stage, 1014 studies were excluded after reviewing the study titles and abstracts. The full texts of the remaining 85 studies were reviewed, and 57 studies were excluded based on the eligibility criteria. Finally, 28 studies were included in the

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systematic review. The final selection was recorded in a PRISMA flowchart in Figure 2.

Figure 2. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart illustrating the selection of the included studies and the inclusion and exclusion criteria. SCD: sickle cell disease.



Study Characteristics

The 28 studies included in this review were conducted across diverse global regions (Multimedia Appendix 2). The largest number of studies was conducted in the United States (n=7, 25%) [11,15,20,42-45], followed by Nigeria (n=4, 14%) [46-49], India (n=4, 14%) [50-53], broader sub-Saharan Africa (n=2, 7%) [54,55], and China (n=2, 7%) [56,57]. Additional studies were conducted in Uganda (n=1, 4%) [14], Congo and Zambia (n=1, 4%) [58], Europe (n=1, 4%) [59], the Dominican Republic (n=1, 4%) [60], Taiwan (n=1, 4%) [18], Malaysia (n=1, 4%) [61], Iraq (n=1, 4%) [21], and globally (n=1, 4%) [62]. The publication years spanned from 2021 to 2025, with most studies (n=16, 57%) published between 2024 and 2025 [18,20,21,43-46,51-54,58-60,62,63], reflecting rapidly emerging research on stroke screening technologies and accessibility. Most studies were published in 2024 (n=9, 32%) [18,20,44-46,51-53,59], followed by 2025 (n=7, 25%) [21,43,54,58,60,62,63], 2022 (n=5, 18%) [14,48-50,55], 2021 (n=5, 18%) [11,42,47,56,61], and 2023 (n=2, 7%) [15,57]. Earlier foundational studies from 2021 to 2022 represented 10 (36%) of the included works [11,14,42,47-50,55,56,61].

Regarding research design, the studies used a wide range of methodologies, including qualitative descriptive studies (n=2, 7%) [42,46], retrospective observational analyses (n=4, 14%) [11,15,44,58], retrospective cohort studies (n=2, 7%) [18,43], narrative reviews (n=3, 11%) [54,56,62], cross-sectional studies (n=2, 7%) [14,59], mixed methods design and evaluation studies (n=2, 7%) [48,63], quantitative observational studies (n=2, 7%) [47,49], cluster randomized controlled trial (n=1, 4%) [61], the SACRED (Stroke Avoidance for Children in República Dominicana) trial (n=1, 4%) [60], an observational comparative study (n=1, 4%) [20], a systematic review (n=1, 4%) [55], and feasibility or technology evaluation studies (n=8, 29%) [21,44,45,50-53,57]. The focus of the studies also varied substantially, with a large proportion (n=10, 35%) centered on stroke screening accessibility and implementation challenges in LRS in both LMICs and HICs for children with sickle cell anemia (SCA) [42,43,46-49,54,55,59,60]. Additionally, 11 (39%) studies focused on novel or emerging stroke screening technologies, including MRI or MRA, optical and laser spectroscopy, blood biomarkers, AI-enhanced electrocardiogram (ECG), mobile apps, and AI-enabled multimodal tools [11,14,15,18,20,21,44,45,50-53,56-58,61-63]. Across these studies, population types ranged from children with SCA, caregivers, patients with stroke, healthy volunteers, and health care providers, allowing for a broad understanding of both accessibility barriers and technological advancements.

RoB Assessment

Based on the assigned tools and corresponding assessments, the overall RoB across the 28 included studies showed substantial variation by study design (Multimedia Appendix 1). Of the included studies, 43% (12/28) were assessed as having low RoB. A moderate RoB was identified in 32% (9/28) of the studies, primarily among retrospective observational,

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cross-sectional, mixed methods, and observational study designs. In contrast, a high RoB was observed in 25% (7/28) of the studies, especially among feasibility and technology-based diagnostic accuracy studies assessed with QUADAS-2 and PROBAST, as well as more complex trial designs such as cluster randomized controlled trials. The distribution of RoB assessments across different study types and tools is summarized in Multimedia Appendix 1. As this review used narrative synthesis rather than quantitative meta-analysis, statistical assessments of reporting bias were not applicable. We qualitatively evaluated whether studies selectively reported outcomes or omitted key information. Several included studies provided limited or no details about performance, training requirements, or implementation challenges, suggesting a potential risk of reporting bias. Additionally, feasibility and technology development studies frequently emphasized only positive findings without fully reporting negative results. These limitations may lead to an incomplete representation of screening tool performance across settings.

Barrier Characteristics

Overview

Using narrative synthesis, barriers were grouped into 4 domains: workforce and training constraints, health care system and infrastructure barriers, sociocultural and awareness factors, and economic and logistical constraints. The synthesized major barriers to stroke screening accessibility in LRS are presented in Multimedia Appendix 3. Of the included studies, 36% (10/28) reported barriers related to stroke screening accessibility and its implementation in different health care settings. Table 2 provides an overview of how all identified barrier categories mapped onto 4 major thematic domains: workforce and training constraints, health care system and infrastructure barriers, sociocultural and awareness factors, and economic and logistical constraints.

Table . Major categories and their corresponding barrier categories.

Major category	Barrier categories included
1. Workforce and training constraints	Lack of trained staff, lack of specialists, lack of TCD[a] sonographers, lack of operator training, costly training, high patient volume, low provider knowledge or lack of knowledge, dependence on external examiners or visiting researchers, and limited clinical workforce capacity
2. Health care system and infrastructure barriers	Inadequate infrastructure, lack of machines or insufficient equipment, inefficient infrastructure, inefficient scheduling, coordination of appointments or fragmented care, no electronic medical records, screening services only in academic hospitals, limitations in hydroxyurea initiation or monitoring capacity, infrastructure gaps for sustained monitoring, poor health system organization, restricted TCD service availability, weak hospital leadership and partnerships, and limited neurological evaluation access
3. Sociocultural and awareness factors	Lack of awareness, cultural misconceptions, cultural disbelief, social burden, linguistic barriers, low understanding of SCA[b] or stroke prevention, need for community engagement, fear or distrust of medical interventions, caregiver education gaps, and low health literacy.
4. Economic and logistical constraints	Costly treatment, high cost of TCD, MRA[c], or CBT[d], transportation issues, logistical difficulties, high lifestyle demands, low funding, socioeconomic treatment variation, travel burdens, competing domestic responsibilities, geographic inaccessibility, out-of-pocket expenses for care, appointment scheduling conflicts, and caregiver time constraints.

[a]TCD: transcranial Doppler.

[b]SCA: sickle cell anemia.

[c]MRA: magnetic resonance angiography.

[d]CBT: chronic blood transfusion therapy.

Workforce and Training Challenges

As depicted in Multimedia Appendix 3, the lack of trained staff was reported in 60% (6/10) of the studies [46,47,54,55,59,60]. These studies indicated that stroke screening methods such as Doppler ultrasound and TCD require specialized training for operators, which is one of the major barriers to performing TCD screening in many LMICs. Several studies mentioned the need to train a specialized team to operate TCD, while others suggested training existing physicians and nurses to conduct the screening method, thereby reducing the need for specialists. From the 10 studies, 1 (10%) reported a lack of specialists [48] and 1 (10%) reported a lack of TCD sonographers [49].

Health Care Systems and Infrastructure

Thirty percent (3/10) of the studies highlighted inadequate infrastructure [47,54,55], and 20% (2/10) reported complex health care as a major health care system and infrastructure-related barrier [43,60] (Multimedia Appendix 3). Many rural and remote areas lack adequate infrastructure to perform screening procedures due to lack of equipment, poor coordination of scheduling, and a lack of laboratories to perform required tests. Additionally, follow-up care is inconsistent due to transportation difficulties and health care system inefficiencies, even when screenings are completed [42,48].

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Sociocultural and Awareness

Forty percent (4/10) of the studies reported that a lack of awareness among patients and health care providers indicates that their knowledge of the importance of stroke screening is significantly low [46,55,59,60] (Multimedia Appendix 3). Health care providers are not aware of the annual TCD screening, and their lack of knowledge about stroke symptoms and risk factors further results in delayed diagnosis and treatment. Most of the time, caregivers are also not aware of the importance of early detection and risk factors, which diminishes the effectiveness of screening programs. Additionally, 40% (4/10) of the studies revealed that social burden and cultural disbelief contribute to reduced stroke screening assessments [46,49,54,55].

Economic and Logistical Challenges

Fifty percent (5/10) of the studies identified costly treatment as a primary barrier [43,47,49,55,60] (Multimedia Appendix 3). From the 10 studies, 1 (10%) revealed costly operator training [48], 1 (10%) revealed costly TCD examination [49], and 1 (10%) revealed costly blood transfusion therapy [49]. Additionally, 1 (10%) study reported that many public health care systems lack the funding essential to subsidize these costs [59]. In some LMICs, the cost of screening depends on patients' personal expenses, further limiting accessibility.

Disparities of Stroke Screening Access in LRS, HICs, and LMICs

From Multimedia Appendix 3, a clear disparity exists in stroke screening accessibility across low-resource environments in both LMICs and LRS in HICs. Evidence from LMICs shows that shortages of trained personnel, limited availability of TCD machines, fragile health care infrastructure, and high out-of-pocket costs consistently restrict early stroke detection among children with SCA. Caregivers also face substantial financial and social burdens, along with inadequate awareness of stroke risks and limited community outreach mechanisms in LMICs. Infrastructure challenges, such as shortages of electronic medical records, insufficient specialists, and dependence on external partnerships, hinder the accessibility of stroke screening. Similarly, LRS within HICs demonstrated parallel barriers; however, they mostly face logistical difficulties in scheduling and coordinating care in already established health care facilities. Other significant barriers in HICs include transportation limitations and high lifestyle demands that interfere with attending appointments. Socioeconomic disadvantages are strong in HICs and are strongly associated with inconsistent access to screening, reduced follow-up, and poorer biological risk markers, reflecting systemic inequities despite comparatively advanced health systems. On the other hand, LMICs face widespread difficulties in accessing stroke screening facilities. In both contexts, limited trained staff, operational inefficiencies, and socioeconomic barriers are major concerns regarding reduced early stroke prevention.

Existing Core and Emerging Stroke Screening Technology Characteristics

Narrative synthesis from 64% (18/28) of the included studies revealed 5 distinct categories of stroke screening technologies [11,14,15,18,20,21,44,45,50-53,56-58,61-63] (Multimedia Appendix 4). At a higher level, we could categorize as follows: (1) nonimaging technology-based tools, such as TCD, (2) imaging-based modalities, such as MRI and MRA, (3) light-based optical spectroscopy-based devices, including SCOS and laser-based approaches, (4) biomarker-based and physiological signal-based approaches, such as routine blood test-derived markers, and (5) AI- and ML-enabled mHealth and wearable tools. These technologies could overlap with each other for stroke screening purposes. The last 3 categories could be considered emerging technologies as they are still progressing toward validation.

Existing Technologies

Of the included studies, 7% (2/28) reported that nonimaging TCD is suitable for early-age screening and has a low technical failure rate but is highly specialized and operator-dependent [11,58]. Similarly, 7% (2/28) of the studies focused on magnetic field-based imaging screening, such as MRI and MRA stroke screening tools, which produce high sensitivity and detailed cerebral imaging. However, these tools require radiologists to perform and interpret the results [14,15] (Multimedia Appendix 4). They are limited by high cost, inadequate infrastructure, and portability issues and are recommended only for children in serious condition.

Emerging Technologies

Light-based optical spectroscopy devices are among the emerging stroke screening technologies in 7% (2/28) of the studies. These devices are lightweight and require only basic instructions [20,21]. Similarly, 7% (2/28) of the studies examined blood biomarker-based stroke screening, whose main advantage is that it can be conducted using clinically accessible, routine blood test data [18,44]. AI and ML were used in 29% (8/28) of the studies to enhance mobile and wearable apps, as well as to improve blood biomarkers-based stroke detection or risk prediction [18,45,50,52,53,56,62,63]. These technologies showed promise in terms of accessibility, real-time analysis, and scalability. Wearable-based technologies for stroke screening were reported in 11% (3/28) of the studies [56,57,62], while 18% (5/28) examined mobile app–based stroke screening tools [45,51,52,61,63]. In addition, ECG-based cerebral blood flow monitoring devices were evaluated in 4% (1/28) of the studies and demonstrated strong performance in real-time monitoring and stroke prediction [50].

Cost, Portability, Scalability, and Infrastructure Needs

Low-cost stroke screening methods were reported in 25% (7/28) of the studies [11,20,21,44,56,58,61]. Among these studies, 7% (2/28) involved TCD-based stroke screening [11,58], 7% (2/28) examined light-based optical devices [20,21], 4% (1/28) examined blood biomarker-based screening methods [44], 4% (1/28) evaluated mobile-based solutions [61], and 4% (1/28) evaluated wearable solutions [56], which were considered highly suitable for LRS. In contrast, 7% (2/28) of the studies mentioned MRI or MRA-based techniques as high-cost [14,15], and these imaging technologies require significant infrastructure and trained specialists, making scalability challenging in LRS. Furthermore, 7% (2/28) of the studies are highly portable as they are lightweight, light-based imaging technologies [20,21].

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Finally, 36% (10/28) of the studies show potential for highly scalable tools, including mobile-based technologies [45,51,52,61,63], wearable-based technologies [56,57,62], and biomarker tests [18,44], which are easily deployable in LRS due to their minimal to no infrastructure requirements.

Training Requirements

High dependency on the machine operator was mentioned in 14% (4/28) of the studies [11,14,15,58]. Emerging technologies such as light-based optical spectroscopy, blood biomarkers, mobile-based tools, AI-based systems, and wearables were reported in 50% (14/28) of the studies as being less operator-dependent and easily adoptable in LRS [18,20,21,44,45,50-53,56,57,61-63]. AI tools that are easily integrated with various devices and require little to no technical training were explored in 22% (6/28) of the studies, making them ideal for self-use or by basic clinical staff [18,45,52,53,62,63]. Mobile app devices and decision support systems, providing a new way for self-management of stroke screening, were reported in 18% (5/28) of the studies [45,51,52,61,63].

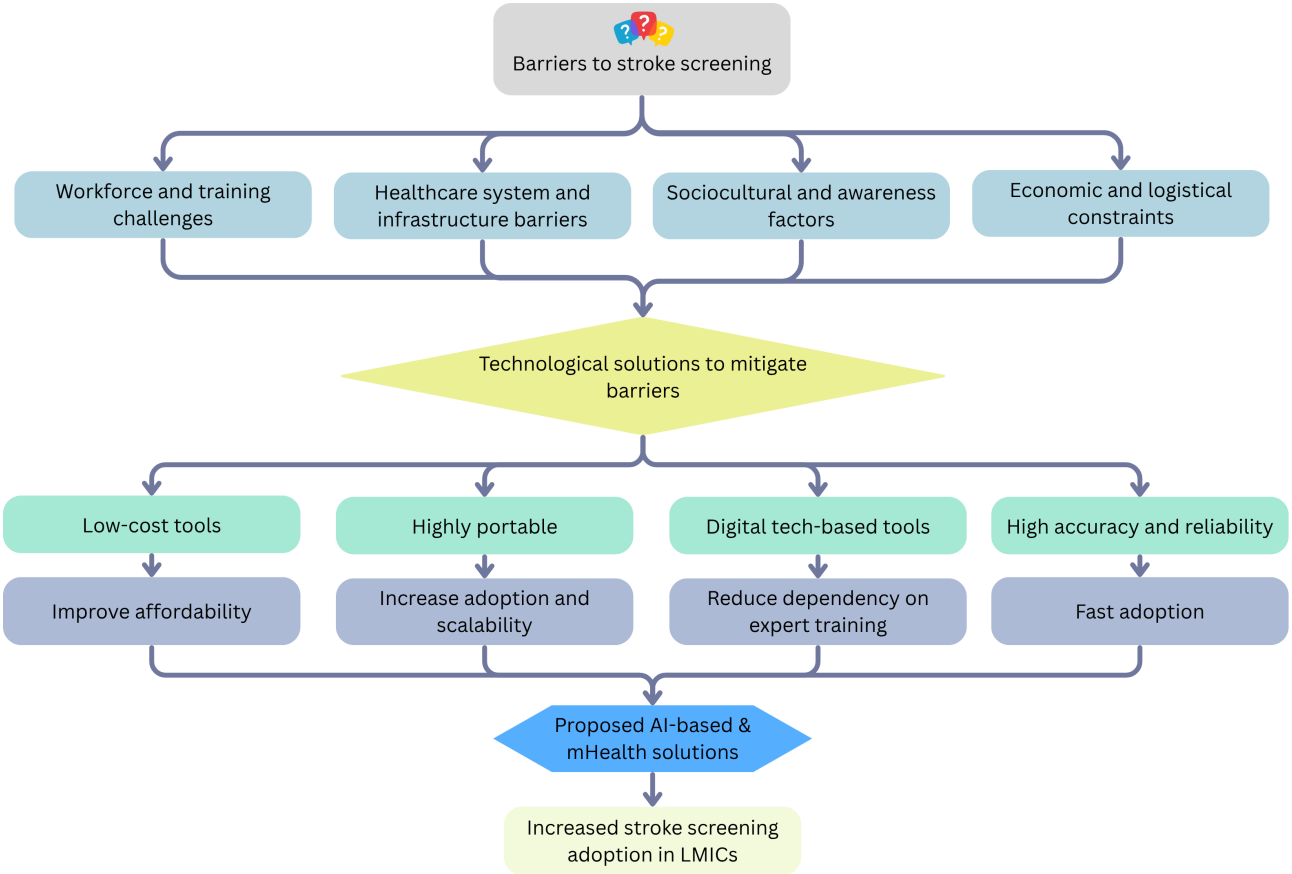
Outcomes and Challenges

Wearable-based studies showing potential for high scalability in the future were reported in 11% (3/28) of the studies [56,57,62]. AI- and ML-based studies showing an accuracy of around 90% were identified in 22% (6/28) of the studies [18,45,50,53,62,63]. An AI- and ECG-based stroke screening solution model with more than 90% accuracy was developed in 4% (1/28) of the studies [50]. An ML-based mobile app reporting around 88% user satisfaction during use was described in 4% (1/28) of the studies [63]. A multimodal mobile app demonstrating an accuracy of 80.25% was reported in 4% (1/28) of the studies [45] and 7% (2/28) of the studies focused on the implementation of TCD [11,58], which mentioned that TCD has a low technical failure rate of around 4.3% but encountered problems due to implementation challenges.

mHealth Solution From Identified Barriers and Technological Tools Characteristics

We integrate our findings from RQ1 and RQ2 to build a conceptual framework that illustrates how various barriers in LRS impact stroke screening accessibility and how different aspects of technological solutions for stroke screening can lead to an innovative approach that increases the adoption of stroke screening technologies in LMICs. The framework is illustrated in Figure 3.

Figure 3. Conceptual framework integrating the key barriers identified in research question (RQ) 1 with the benefits and addressing the limitations of stroke screening technologies from RQ2, aiming to develop an innovative mobile health (mHealth)–enabled solution for low-resource settings. AI: artificial intelligence; LMIC: low- and middle-income country.

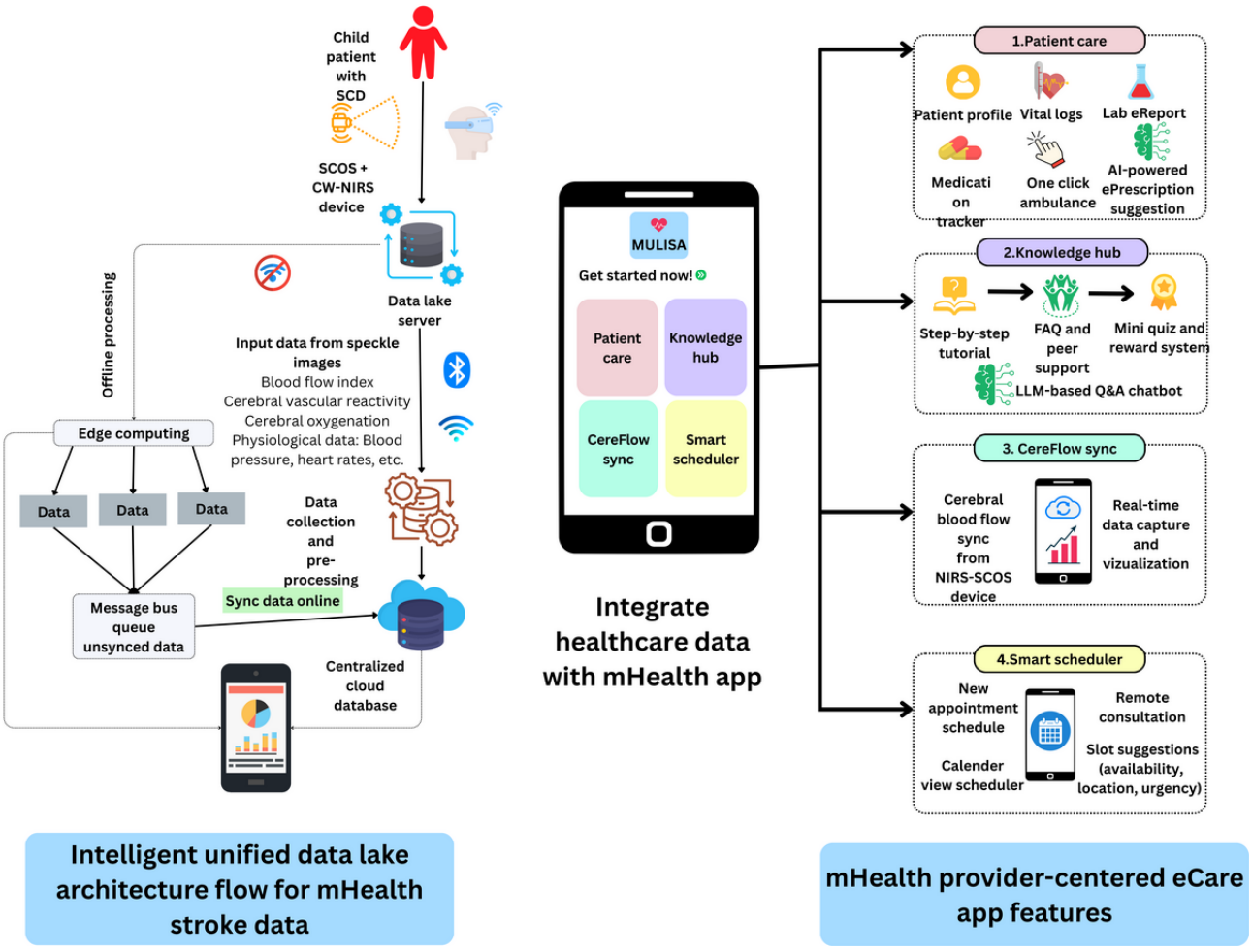


This section addresses RQ3 by proposing a modular mHealth system specifically tailored to support stroke screening and care management in children with SCD. The system embraces a user-centered approach, emphasizing real-world health care provider workflows, intuitive mobile interfaces, and accessibility in low-resource environments. By analyzing barriers identified

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from RQ1 and examining stroke screening technologies from RQ2, we suggest an end-to-end solution for stroke screening and assessment for SCD among pediatric patients. This solution will integrate a mobile app with dual-wavelength SCOS and continuous wave near-infrared spectroscopy (NIRS) devices, which will measure cerebral blood flow and oxygenation noninvasively, providing real-time, actionable insights about stroke risk into the portable mobile dashboard. This system will process real-time data, provide interactive clinical guidance and remote consultations, and enable health care providers to quickly assess a patient's condition by viewing user-friendly dashboards, allowing them to respond and provide care more easily [64]. Additionally, the solution will incorporate edge computing, making it accessible even in offline environments and ensuring stability in LRS. Overall, this innovative approach will ensure continuous monitoring, early intervention, and enhanced clinical decision-making, ultimately improving health outcomes for children with SCD. Figure 4 illustrates our novel mHealth system architecture designed to facilitate stroke screening and patient management, integrated with an NIRS-SCOS stroke screening tool. These features will be co-designed in accordance with user-centered guidelines [65], ensuring that the interface and data visualizations are both understandable and actionable, even for nonspecialist providers.

Figure 4. Modular unified lightweight intelligent stroke assistant (MULISA) mobile health (mHealth) system architecture consists of 5 major modules (data lake for raw data inputs, data processing unit, centralized server, artificial intelligence [AI] data analyzer, and main application module) and 3 supporting modules. FAQ: frequently asked questions; LLM: large language model; SCD: sickle cell disease; SCOS: speckle contrast optical spectroscopy; CW-NIRS: continuous wave–near-infrared spectroscopy.



Discussion

Principal Findings

This systematic review examined the multilevel barriers to PSCD stroke screening (RQ1), summarized existing and emerging screening technologies (RQ2), and explored opportunities for user-centered mHealth integration to address accessibility gaps in low-resource environments (RQ3).

Narrative synthesis allowed us to integrate diverse evidence and identify core barrier themes across settings, highlighting structural constraints and workflow gaps that must be addressed through integrated mHealth solutions. This review identified substantial barriers in stroke screening accessibility for patients with PSCD across LRS, driven largely by workforce challenges, limited infrastructure, awareness, and financial constraints (RQ1; Multimedia Appendix 3). Across LMICs and HICs, we found consistent themes related to a lack of staff, inadequate infrastructure, lack of knowledge, and financial constraints. These findings align with earlier regional studies reporting that TCD uptake remains low due to limited trained sonographers, insufficient radiology capacity, and fragmented care pathways [54,55]. It is also evident that economic limitations are among the most significant barriers in LMICs [49,55]. Procedures like

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TCD, MRA, and chronic blood transfusion therapy are efficient stroke prevention methods but are often out of reach due to high costs [11,14,49]. Even when TCD equipment was implemented, services could not be scaled due to a lack of lab facilities, a proper appointment scheduling structure, and insufficient operational resources [47,54]. These studies also reveal that some programs fail to achieve sustainability despite initial investments due to systemic weaknesses in health care infrastructure and coordination. In HICs, cost is not reported as a dominant factor; however, operational and logistical inefficiencies, such as scheduling conflicts, limited radiology hours, and poor integration of stroke screening tools, affect screening adherence [42,43]. Cultural beliefs, socioeconomic factors, and low awareness about stroke prevention among patients' primary caregivers and health care providers reduce the possibilities of taking preventive measures in LRS in both LMICs and HICs [43,46,49,54,60]. Most people fear long-term dependency on medical treatments like blood transfusions, leading them to avoid taking medical help in the early stages of the disease [49].

To answer RQ2, we explored screening technologies and found out 5 major categories of stroke screening technologies (imaging, nonimaging, biomarkers, SCOS-based tools, and mHealth or AI solutions), each demonstrating unique strengths but varying widely in accessibility and feasibility. Furthermore, an exploration of both existing and emerging technologies related to stroke screening (Multimedia Appendix 4) highlights critical attributes, including cost, portability, scalability, infrastructure needs, training requirements, and outcomes. It reveals the significant potential of AI-driven mHealth solutions for the early diagnosis of stroke risk by analyzing the key characteristics of each stroke screening tool, particularly in resource-limited settings, and the flexibility of customizing mHealth solutions for patients with PSCD [45,52,53,63].

Finally, our findings underscore the need for an integrated, user-centered mHealth solution capable of responding to the identified barriers and leveraging the key functional attributes of emerging stroke screening tools for early stroke detection in patients with PSCD (RQ3). The potential impact of these barriers and screening tools, introduced in Figure 4, will help bridge gaps in early diagnosis, empower local health care workers, and promote timely follow-up care for critical conditions such as SCD. As this solution will be mHealth-based, it will be low-cost, highly portable, and scalable in LRS. A knowledge hub module will be incorporated to address the lack of knowledge and inadequate operator training in stroke screening assessments. This module will aid in decision-making by providing step-by-step instructions, a peer support system, and a large language model–based chatbot. AI will be used to provide advanced analytics on patient risk assessment reports by analyzing historical data [66]. User engagement will be promoted through the app, where we will design and assess the app's interactive dashboard built from collected stroke screening data from the SCOS device [67], support remote consultation, and include SCD-specific care recommendations, such as hydration tracking and pain episode logs [68]. Furthermore, the system's mobile-first architecture (using a Flutter frontend and Django backend) will ensure cross-platform compatibility and offline functionality, key advantages for deployment in rural or infrastructure-challenged areas. The whole solution will be incorporated with edge computing so that it will have consistent connectivity even in offline environments, which is a major requirement in LRS. Future field testing will involve pilot studies to evaluate usability, adoption rates, clinical effectiveness, and user satisfaction, to make this a real-world tool. Overall, this research demonstrates a promising path forward for scalable, user-centered mHealth solutions that can significantly improve pediatric stroke risk management in resource-limited settings.

Limitations

This review has several methodological limitations. There may be language and publication bias, as only English-language publications were included. Additionally, the exclusion of gray literature, conference abstracts, and non–English-language publications could mean that we have omitted valuable regional or local insights, especially from non–English-speaking LMICs, where relevant work might be found. Additionally, valuable information from other sources that are not indexed in major databases may be overlooked. Although the review followed PRISMA guidelines, screening and data extraction were independently conducted by two reviewers to minimize selection and interpretation bias. However, small differences in interpretation are likely to occur naturally.

This systematic review aimed to capture the most up-to-date stroke screening technologies; however, it has certain limitations. One of the primary concerns is the heterogeneity of the studies included in terms of their methodologies, the technologies evaluated, and the outcome measures used, which prevented us from performing a meta-analysis. As a result, this review was unable to determine which stroke screening technology is most closely linked to effective interventions.

Another notable limitation is related to the rapidly evolving and growing nature of artificial intelligence and mHealth technologies. Some of the most recent developments may not yet be available in peer-reviewed literature and, therefore, were excluded from our analysis. Furthermore, many studies focus on technical performance rather than evaluating real-world deployment, usability, and long-term sustainability.

Future Directions

There is a clear need for further research to understand the barriers present in LRS involving large populations. Emerging technologies like AI-based mobile apps stand out for their low cost and high portability, making them highly adoptable and scalable in LRS. Integrating mobile-based apps with stroke screening devices will increase the ability to detect unknown stroke signs early. Integrating AI with imaging technologies may offer future pathways to overcome some of the prevailing infrastructure and cost barriers, making imaging more accessible and enhancing diagnostic accuracy. Furthermore, additional research is needed to refine and validate emerging stroke screening technologies. Future work should also focus on improving the generalizability of these tools across diverse populations and different stroke severities, as well as enhancing the integration of these technologies with existing health care

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systems. There is also potential for multimodal AI systems to provide a more comprehensive and accurate risk assessment for strokes, as well as the integration of mHealth systems with emerging technologies such as NIRS tools or ECG tools.

Conclusions

In this review, the authors have identified various key barriers limiting access to stroke screening for children with SCD in LRS and evaluated the sustainability of both standard and emerging technological solutions. This review revealed a wide array of prevailing tools that remain inaccessible due to several economic, cultural, and infrastructural barriers commonly encountered in LRS, as well as emerging stroke screening technologies that could be easily used in various health care settings. Additionally, this review demonstrated potential solutions for stroke screening and assessment, underscoring the promise of integrating mHealth solutions with portable devices and imaging systems. While significant advancements have been made in the development of stroke screening technologies, there still remains a critical challenge to ensure that these tools are accessible, accurate, and scalable in real-world settings. Finally, we uncovered an AI-enabled solution customized to address the identified barriers. This holistic solution offers a practical foundation to revolutionize stroke prevention and management, guide clinical implementation, and drive health innovation in the future, particularly in resource-limited environments.

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Data Availability

In this study, all data are generated or analyzed from previously published sources. The extracted data and findings are presented within the manuscript and as multimedia appendices. Additional information about procedures and data analysis is available from the corresponding author on reasonable request.

Authors' Contributions

Conceptualization: NJ (lead), NS (equal)
Data curation: NJ (lead), NA (supporting)
Formal analysis: NJ (lead), NA (equal)
Funding acquisition: NS (lead), SYL (equal), MS (equal), SS (equal), SC (equal), AP (equal), CK (equal)
Investigation: NJ (lead), NA (supporting)
Methodology: NJ (lead), NA (supporting)
Project administration: NS (lead), SYL (supporting), MS (supporting), SS (supporting), SC (supporting), AP (supporting), CK (supporting)
Resources: NS (lead), SYL (supporting), MS (supporting), SS (supporting), SC (supporting), AP (supporting), CK (supporting)
Supervision: NS (lead), SYL (supporting), MS (supporting), SS (supporting), SC (supporting), AP (supporting), CK (supporting)
Validation: NJ
Visualization: NJ
Writing - original draft: NJ
Writing - review & editing: NJ (lead), NA (supporting), NS (supporting), SYL (supporting), MS (supporting), SS (supporting)

Conflicts of Interest

None declared.

Checklist 1
PRISMA checklist.
[DOCX File, 278 KB - pediatrics_v9i1e76937_app1.docx]

Multimedia Appendix 1
Risk-of-bias assessment of included studies.
[DOCX File, 191 KB - pediatrics_v9i1e76937_app2.docx]

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Multimedia Appendix 2
Study characteristics.
[DOCX File, 143 KB - pediatrics_v9i1e76937_app3.docx]

Multimedia Appendix 3
Barriers to stroke screening accessibility.
[DOCX File, 85 KB - pediatrics_v9i1e76937_app4.docx]

Multimedia Appendix 4
Stroke screening technologies.
[DOCX File, 122 KB - pediatrics_v9i1e76937_app5.docx]

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Abbreviations

AI: artificial intelligence
CHERRIES: Checklist for Reporting Results of Internet E-Surveys
ECG: electrocardiogram
GRADE: Grading of Recommendations Assessment, Development and Evaluation
HIC: high-income country
JBI: Joanna Briggs Institute
LMIC: low- and middle-income country
LRS: low-resource settings
MeSH: Medical Subject Headings
mHealth: mobile health
ML: machine learning
MMAT: Mixed Methods Appraisal Tool
MRA: magnetic resonance angiography
MRI: magnetic resonance imaging
NIRS: near-infrared spectroscopy
PICO: population, intervention, comparison, and outcome
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROBAST: Prediction Model Risk of Bias Assessment Tool
PSCD: pediatric sickle cell disease
QUADAS-2: Quality Assessment of Diagnostic Accuracy Studies–2
RoB: risk-of-bias
RQ: research question
SACRED: Stroke Avoidance for Children in República Dominicana
SCA: sickle cell anemia
SCD: sickle cell disease
SCOS: speckle contrast optical spectroscopy
TCD: transcranial Doppler

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Digital Health Interventions for Sexual Health Education Among Adolescents With Autism Spectrum Disorder: Scoping Review

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Abstract

Background: Adolescents with autism spectrum disorder (ASD) experience persistent barriers to accessing comprehensive and developmentally appropriate sexual health education. Conventional curricula often fail to reflect their cognitive, social, and communication needs, increasing vulnerability to misinformation and sexual exploitation. Digital health interventions offer a promising avenue to deliver tailored, interactive, and accessible learning experiences for adolescents with ASD.

Objective: This scoping review aimed to map and synthesize the evidence on digital health interventions designed to provide sexual health education to adolescents with ASD.

Methods: A scoping review was conducted using Arksey and O'Malley's framework, refined with Joanna Briggs Institute guidance and reported following the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) standards. In total, 6 databases (ie, PubMed, Scopus, CINAHL, ERIC, PsycINFO, and Web of Science) were searched from 2010 to June 2025. Eligible studies involved adolescents aged 10 to 19 years with ASD, used digital platforms to deliver sexual or reproductive health education, and were published in English. Two reviewers independently screened, extracted, and synthesized data using descriptive and thematic approaches.

Results: A total of 16 studies met the inclusion criteria. Most studies were conducted in high-income countries and delivered content through video-based, web-based, or mobile modalities. Key features associated with positive learning outcomes included personalization, strong visual interactivity, and caregiver involvement. Reported improvements focused on sexual knowledge, behavioral understanding, and user acceptability. However, methodological limitations were common, including small and nonrepresentative samples, a lack of standardized outcome measures, and minimal gender-specific or culturally adapted content. Notably, co-design with autistic adolescents and implementation in low- and middle-income countries was scarce.

Conclusions: Digital health interventions demonstrate promising early effectiveness for delivering inclusive, developmentally appropriate sexual health education to adolescents with ASD. To advance this field, future research must strengthen methodological rigor, include diverse and gender-balanced populations, use participatory design, and ensure cultural adaptability to support equitable access globally.

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KEYWORDS

autism spectrum disorder; digital health; sexual education; adolescents; scoping review; PRISMA

Introduction

Adolescents diagnosed with autism spectrum disorder (ASD) often miss out on crucial sexual health education, despite ASD affecting more than 1% of young people worldwide [1]. The World Health Organization recognizes sexual health as a fundamental human right critical to psychosocial well-being [2]. Yet, adolescents with ASD commonly receive insufficient, delayed, or entirely absent sexuality education [3] during a developmental period marked by puberty, identity formation, and increasing social complexity.

Growing evidence shows that young people with ASD face distinct and systemic inequalities in sexual health education. These inequalities are characterized by (1) assumptions that individuals with ASD are asexual or permanently dependent, which lead caregivers and educators to avoid sexuality topics [4]; (2) curricula that overemphasize risk avoidance rather than fostering autonomy, intimacy, and healthy relationships [5]; (3) a lack of instructional approaches adapted to ASD-specific cognitive and behavioral characteristics, such as a preference for concrete, visual, and highly structured learning, and challenges with interpreting social cues and implicit norms [6]; and (4) limited access to peer-learning environments where informal sexuality knowledge is typically developed [7]. As a

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result, adolescents with ASD experience greater exposure to harm, including a 2 to 3 times higher risk of sexual victimization (30% - 50% lifetime prevalence) compared with neurotypical peers [8,9], alongside difficulties recognizing consent and personal boundaries [10]. Despite these risks, adolescents with ASD often display developmentally typical sexual curiosity, which is frequently misunderstood as problematic behavior, further impeding their access to affirmative and accurate sexual health education [11].

Traditional school-based programs generally rely on abstract verbal instructions, implicit social rules, and group discussions [9], pedagogical methods that do not adequately address the processing preferences and social learning challenges characteristic of ASD. Although some adapted interventions using visual supports, role-play, behavioral modeling, and caregiver participation have shown potential benefits [10,12], they remain resource intensive, highly dependent on trained specialists, and often limited to high-income settings, thus restricting equitable scale-up [11,12].

Digital health technologies provide an opportunity to address these barriers specifically within the context of sexual health education. Mobile apps, interactive videos, and virtual learning environments can deliver content visually, sequentially, and at a self-paced rhythm aligned with ASD learning patterns [13]. Privacy features allow adolescents to engage with sensitive topics without fear of stigma or embarrassment [14], which is particularly important for those who struggle with discussing sexuality face-to-face. Additionally, cultural and linguistic adaptation can be built directly into platforms, supporting contextual relevance in settings where sexual health remains taboo or tightly regulated.

Despite these benefits, only a small number of digital interventions have focused specifically on sexual health for autistic adolescents. Reviews of technology-based learning for neurodiverse youth [13] and reviews of sex education for people with disabilities more broadly [14] have not examined the unique intersection of ASD-specific pedagogy, adolescent development, sexual content, and digital delivery. Moreover, implementation in low- and middle-income countries (LMICs) is largely absent. Limited digital infrastructure, lower availability of trained providers, and cultural discomfort surrounding discussions of sexuality create additional barriers to uptake and sustainability.

Given these gaps, this scoping review maps digital sexual health interventions for adolescents with ASD, describing digital modalities, educational foundations, implementation contexts, and reported outcomes. We also identify 3 cross-cutting gaps (ie, limited participatory co-design, underrepresentation of girls, and scarce implementation in LMIC settings), which are analyzed in the Discussion to inform future directions.

Methods

Study Design

This review follows the scoping methodology originally outlined by Arksey and O'Malley and later refined by Levac et al [15], incorporating the latest methodological recommendations from the Joanna Briggs Institute [16]. The reporting process adheres to the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) checklist [17].

Review Questions

The review aims to address the following questions:

1. What types of digital health interventions have been developed to deliver sexual health education to adolescents with ASD?
2. How are these interventions designed and implemented in practice?
3. What outcomes, such as educational, behavioral, or usability-related, have been reported?
4. What evidence gaps and contextual challenges emerge from the current literature?

Eligibility Criteria

The inclusion and exclusion criteria were developed based on the PCC (population, concept, context) framework recommended by the Joanna Briggs Institute Manual for Evidence Synthesis (Table 1).

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Table . Inclusion and exclusion criteria.

PCC component	Inclusion criteria	Exclusion criteria
Population	• Adolescents aged approximately 10 - 19 y diagnosed with ASD[a]; OR studies involving young adults, caregivers, or practitioners if findings are directly relevant to adolescent sexual health education in ASD	• Studies involving only adults with ASD where findings lack relevance to adolescents • Studies focused solely on non-ASD neurodevelopmental disorders
Concept	• Sexual health education delivered in a digital format, including mobile apps, web platforms, video modeling, virtual simulations, digital social stories, or tele-education • Interventions focused on sexual knowledge, boundaries, consent, relationships, hygiene, or online safety	• Interventions unrelated to sexual health content • Tools designed exclusively for skill areas not linked to sexuality (eg, employment and general social skills)
Context	• Any educational, clinical, family, or community setting • All cultural and socioeconomic contexts	• Studies focused solely on institutional care settings without educational intent
Study design	• All empirical study types (RCTs[b], pilots, mixed methods, qualitative) and co-design or framework studies relevant to digital tools • Peer-reviewed journal articles	• Reviews, editorials, and commentaries without original data • Conference abstracts without full text
Language	• Published in English	• Non-English publications
Publication date	• 2010 - 2025	• —[c]

[a]ASD: autism spectrum disorder.

[b]RCT: randomized controlled trial.

[c]Not applicable.

Studies published from January 2010 to June 2025 were included because this period reflects major advancements in digital health technologies and their integration into health education, including sexuality education for neurodiverse populations. Earlier digital interventions lacked comparable accessibility and interactive features, making them less relevant to current implementation contexts. Only English-language publications were included due to resource and feasibility constraints in translating non-English texts. While this may introduce language bias, limiting the review to English publications ensured consistency in screening and methodological appraisal, although some evidence from non-English-speaking regions may be underrepresented.

Search Strategy

A comprehensive search was conducted across six major electronic databases: PubMed/MEDLINE, Scopus, CINAHL, ERIC, PsycINFO, and Web of Science. The search strategy combined controlled vocabulary (eg, Medical Subject Headings [MeSH] terms) with relevant free-text keywords related to ASD, adolescence, sexual health education, and digital health interventions. An example of the search string used in PubMed was as follows: ("Autism Spectrum Disorder"[MeSH] OR autism OR ASD) AND ("Adolescents"[MeSH] OR adolescent OR youth) AND ("Sex Education"[MeSH] OR sexual health) AND ("Digital Health"[MeSH] OR eHealth OR mHealth OR digital intervention). To enhance the comprehensiveness of the review, the reference lists of all included studies were manually screened for additional eligible articles that were not captured through database searches.

Study Selection and Screening Process

All retrieved citations were imported into EndNote for systematic deduplication. The remaining records were then uploaded into Rayyan, a web-based screening platform, to facilitate an organized and blinded review process. Before formal screening, both reviewers conducted a pilot calibration exercise using 20 randomly selected citations from the initial search results (n=243). This was done to refine operational definitions and ensure a shared understanding of the eligibility criteria. Once sufficient agreement was achieved, independent title or abstract screening proceeded for all remaining records. Following calibration, 2 independent reviewers screened titles and abstracts using predefined inclusion and exclusion criteria. Full texts were retrieved for all articles deemed potentially relevant. Discrepancies at any stage were discussed, and if consensus could not be reached, a third reviewer served as adjudicator. This multistep process strengthened the reliability and reproducibility of study selection.

Data Extraction

A structured and pilot-tested data extraction form was used to ensure consistent and comprehensive data collection across all eligible studies. Extracted information included authorship,

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publication year, country of origin, study design, participant characteristics, digital modality and duration, theoretical or pedagogical frameworks, educational content and delivery strategies, outcome domains, key findings, and reported limitations or implementation barriers. Data extraction was performed independently by 2 reviewers. Any discrepancies in extracted information were resolved through discussion and consensus; when agreement could not be reached, a third reviewer was consulted to adjudicate. This process ensured accuracy and minimized individual reviewer bias throughout the synthesis.

Quality Appraisal

Although not mandatory in scoping reviews, a methodological quality assessment was conducted to enhance the interpretative rigor of the findings. The Mixed Methods Appraisal Tool (2018) was used to evaluate each study across 5 design-specific criteria. Two reviewers independently completed the appraisal, resolving any disagreements through discussion and third-reviewer adjudication when necessary. The appraisal was used to contextualize findings rather than to exclude studies.

Overall, the quality of included studies was moderate. Approximately one-quarter of the studies demonstrated high methodological quality (scores of 4/5), typically characterized by clearly defined outcomes and appropriate study designs, including randomized trials and multisite implementations. The majority of studies scored 3 out of 5, reflecting acceptable methodological rigor but common limitations, such as small sample sizes, lack of control groups, and short intervention durations. Lower-quality studies (scores of ≤2/5), primarily narrative or commentary pieces, provided useful context but limited empirical evidence. A full scoring results are presented in the *Results* section (Table 2).

Table . Quality of study assessment.

Authors, country	MMAT[a] score (out of 5)	Comments
Chan and John [18], USA	1	Not an empirical study; and lacks data collection, analysis, or measurable outcomes.
Strauss [19], the Netherlands	4	Strong RCT[b] design, clear measures, and lacks digital delivery and generalizability.
Lou and Arriaga [20], USA	3	Exploratory, appropriate design, and lacks outcome depth and scope.
Teti et al [21], USA	3	Qualitative depth, small sample, and no intervention tested.
Drozdowicz et al [22], USA	4	Well-executed implementation, and lacks ASD[c]-specific data and long-term outcomes.
Pugliese et al [23], USA	4	Feasibility well assessed and pilot scope limits generalization.
Zervogianni et al [24], multicountry	3	Framework development, strong stakeholder input, and lacks effectiveness testing.
Gil-Llario et al [3], Spain	4	Pre-post design, positive results, and small sample and no long-term follow-up.
Chin and Ramachandram [10], Hong Kong	3	Clear pre-post design and lacks control group and large sample.
Ballan and Freyer [11], USA	1	Expert opinion and lacks empirical data.
Shakuri and Alzahrani [25], Saudi Arabia	3	Clear qualitative insights and no intervention tested.
Camilleri et al [26], UK	3	Exploratory design, good engagement data, and lacks outcome rigor.
Panagiotakopoulou et al [27], Greece	3	Focused parent perspective and lacks youth input and intervention.
Quayle et al [28], UK	2	Relevant insights, not ASD specific, and lacks outcome data.
Oğur and Olçay [29], Turkey	3	Clear intervention protocol, small sample, and adult focused.
Wang et al [30], China	3	Important gender-specific insights and lacks adolescent voices and tool testing.

[a]MMAT: Mixed Methods Appraisal Tool.

[b]RCT: randomized controlled trial.

[c]ASD: autism spectrum disorder.

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Data Analysis and Synthesis

Extracted data were organized into structured summary tables capturing key study features, intervention characteristics, and reported outcomes. A narrative synthesis was then conducted using a combined inductive-deductive thematic approach. Deductive coding was informed by the review objectives and a priori categories, such as digital modality, educational strategies, implementation context, and outcome domains. In parallel, inductive coding allowed new concepts to emerge directly from the data, including participant engagement needs, caregiver involvement, and cultural adaptation factors. Themes were iteratively refined through reviewer discussion to ensure consistency and accuracy. Studies were grouped by platform type (eg, mobile apps, web-based interventions, and interactive video tools) and interpreted alongside their methodological quality to contextualize confidence in the findings. Recurring evidence gaps, such as limited sample diversity, scarce LMIC representation, and a lack of standardized behavioral outcomes or long-term follow-up, were also identified to inform directions for future digital sexual health intervention development.

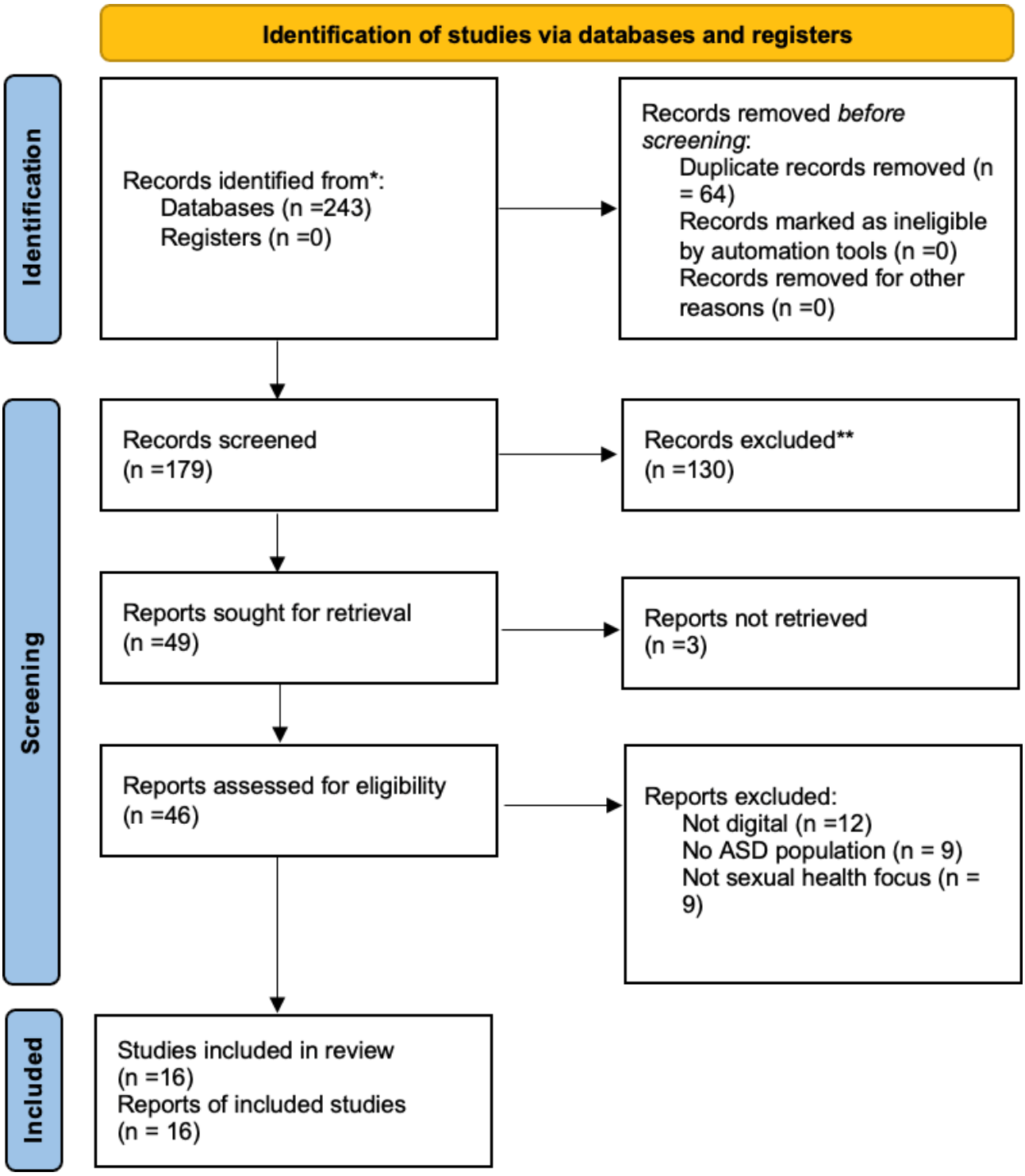
Results

Searching Result

The PRISMA-ScR flow diagram presents the full screening process. A total of 243 records were identified across databases, with 64 duplicates removed. Following title and abstract screening, 130 records were excluded, leaving 49 full-text articles assessed for eligibility. Three articles could not be retrieved despite attempts to contact authors. Ultimately, 16 studies met the inclusion criteria and were included in this scoping review (Figure 1).

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Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 flow diagram for new scoping reviews, which included searches of databases and registers only. ASD: autism spectrum disorder.



Study Characteristics

All 16 included studies were published between 2012 and 2025. Study designs were diverse, including randomized controlled trials, mixed-methods feasibility studies, qualitative exploratory research, participatory framework development, and case series. Research was conducted in the United States, the United Kingdom, Spain, Turkey, China, Greece, Saudi Arabia, Hong Kong, and multicountry collaborations. Notably, 8 studies directly implemented digital sexual health interventions or closely related digital training, whereas 8 studies explored contextual needs, stakeholder perspectives, theoretical frameworks, or digital adoption challenges without delivering a formal intervention. Studies including broader age groups (eg, young adults) were retained when their findings were directly relevant to adolescent-focused intervention design. Participant groups included autistic adolescents, autistic young adults, parents of autistic youth, clinicians, and digital health practitioners. Reporting of demographic and diagnostic characteristics was highly variable, as summarized in Table 3.

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Table . Characteristics of included studies and summary of findings.

Authors, country	Study design and methodology	Population characteristics	Digital intervention details	Educational content and delivery	Outcomes measured	Key findings and limitations
Chan and John [18], USA	Review with clinical guidance	*No sample and narrative guidance only*	None	Guidance for nurse practitioners on how to discuss sexuality with ASD[a] youth; not a formal intervention	None	Emphasizes early, tailored, and clear communication about sexual health with ASD youth. Not a digital intervention; not a research study
Strauss et al [19], USA	RCT[b]; quantitative, pre-post with control group	Adolescents with ASD, n=96, age 12 - 18 y, mixed gender	Face-to-face psychosexual training (tackling teenage program)	Manualized group sessions on puberty, boundaries, consent, and relationships using visual aids	Knowledge, self-esteem, social functioning, ASD-specific sexual behaviors	Significant improvement; limited by lack of digital tools and generalizability
Lou and Arragia [20], USA	Prototype development and exploratory pilot	Adolescents and young adults with ASD, n=14, age 16 - 21 y	eLIFE social network application	Social support and communication via mobile app	User engagement and perceived usefulness	Feasibility shown, limited sample, and not sexual health specific
Teti et al [21], USA	Qualitative comparative study	Youth with ASD and caregivers, n=10 dyads, youth age 16 - 21 y	No specific tool tested	Need for structured and multimedia sexual education	Themes on miscommunication, autonomy, and relationships	Support for structured education, small sample, and no intervention
Drozdowicz [22], USA	Multisite implementation study using synchronized videoconferencing with standardized patients	Psychiatry trainees and clinical teams, n=42 (not ASD specific)	Educational videoconference sessions involving standardized patient scenarios and delivered synchronously across sites	Sexual health communication training using video-based standardized patient interactions and real-time delivery with feedback	Participant engagement, knowledge gains, comfort in addressing sexual health	Improved comfort and preparedness reported; not ASD specific; no long-term follow-up
Pugliese [23], USA	Pilot feasibility study; mixed methods	Youth with ASD, n=22, age 10 - 17 y; parents involved	Parent-mediated digital materials	Anatomy, consent, communication, and parent led	Knowledge gain and parent-teen interaction	Feasible and acceptable and small pilot scope
Zervogianni et al [24], multicountry	Participatory framework development	Individuals with ASD, n=31, mixed age (including adolescents)	Multiple platforms considered	Co-created framework for digital interventions	Process evaluation and stakeholder satisfaction	Robust framework and no implementation or effectiveness measured
Gil-Llario et al [3], Spain	Quantitative and pre-post design	Youth with ASD, n=27, age 12 - 18 y	Video-based and web-delivered	Anatomy, consent, and boundaries; and interactive videos	Knowledge and acceptability	Improved knowledge, small sample, and no follow-up
Siah [10], Hong Kong	Pilot study and single group pre-post	Youth with ASD, n=18, age 13 - 17 y	Video modeling (3 sessions)	Sexual boundaries, hygiene, and behaviors	Knowledge gain and behavioral understanding	Increased knowledge, no control group, and small sample
Ballan and Freyer [11], USA	Narrative or expert commentary	*No sample; narrative review*	None	Critique of existing nondigital approaches	None	Calls for inclusive digital tools; not empirical
Shakuri and Alzahrani [25], Saudi Arabia	Qualitative study using semistructured interviews with parents	Parents only, n=15, adolescents represented indirectly	No direct intervention and explored digital needs and barriers	Explored parental perceptions of content needs and discussed digital adaptation opportunities	Themes related to cultural, religious, and informational barriers	Strong parental demand for culturally sensitive, digital sexual health resources, and lacks intervention testing
Camilleri [26], UK	Exploratory qualitative study	Autistic youth and parents, n=12, youth age 10 - 18 y	Digital social stories and co-designed	Tailored social-sexual themes	Engagement and parent satisfaction	Improved communication and limited by exploratory scope

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Authors, country	Study design and methodology	Population characteristics	Digital intervention details	Educational content and delivery	Outcomes measured	Key findings and limitations
Panagiotakopoulou et al [27], Greece	Qualitative and interviews with parents	Parents of adolescents with ASD, n=14, adolescents indirectly described	No direct intervention	Need for structured and digital tools	Parental perceptions and barriers	Preference for mobile, visual tools, and no youth data
Quayle [28], UK	Qualitative study involving semistructured interviews with child protection and mental health practitioners	Practitioners only, n=20, *not ASD specific*	Discussion of digital health tools (apps, online therapy, AI[c] screening) used or envisioned in abuse prevention services	Focused on service-level integration and digital design for sensitive topics	Perceptions of feasibility, ethical concerns, and implementation barriers	Digital tools viewed as promising but complex to implement and lacking empirical outcome data and ASD focus
Oğur and Olçay [29], Turkey	Case series	Adults with ASD, n=3, age 21 - 23 y, all men	Video BST[d] and digital scenes	Prevention of online sexual abuse	Skill acquisition, competency	Effective training; limited adolescent generalizability
Wang [30], China	Qualitative and interviews with parents	Parents of autistic girls, n=11, age 10 - 17 y	No formal tool	Parental needs for digital sexual education	Unmet needs and preferred formats	Call for visual, gender-sensitive tools and lacks youth voice

[a]ASD: autism spectrum disorder.

[b]RCT: randomized controlled trial.

[c]AI: artificial intelligence.

[d]BST: behavioral skills training.

Digital Intervention Modalities and Implementation

Among the 16 included studies, 8 evaluated digital tools. These interventions primarily used, including interactive video-based sexual education (eg, anatomy, boundaries, and consent), video modeling, and behavioral skills training for online exploitation prevention, mobile and web-based platforms, including social stories and facilitated parental modules, and prototype digital applications supporting psychosexual communication. The remaining 8 studies did not implement a digital intervention but provided essential contextual evidence about acceptability, cultural relevance, and caregiver and professional perspectives that inform digital tool development.

Video-based education was the most frequently used modality. For instance, Gil-Llario et al [3] and Siah et al [10] implemented interactive and modeling-based digital videos to deliver content on consent, boundaries, and appropriate sexual behavior. Similarly, Çimen Oğur and Olçay [29] used video visual scene displays in behavioral skills training to teach online sexual abuse prevention. Pugliese et al [23] and Camilleri et al [26] incorporated parent-mediated modules and co-designed digital social stories, respectively, emphasizing personalized learning.

Mobile and web-based technologies were also explored. Lou and Arriaga [20] tested eLIFE, a prototype social network app aimed at enhancing social communication among youth with ASD, and Zervogianni et al [24] proposed a multiplatform, evidence-based co-design framework for digital tool development. While not always focused specifically on sexual health, these studies revealed key design principles applicable to future interventions. In contrast, several studies [11,27,30] emphasized the need for accessible, culturally responsive, and multimedia sexual health education tools but reported no direct implementation. Parents, in particular, expressed strong preferences for mobile-friendly, visually rich, and repeatable learning formats tailored to the cognitive and developmental profiles of their children.

Educational Content and Delivery Strategies

The digital interventions identified varied in their educational content and delivery strategies. Commonly addressed topics included sexual anatomy, personal hygiene, consent, social boundaries, healthy relationships, and online safety. Interactive video formats and story-based learning were used to model both appropriate and inappropriate behaviors, particularly in studies with youth aged 13 to 18 years. Parent-mediated tools [23] often used structured modules with guided discussions, while other programs [26] emphasized autonomy and co-creation with autistic youth. Despite this diversity, few studies reported the use of established theoretical frameworks, and most lacked standardized instructional approaches, limiting cross-comparability. Duration and frequency of interventions also varied, with only 3 studies clearly reporting session length and instructional pacing.

Outcome Domains and Reported Effects

The most frequently measured outcomes were sexual health knowledge, behavioral understanding, skill acquisition, and acceptability or usability. Quantitative studies such as those by Gil-Llario et al [3] and Siah et al [10] reported significant gains in sexual knowledge postintervention. In Çimen Oğur and Olçay [29], participants demonstrated improved behavioral skills for resisting online exploitation. Pugliese et al [23] reported enhanced parent-child communication, while Camilleri et al [26] noted increased engagement and satisfaction among both youth and parents.

Qualitative studies underscored the emotional, relational, and cognitive barriers that youth with ASD face regarding sexuality.

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Teti et al [21] and Wang et al [30] highlighted themes of communication breakdown, information gaps, and parental uncertainty, while Lou and Arriaga [20] emphasized the socioemotional impact of peer-based digital tools. However, many of these studies did not measure outcomes longitudinally, limiting insight into sustained effectiveness.

Methodological Limitations and Evidence Gaps

Across studies, common limitations included small samples, absence of control groups or randomization, nonstandardized outcomes, and short follow-up periods. Three recurrent evidence gaps were reported: (1) limited participatory co-design with autistic adolescents, (2) underrepresentation of female participants and lack of gender-specific content, and (3) few implementations in LMICs. These gaps were noted but not tested as effect modifiers. Only Wang et al [30] addressed female-specific educational gaps, emphasizing the lack of tailored content. Co-design with autistic adolescents was inconsistently applied, although Zervogianni et al [24] and Camilleri et al [26] provided important examples of participatory development.

Thematic Patterns

The narrative synthesis revealed several recurring patterns across the included studies. One prominent theme was the need for personalization and visual interactivity within digital sexual health interventions designed for adolescents with ASD. Interventions that used video modeling, interactive storytelling, or visual scene displays were notably more effective in enhancing comprehension and engagement, particularly among youth with ASD, who often benefit from visual structure and concrete representations of social behavior [10,26,29].

Another consistent finding was the strong demand from caregivers for mobile-accessible, culturally sensitive, and repeatable educational content. Parents expressed a clear preference for digital tools that could be used flexibly within the home, reflect local sociocultural values, and offer structured, developmentally appropriate guidance on sexual health topics [23,27,30].

A third thematic pattern highlighted critical gaps in the implementation and evaluation of digital interventions. Many studies lacked contextual diversity, with limited representation of LMICs, and often failed to incorporate adolescent end users in the design process [11,24]. Inadequate attention to co-design and cultural adaptability may reduce the acceptability and effectiveness of digital interventions across different settings. Moreover, few studies included long-term follow-up or robust behavioral outcome measures, limiting the ability to assess sustained impact [3,20].

Methodological Quality Appraisal

The overall methodological quality of the included studies varied. High-quality studies, such as those by Strauss et al [19], Drozdowicz et al [22], Pugliese et al [23], and Gil-Llario et al [3], scored 4/5 on Mixed Methods Appraisal Tool, reflecting strong designs with clear outcomes, although some lacked digital focus or generalizability. Moderate-quality studies (3/5), including Lou and Arriaga [20], Teti et al [21], and Siah et al [10], showed feasibility or insight but were limited by sample size or lack of control groups. Lower scores (≤2/5), such as Chan and John [18] and Ballan and Freyer [11], were nonempirical or lacked data collection, limiting their evidentiary value (Table 2).

Discussion

Principal Findings

This scoping review maps the emerging landscape of digital sexual health education for adolescents with ASD. Across diverse study designs and settings, the evidence indicates early effectiveness for formats that align with ASD learning characteristics, particularly visually rich, structured, and repeatable content, while also revealing systemic gaps that limit generalizability and equity. Below, we interpret key patterns and translate them into actionable implications for design, implementation, and evaluation.

Expanding upon foundational reviews by Pownall et al [31] and Dewinter et al [32], which underscored the scarcity of structured, inclusive sex education for neurodiverse individuals, this review uniquely updates the evidence base with a focus on digital modalities. Previous syntheses primarily emphasized content deficits and the inadequacy of traditional education formats for autistic learners. In contrast, our findings highlight a tangible shift toward digital, video-based, and mobile platforms that are more aligned with the cognitive, sensory, and social processing styles of autistic adolescents. This shift marks a substantial evolution in approach, emphasizing not only what is taught, but how and by whom it is delivered. Unlike earlier reviews that often conflated multiple developmental disabilities, this scoping review centers specifically on ASD, revealing critical insights into learning preferences, gender disparities, and digital engagement unique to this population. A notable distinction is the emerging but still limited incorporation of co-production and participatory design, reflecting a movement toward user-centered innovation in health education. This is particularly significant, given the evidence that autistic individuals benefit from interventions designed with their direct input [24].

A central theme across the reviewed literature is the demonstrated effectiveness of video-based interventions in enhancing sexual knowledge and social comprehension. Studies by Gil-Llario et al [3], Siah et al [10], and Çimen Oğur and Olçay [29] illustrate that interactive video, especially those incorporating role modeling, repetition, and guided narration, can support autistic adolescents in understanding abstract concepts, such as consent, bodily autonomy, and relationship boundaries. These pedagogical strategies are fundamentally aligned with the cognitive characteristics of ASD [26], including a preference for visual, concrete, structured learning, reduced social inference skills, and challenges in generalization across contexts. Therefore, future digital interventions should increasingly incorporate visual prompts, stepwise sequencing, clearer discrimination between appropriate and inappropriate behaviors, and opportunities for individualized feedback and repeated practice.

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Another critical finding emerging from the reviewed studies is the central role of caregivers in facilitating sexual health learning among autistic adolescents. Evidence from Pugliese et al [23] and Panagiotakopoulou et al [27] shows that parents overwhelmingly favor visually rich, repeatable, and culturally adaptable content—particularly in contexts where formal sex education is limited or inconsistently delivered to neurodiverse youth. These preferences reflect the widespread reliance on the family as a primary learning environment and suggest that digital tools are more likely to be used when they can be integrated into existing home routines and communication patterns.

Despite these promising developments, the body of evidence remains fragmented and unevenly distributed. Most studies originate from high-income settings, with limited consideration for sociocultural values, digital access, and educational policies in LMICs. This geographic concentration reduces the transferability of findings to resource-constrained settings, where formal sexuality education may be stigmatized or absent. The lack of reporting on cultural or religious context in intervention design also limits understanding of how well existing programs align with local expectations regarding sexual behavior and autonomy. Across studies, intervention samples frequently overrepresented male adolescents, meaning that the needs, experiences, and risks faced by autistic girls remain insufficiently represented. Only a small number of studies, such as Wang et al [30], explicitly examined female perspectives in digital development or outcome reporting. This gender imbalance reflects a broader trend in autism research and raises concerns that current interventions may unintentionally reinforce a male-centric understanding of autistic sexuality.

Taken together, these findings indicate that while digital interventions hold considerable promise in tailoring sexual health education to autistic adolescents' learning profiles, important equity considerations persist. Variability in sampling, design rigor, cultural contextualization, and gender representation highlights the need for continued refinement before such interventions can be confidently translated into routine education and clinical practice. Strengthening methodological quality and ensuring inclusive design processes will be essential to develop interventions that are not only effective but also broadly relevant and accessible.

Importantly, the underrepresentation of female adolescents with ASD has long been recognized as a systemic gap in autism research and persists. Only a handful of studies, such as Wang et al [30], explored the unique needs and experiences of girls, raising concerns about gender equity in intervention design and delivery. Without targeted inclusion, current tools risk reinforcing a male-centric view of autism that excludes a significant portion of the population. Geographic and socioeconomic disparities also limit the generalizability of current findings. Very few studies examined implementation in LMICs, where digital infrastructure, cultural norms, and access to health education differ markedly from high-income contexts. As Ballan and Freyer [11] argue, failing to address these structural factors risks exacerbating existing inequities, particularly for youth in marginalized communities. Future tools must therefore ensure gender-responsive adaptation of content, particularly around puberty, menstrual health, privacy, and romantic relationships.

Collectively, these findings affirm that digital interventions hold transformative potential for delivering inclusive, accessible, and developmentally appropriate sexual health education to adolescents with ASD. However, a shift from proof-of-concept studies to large-scale, context-sensitive, equity-driven research is urgently required. This includes participatory design methods that meaningfully involve autistic adolescents, families, and educators in LMICs to ensure interventions are relevant, feasible, and ethically grounded.

Limitations

This scoping review has several limitations that should be considered when interpreting the findings. First, significant methodological heterogeneity across the included studies, particularly in sample sizes, designs, and outcomes, restricted the ability to compare results directly or assess effectiveness at scale. Second, limiting the search to English-language publications may have led to the exclusion of relevant evidence from non-English-speaking regions, potentially underrepresenting interventions developed in culturally diverse contexts. Third, most studies were conducted in high-income countries, which limits the generalizability of findings to low- and middle-income settings where resources, digital access, and sociocultural norms related to sexuality education differ markedly. Fourth, although a methodological quality appraisal was conducted, many studies provided only preliminary or feasibility data, making it difficult to draw strong conclusions about long-term behavioral impact. Finally, rapid technological evolution means that some digital tools reviewed may already be outdated, affecting the current applicability of results. Collectively, these limitations emphasize the need for more rigorous, inclusive, and globally representative evaluations to strengthen the evidence base for digital sexual health education among autistic adolescents.

Implications for Nursing Practice

This review underscores the essential role of nurses in facilitating and advocating for digital sexual health education for autistic adolescents. To ensure interventions are effective and sensitive to ASD-specific learning needs, nurses require competencies in both sexual health communication and digital literacy. As caregivers often serve as primary educators on sexuality, nursing support should extend to families by offering structured guidance and training in the confident and appropriate use of digital tools. In addition to direct education, nurses act as key advocates in shaping school and community policies that promote equitable digital access, safeguard privacy, and ensure culturally and linguistically responsive resources, particularly in LMICs where stigma and limited services remain major barriers to sexual health education.

Future research and program development should prioritize participatory co-design involving autistic adolescents, ensure more gender-responsive content that better represents girls, and adopt standardized outcomes with longitudinal or controlled designs to improve evidence strength and real-world applicability. Emerging approaches such as gamification and

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artificial intelligence–driven personalization hold promise for enhancing engagement and adaptive learning. Through continued leadership in policy, practice, and interdisciplinary collaboration, nurses will play a critical role in ensuring digital interventions are ethical, accessible, and inclusive, ultimately empowering autistic adolescents to build autonomy, agency, and personal safety in their relationships and sexual health.

Conclusions

Digital health interventions show considerable promise in closing the longstanding gap in sexual health education for adolescents with ASD, particularly when designed to reflect their visual, structured, and self-paced learning needs. Current evidence demonstrates early effectiveness but remains limited by small samples, inconsistent measurement, and underrepresentation of girls and youth from low-resource settings. Moving forward, progress depends on participatory co-design with autistic adolescents, gender-responsive content, and culturally adaptable formats suitable for LMICs. Strengthening methodological rigor through standardized outcomes and longer follow-up will be essential to understanding long-term impact. Ultimately, digitally enabled, inclusive sexual health education can equip autistic adolescents with the autonomy, safety skills, and confidence needed to navigate relationships and well-being throughout their lives.

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Conflicts of Interest

None declared.

Checklist 1
PRISMA-ScR Checklist.
[DOCX File, 67 KB - pediatrics_v9i1e79009_app1.docx]

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Abbreviations

ASD: autism spectrum disorder
LMIC: low- and middle-income country

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MeSH: Medical Subject Headings
PCC : population-concept-context
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews

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Effectiveness of Different Virtual Reality Technologies for Social and Communication Skills in Children With Autism Spectrum Disorder: Systematic Review and Network Meta-Analysis of Current Evidence and Future Directions

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Abstract

Background: Virtual reality (VR) technology offers a new approach for the intervention of social communication skills in children with autism spectrum disorder (ASD), but the comparative effects of different forms of VR technology remain unclear.

Objective: This study aims to conduct a systematic review and network meta-analysis (NMA) based on existing randomized controlled trials (RCTs) to initially explore and compare the effects of different VR technologies on improving the social and communication skills of children with ASD.

Methods: We systematically searched relevant RCTs in both Chinese and English databases from January 1990 to February 2025. The quality of the literature was evaluated using the revised Cochrane risk of bias assessment tool (RoB-2), and an NMA was conducted under the frequentist framework using STATA 18.0 software. The quality of evidence was assessed using the Confidence in Network Meta-Analysis framework.

Result: A total of 11 RCTs (718 children) were included, evaluating 8 VR technologies. The evidence network was extremely sparse, with most interventions connected by single studies. Pairwise meta-analysis revealed overwhelming heterogeneity (I^2=91.9%, P<.001), indicating profound clinical and methodological diversity. Due to this heterogeneity and the sparse network, the NMA model failed to produce stable or clinically interpretable effect estimates. Formal assessment using the Confidence in Network Meta-Analysis framework rated the confidence in all comparisons as very low.

Conclusions: The existing evidence is insufficient to support any comparative efficacy conclusions or rankings among VR technologies for ASD social skills. The key finding is the demonstration that current evidence is too heterogeneous and immature for valid quantitative synthesis. Future research must prioritize methodological standardization before head-to-head trials can be meaningfully conducted.

Trial Registration: PROSPERO CRD420250654696; https://www.crd.york.ac.uk/PROSPERO/view/CRD420250654696

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KEYWORDS

autism spectrum disorder; virtual reality; social communication skills; network meta-analysis; children

Introduction

Autism spectrum disorder (ASD), commonly referred to as autism, is a neurodevelopmental disorder that originates in early childhood. Its primary characteristics include impairments in social interaction and communication, repetitive patterns of behavior, and restricted interests or activities [1]. The global prevalence of autism is on the rise [2]. According to the 2023 report from the US Centers for Disease Control and Prevention, by 2020, the prevalence of ASD among 8-year-old children was

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approximately 1 in 36 (4% for boys and 1% for girls), which is higher than the estimation of the Autism and Developmental Disabilities Monitoring network from 2000 to 2018 [3]. A multistage convenience cluster sampling study in China indicates that the estimated prevalence of ASD among children aged 6 to 12 years in China is 0.70%, equivalent to approximately 700,000 children [4]. One of the core symptoms of ASD is social impairment, which manifests as a lack of early social interest and motivation compared to peers, ultimately affecting their ability to engage socially [5]. Even when they exhibit social interest, they often lack the necessary social skills for appropriate interaction with others [6]. This leads to difficulties in effectively communicating and interacting with others, hindering their ability to maintain normal social relationships, which further impacts their language skills and mental health [7]. Therefore, it is essential to identify effective and sustainable measures to enhance social and communication skills among individuals with ASD.

Although current medical research has made certain progress, the exact cause of the disease has not been fully clarified. Existing studies suggest that the disorder may be caused by the interaction of multiple factors, such as genetic susceptibility [8], environmental exposure [9], and abnormal changes in the neurodevelopmental process. Due to the complexity of its pathogenesis, there is currently no specific treatment strategy targeting the cause [10]. Currently, clinical practice primarily employs comprehensive treatment, encompassing drug therapy, behavioral modification, educational training, and physical therapy [11,12]. However, traditional treatments still have some limitations. For example, behavioral training relies heavily on the therapeutic room environment and lacks ecological validity in real-world social scenarios, making it difficult to transfer skills [13]. Second-generation antipsychotic drugs (such as risperidone) can alleviate aggressive behavior but cannot improve core symptoms and carry the risk of metabolic syndrome [14]. In addition, autism is characterized by a high disability rate and currently lacks an effective cure. Its management primarily involves long-term, intensive professional rehabilitation interventions aimed at enhancing the overall abilities of children with autism. Nevertheless, these interventions impose significant economic burdens, demand substantial time commitments from caregivers, and exert considerable psychological pressure [15]. Moreover, they present formidable challenges for the allocation of social public resources, the establishment of professional service systems, and ensuring their long-term sustainability.

Since the 1990s, numerous empirical studies have systematically explored the feasibility and effectiveness of utilizing virtual reality (VR) for training and intervention in individuals with ASD [16]. VR technology is capable of integrating the real and virtual worlds, replicating diverse scenarios via algorithms, generating immersive experiences, and enabling human-computer interaction through controllers, thereby embodying the characteristics of immersion, interactivity, and imagination [17]. Over the past 2 decades, VR has been extensively applied in medicine and has garnered increasing attention in clinical cognitive rehabilitation [18]. Relevant research indicates that VR not only enhances the life skills of individuals with ASD [19], but also improves their cognitive abilities [20], emotional regulation and recognition skills [21], as well as social and communication competencies [22]. Studies demonstrate that VR technology exhibits unique advantages in addressing core symptoms in children with ASD through mechanisms, such as neuroplastic remodeling, behavioral reinforcement learning, and multimodal compensation [23].

Current VR intervention studies encompass desktop-based, augmented reality, immersive, and hybrid technologies [24], with intervention content spanning areas, such as social communication and emotional cognition [25]. However, the evidence base is characterized by profound heterogeneity in intervention protocols, outcome measurement instruments, and participant characteristics. Moreover, head-to-head comparisons between different VR modalities are virtually absent, and the existing studies primarily compare each active intervention against heterogeneous control conditions. This fragmented evidence landscape renders conventional pairwise meta-analysis insufficient for comparative efficacy questions, but it also raises fundamental concerns about whether the more complex network meta-analysis (NMA) can be validly applied.

While NMA offers a theoretical framework to integrate direct and indirect evidence and derive comparative effect estimates even when head-to-head trials are lacking, its validity critically depends on the assumptions of transitivity and consistency. Given the anticipated clinical and methodological diversity among studies in this nascent field, these assumptions are likely to be violated.

Therefore, we aim to (1) systematically map the existing randomized controlled trial (RCT) evidence on VR interventions for social and communication skills in children with ASD; (2) formally assess whether the current evidence base satisfies the assumptions required for a valid NMA; (3) assess if these assumptions are seriously violated, to conduct a detailed methodological “autopsy” to characterize the sources and magnitude of heterogeneity, network sparsity, and evidence gaps; and (4) derive concrete, prioritized recommendations for future research that address the identified methodological barriers. By reframing the analysis from hypothesis verification to hypothesis generation and from comparative efficacy assessment to evidence readiness assessment, this study aims to provide a rigorous foundation for the design of future comparative effectiveness trials and for the eventual translation of VR technologies into clinical practice.

Methods

This systematic review was conducted in accordance with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) and the PRISMA extension of the NMA guidelines [26], the details of which can be found in Checklist 1. This study is registered in the PROSPERO (International Prospective Register of Systematic Reviews) international systematic evaluation platform (CRD420250654696).

Search Strategy and Inclusion and Exclusion Criteria

The selection and search strategies for eligible studies were constructed based on the PICOS (population/patient,

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intervention, comparator, outcome, and study design) framework. We systematically retrieved data from 8 electronic databases (PubMed, Embase, Cochrane Library, Web of Science, EBSCOhost, CNKI, VIP, and Wanfang) from 1990 to February 26, 2025. To ensure no eligible literature was overlooked, we also examined the reference lists of earlier systematic reviews [23,27-30] and the included studies as supplementary sources. Due to the limitations of obtaining professional resources, only literature published in both Chinese and English was included in this search. The detailed search strategy is introduced in Multimedia Appendix 1. Following a thorough search of numerous databases, duplicate publications were discarded. Titles and abstracts were then screened, and full texts were assessed according to the inclusion and exclusion criteria. The screening and selection processes were independently conducted by 2 evaluators (L.W and XG). Any differences are determined through consultation by a third evaluator (XB).

Table 1 displays the specific selection criteria. Overall, if a study meets the following conditions, it is considered to be eligible: (1) the trial design is an RCT aiming to evaluate the effectiveness of any VR intervention on children with autism; (2) recruitment of children diagnosed with ASD is based on clinical assessments or the criteria from the *DSM-5* (*Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*) or other recognized diagnostic standards (such as the *Autism Diagnostic Observation Schedule, 2nd Edition* or the *International Classification of Diseases, 10th Edition*); (3) participants in the control group underwent non-VR interventions, nondrug treatments, or routine nursing care, whereas those in the experimental group were exposed to VR interventions; and (4) at least 1 outcome related to social or communication function is reported in the outcome indicators. Studies will be excluded if they (1) are republished articles; (2) cannot provide the full text or have a high risk of bias (such as an unrigorous trial design, lack of participant data, etc); or (3) are reviews, observational studies, case reports, letters to the editor, or conference abstracts.

Table . PICOS (population/patient, intervention, comparator, outcome, and study design) criteria for inclusion of studies.

Parameter	Criteria
Population	Children and adolescents under 18 years of age and were diagnosed with ASD[a]
Intervention	Research involving any type of virtual reality intervention
Comparator	No limitations on the control group except virtual reality interventions, such as no-treatment, waiting-list control, traditional care, or cannot be included in other treatment nodes
Outcomes	Any outcomes regarding social and communication skills that can be measured
Study design	Randomized controlled trials

[a]ASD: autism spectrum disorder.

Outcome

The primary outcome was social and communication skills. The efficacy was expressed as the change in the overall social and communication symptom assessment score after the VR intervention (data collected before and after the intervention).

Data Extraction

Two independent reviewers (XG and SL) extracted relevant information in a standard manner, including bibliographic data (author, publication year, and country/region), participant characteristics (age, gender, and sample size), intervention components (category, frequency, and duration), and immediate postintervention primary outcome measures. In cases where studies used 2 or more measurements for the same outcome indicator, the task most commonly utilized was included. If a single task had multiple raw scores, higher-quality results were preferred. The formula from the Cochrane Handbook was used to calculate the changes in mean and SD relative to the baseline when they were not fully reported [31]. We reached out to the corresponding author via email to gather more information if any data were missing. The Cochrane risk of bias tool for randomized trials [32] was used to assess the methodological quality of the included RCTs. The evidence quality of social and communication abilities was evaluated within the framework of CINeMA (Confidence in Network Meta-Analysis) [33].

For the purpose of this NMA, interventions were grouped based on their primary technological interface as reported in the original studies. Given the significant variation in specific hardware, software, and intervention protocols even within the same broad category and the diversity of control conditions, we explicitly acknowledge that these operational groups may encompass substantial clinical and methodological heterogeneity. This heterogeneity is a critical consideration when interpreting the transitivity assumption of the NMA and the pooled results, as discussed in the *Limitations* section.

Data Analysis

The data analysis was conducted jointly by 2 researchers (LW and DL). Given the significant clinical and methodological differences among the included studies in terms of population characteristics, intervention protocols, outcome measures, and the sparse preliminary evidence network, this study adopts a hierarchical analysis strategy. First, we will conduct a detailed descriptive synthesis, systematically presenting and comparing the key features and main findings of each study. Subsequently, we will perform an exploratory NMA to visualize the evidence structure and generate preliminary, hypothetical comparative

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results. It must be emphasized that due to the aforementioned limitations, the point estimates and ranking results of the NMA have high uncertainty and should be regarded as a hint for future research directions rather than definitive efficacy conclusions or clinical recommendation bases.

All data analyses were performed using STATA 18.0 (StataCorp LLC) software, following the protocol outlined below.

All outcomes were continuous variables. To mitigate baseline discrepancies, effect sizes were pooled using changes in mean values and SDs before and after the intervention. Given the variability in assessment tools and units across studies, standardized mean differences (SMDs) were adopted as the effect metric. First, traditional pairwise meta-analyses were conducted using the "metan" command to compute pooled SMDs and their 95% CIs for all comparisons between VR interventions and usual care, with forest plots generated for visualization. A random-effects model was employed to account for between-study heterogeneity, which was quantified using the I^2 statistic: $I^2 \leq 50\%$ indicated low heterogeneity, whereas $I^2 > 50\%$ denoted high heterogeneity. Transitivity was evaluated by comparing the distribution of study characteristics across intervention comparison pairs—specifically, examining whether characteristics were balanced across all intervention pairs connected via a common comparator. Systematic differences in characteristic distributions would suggest the potential violation of the transitivity assumption. We compared the distribution of key covariates that might affect the treatment effect between the groups in direct comparison and found no obvious systematic imbalance. This provides a preliminary basis for transitivity in the network analysis. However, due to the limited number of studies, the assessment of this assumption still needs to be cautious. In fact, given the observed clinical diversity in participants, interventions, and outcomes across studies, we anticipated potential violations of these assumptions. Therefore, all NMA results are presented as exploratory estimates, and the ranking of interventions is interpreted with caution, emphasizing the generation of hypotheses for future research rather than definitive clinical conclusions.

Building on descriptive analyses, exploratory NMA was conducted. Evidence networks were visualized using the "network" command to illustrate direct and indirect comparisons among distinct VR technologies. For closed loops within the network, node-splitting was performed to test for consistency; in cases of inconsistency, an inconsistency model was applied [34]. The analysis model was fitted using the "mvmeta" command under a frequentist framework, which allows sharing of a common heterogeneity parameter across comparisons. The surface under the cumulative ranking curve was calculated using the "sucra" command to generate preliminary rankings of interventions [35]. League tables summarizing SMDs and 95% CIs for all pairwise intervention comparisons were produced using the "netleague" command. Funnel plots were generated via the "metafunnel" command, and the Egger test (implemented via the "metabias" command) was used to quantitatively assess small-study effects [36]. Leave-one-out sensitivity analysis was conducted using the "metaninf" command to evaluate the stability of pooled effect sizes by sequentially excluding each study. To explore potential sources of heterogeneity, subgroup analyses were performed based on predefined factors (eg, intervention modality, geographic region, and intervention duration). Additionally, meta-regression was conducted using the "metareg" command to examine the association between continuous variables (eg, sample size and total intervention length) and effect sizes. All analyses were conducted using a 2-tailed test, with the significance level α set at 0.05.

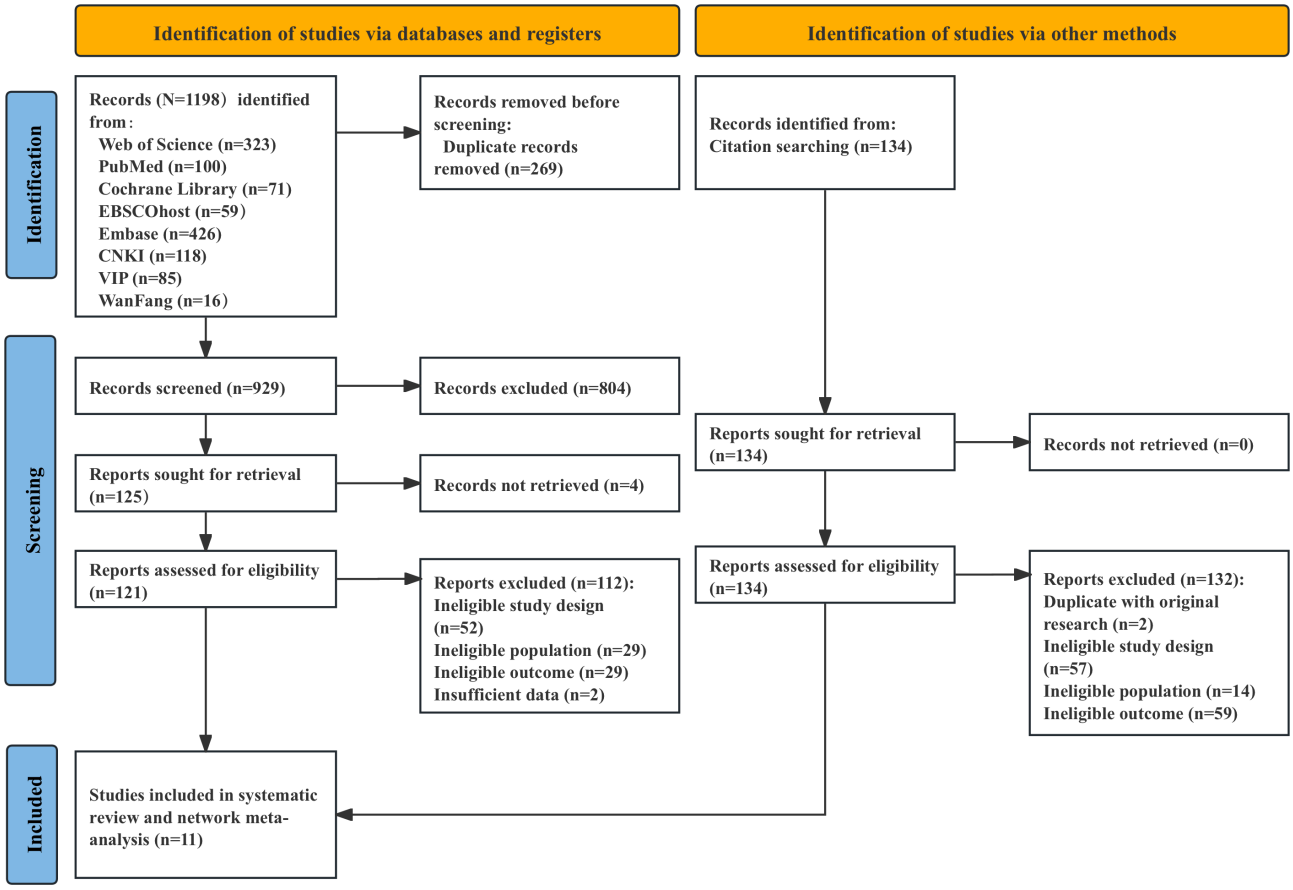
Results

Summary of Results

The retrieval of the system identified 1198 records from the electronic database. Once duplicates were eliminated, the titles and summaries of the bar records were reviewed, and 125 full-text articles were obtained to assess their eligibility. Another 134 records determined from the reference list of the relevant systematic review were also screened as qualified. The method used for literature screening is presented in Figure 1. Finally, a total of 11 studies [37-47] were included in this review, involving 718 children with ASD.

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Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart of study selection.



However, the preliminary synthesis of direct comparison evidence revealed extremely high heterogeneity among the studies (I^2=91.9%, P<.001). This result suggests that there are fundamental differences in intervention protocols, participant characteristics, and outcome measurement tools among the various studies, which make the traditional combined effect size insufficiently robust and clinically meaningful when interpreting the overall efficacy. Therefore, the following analysis will focus on describing the current state of evidence and exploratory findings.

Research Characteristics

Table 2 summarizes the details of each included study. Among the 11 studies, all employed recognized diagnostic criteria for participant identification. The age of participants ranged from preschoolers to adolescents. The experimental interventions comprised 8 distinct forms of virtual technology, classified as digital platform, head-mounted display (HMD), VR glasses, mixed reality, CAVE (cave automatic virtual environment), Half-CAVE, desktop VR, and computer-based magic skill training. HMD was the most frequently evaluated technology (n=3), followed by digital platforms. Control conditions varied and included conventional rehabilitation care, wait-list controls, or other active non-VR therapies.

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Table . Characteristics of included studies.

Study (year)	Country	Diagnostic criteria	Sample size		Sex		Age (y)		Treatment	Protocol details		Length	Duration per session	Frequency	Main outcome index
			E[a]	C[b]	E	C	E	C		E	C				
Wang [37] (2024)	China	DSM-5[c]	30	30	—[d]	—	3-5	3-5	Digital platform[e]	Immersive virtual reality (VR) (HLKF-DT-01 platform): nine modules including (1) attention (piano keys, basketball), (2) language shadowing (progressive sentence repetition), (3) spatial orientation (virtual classroom/street navigation), (4) daily-living rehearsal	Conventional rehabilitation—group OT[f], ADL[g] training, language therapy via Orff music, family-guided outdoor play, and social-story practice	4 weeks	20 min	5 days/week	ABC[h]

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Study (year)	Country	Diagnostic criteria	Sample size		Sex		Age (y)		Treatment	Protocol details		Length	Duration per session	Frequency	Main outcome index
Zhao et al [38] (2021)	China	DSM-5	57	57	—	—	3-5	3-5	HMD[i]	Home-based VR (HMD and smartphone app): identical 9-module curriculum with added (1) affect-expression tasks (avatar facial mimicry), (2) fine/gross-motor tracking games (gesture-based)	Home rehabilitation care—daily scenario education, balanced diet/exercise plans, parent-mediated play, token-economy reward system	6 months	20 min	2 sessions/week	ABC

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Study (year)	Country	Diagnostic criteria	Sample size		Sex		Age (y)		Treatment	Protocol details		Length	Duration per session	Frequency	Main outcome index
Voss et al [39] (2019)	America	DSM-5	40	31	37M/3F[j]	16M/15F[k]	Mean 8.63 (SD 2.52)	Mean 8.74 (SD 1.79)	Superpower Glass[l]	Wearable artificial intelligence (AI) system (Superpower Glass): Google Glass and emotion-recognition Convolutional neural network; provides (1) peripheral green box for face detection, (2) emoji and audio cue for 8 emotions	Home rehabilitation care—applied behavior analysis (ABA); therapist-delivered ABA at home; discrete trial training, naturalistic teaching	6 weeks	20 min	4 sessions/week	VABS-II[m]

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Study (year)	Country	Diagnostic criteria	Sample size		Sex		Age (y)		Treatment	Protocol details		Length	Duration per session	Frequency	Main outcome index
Sayis et al [40] (2022)	Spain	ADOS[n] module 3	36	36	30M/6F	30M/6F	8-12	8-12	MR[o]	Mixed reality floor projection (6-m diameter): cooperative firefly-catching game triggering virtual characters; light emitting diode net tracking and multicamera motion capture	Conventional rehabilitation—HCO cooperative play; therapist-guided dyadic construction of pirate ship; hexagonal table setup; verbal prompting for social initiation	Once	15 min	—	ASS[p]
Yuan and Ip [41] (2018)	Hong Kong, China	DSM-5	36	36	31M/5F	33M/3F	Mean 8.97 (SD 1.10)	Mean 8.73 (SD 1.15)	CAVE[q]	CAVE projection system: six authentic scenarios—(1) morning routine, (2) bus ride, (3) library rules, (4) tuckshop conflicts, (5) playground consolidation	Waitlist control—no VR or structured social skills intervention during the study period	6 weeks	60 min	1 session/week	PEP-3[r]

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Study (year)	Country	Diagnostic criteria	Sample size		Sex		Age (y)		Treatment	Protocol details		Length	Duration per session	Frequency	Main outcome index
Zhao et al [42] (2022)	China	DSM-5	22	22	19M/3F	16M/6F	3-4	3-4	HMD	Unity3D VR scenes: 6 modules—object search, color sorting, animal interaction; AI scaffolding: target-highlight	Conventional rehabilitation—group oral instruction, sensory-integration equipment (balance boards and tactile balls)	12 weeks	15 min	3 sessions/week	PEP-3
Jiang et al [43] (2023)	China	DSM-5	31	31	20M/11F	19M/12F	Mean 13.47 (SD 1.23)	Mean 13.87 (SD 1.08)	HMD	VR eye-tracking (J2-R2-1020): gaze-contingent dialogue initiation; saccade-triggered virtual character interaction (120 Hz sampling, <0.5° calibration)	Conventional rehabilitation—oral vitamin D_3, sand-play therapy twice weekly, no digital component	6 months	30 min	3 sessions/week	ATEC[s]

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Study (year)	Country	Diagnostic criteria	Sample size		Sex		Age (y)		Treatment	Protocol details		Length	Duration per session	Frequency	Main outcome index
Ip et al [44] (2018)	Hong Kong, China	DSM-5	36	36	31M/5F	33M/3F	Mean 8.97 (SD 1.11)	Mean 8.74 (SD 1.15)	H-CAVE[t]	4-side CAVE projection: six social-emotion scenarios with (1) relaxation environment and (2) school rule practice	Wait-list control—standard school curriculum plus usual outpatient therapy; no VR exposure	14 weeks	—	2 sessions/week	PEP-3
Ye et al [45] (2020)	China	DSM-5	32	32	19M/13F	20M/12F	Mean 3.51 (SD 1.03)	Mean 3.54 (1.05)	Computer[u]	VR-SST[v] platform: avatar-mediated role-play (greeting, sharing); AI immediate feedback	Conventional rehabilitation—traditional SST; therapist-led role-play, feedback, homework; 30-min sessions covering peer interaction, emotion expression	3 months	30 min	3 sessions/week	ABC

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Study (year)	Country	Diagnostic criteria	Sample size		Sex		Age (y)		Treatment	Protocol details		Length	Duration per session	Frequency	Main outcome index
Wang et al [46] (2016)	China	DSM-4	35	35	30M/5F	29M/6F	Mean 4.23 (SD 1.63)	Mean 3.91 (SD 1.44)	Digital platform	Dolphin House AV system: 2–8 kHz bionic dolphin sounds and 3D ocean VR and rhythmic lighting (0.5–4 Hz); tactile plush dolphin vibration. Acoustic intensity: 60–75 dB; illuminance 200–400 lux	Conventional rehabilitation—table-top social stories, token reinforcement, therapist-guided play; no digital component	6 months	45 min	15 days/three	ABC

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Study (year)	Country	Diagnostic criteria	Sample size		Sex		Age (y)		Treatment	Protocol details		Length	Duration per session	Frequency	Main outcome index
Yuen et al [47] (2023)	America	DSM-5	9	8	7M/2F	7M/1F	Mean 12.3 (SD 2.3)	Mean 10.5 (SD 1.2)	Computer	Virtual magic training via Zoom: OT-student coaches teach 2–3 tricks/session (cards, rubber bands, and ropes); Hocus Focus Evaluation Scale; mailed prop kit	Wait-list control—1-month delay before identical virtual MTTP[w]; no active intervention during control phase	3 weeks	45 min	3 sessions/week	SSIS[x]

[a]E: experimental group.

[b]C: control group.

[c]DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.

[d]Not available.

[e]Digital platform: Digital evaluation interactive training platform.

[f]OT: occupational therapy.

[g]ADL: activities of daily living.

[h]ABC: Autism Behavior Checklist.

[i]HMD: head-mounted display.

[j]M: male.

[k]F: female.

[l]Superpower Glass: Google Glass works with smartphones.

[m]VABS-II: Vineland Adaptive Behavior Scales Second Edition.

[n]ADOS module 3: Autism Diagnostic Observation Schedule, Module 3.

[o]MR: mixed reality.

[p]ASS: Self-made questionnaire: Affective Slider scales.

[q]CAVE: cave automatic virtual environment.

[r]PEP-3: Psychological Educational Profile - Third Edition.

[s]ATEC: Autism Treatment Evaluation Checklist.

[t]H-CAVE: Half Cave Automatic Virtual Environment.

[u]Computer: Desktop VR common equipment.

[v]VR-SST: virtual reality-based social skills training.

[w]MTTP: magic trick training program.

[x]SSIS: Social Skills Improvement System.

Notably, there was substantial diversity in the intervention protocols. Even within the same technology category, the specific content of virtual scenarios, interaction modalities, session duration, intervention frequency, and total intervention period differed markedly across studies. This indicates that each study investigated a unique “intervention package” rather than a standardized application of a given technology.

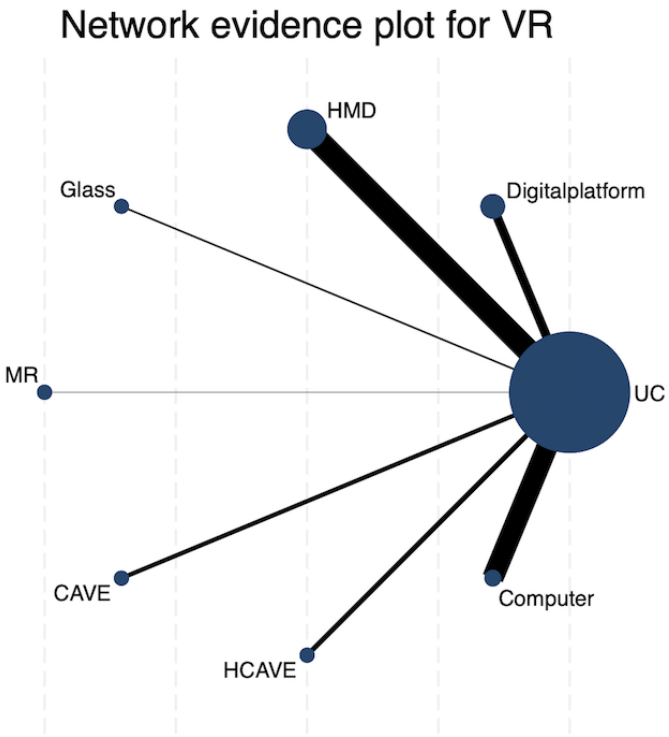
Evidence Network and Assessment of Heterogeneity

Figure 2 presents the geometry of the treatment network for the primary outcome. The network is sparse and unbalanced. While

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several direct comparisons exist between HMD and conventional care (forming the backbone of the network), many other intervention nodes are connected by only a single study. A large number of potential comparisons between different active VR technologies lack direct evidence and must rely entirely on indirect estimations. This sparsity fundamentally limits the stability and reliability of any quantitative comparative estimates derived from the network.

Figure 2. Network of eligible comparisons for the primary outcome (social and communication skills). CAVE: cave automatic virtual environment; H-CAVE: half cave automatic virtual environment; HMD: head-mounted display; MR: mixed reality; VR: virtual reality.



The preliminary pairwise meta-analysis of all VR interventions versus control groups revealed an exceptionally high degree of statistical heterogeneity (I^2=91.9%, P<.001). This overwhelming heterogeneity is not merely statistical but reflects profound clinical and methodological diversity across studies in terms of participant profiles, the nature and intensity of VR interventions, and—most critically—the tools used to measure social and communication skills. These tools assess different constructs and dimensions of social functioning with varying sensitivity. Consequently, the traditional pooled effect size, while indicative of a general positive direction, is too heterogeneous to be meaningfully interpreted as a single, precise estimate of efficacy.

Exploratory Quantitative Synthesis Findings

Given the severe and anticipated violations of the NMA assumptions—demonstrated by the extreme statistical heterogeneity (I^2=91.9%, P<.001) and the sparse, disconnected evidence network—any quantitative synthesis must be interpreted with the highest degree of caution.

Under a frequentist random-effects framework, the model produced comparative effect estimates for all contrasts; however, the 95% CIs were implausibly wide, and the model failed to achieve stable convergence. The leave-one-out sensitivity analysis confirmed that no single study was responsible for these extreme outputs; rather, the instability is an intrinsic mathematical consequence of synthesizing highly heterogeneous studies within an inadequately connected network. The formal assessment of the confidence in the evidence using the CINeMA framework rated all comparisons as “very low,” driven by serious concerns regarding within-study bias, intransitivity, imprecision, and network sparsity (see Multimedia Appendix 1).

Consequently, we do not report any specific SMDs, CIs, or surface under the cumulative ranking curve values in this section. These unstable numerical outputs are provided in Multimedia Appendix 1 for transparency and reproducibility purposes only. They must not be cited, interpreted, or used to infer the comparative efficacy or rank order of the included VR technologies. The sole robust quantitative finding from this analysis is the I^2 statistic of 91.9%, which unequivocally demonstrates that the included studies are too clinically and methodologically diverse to be meaningfully combined for the purpose of comparative effect estimation.

Risk of Bias and Quality of Evidence

We used the revised Cochrane risk of bias tool (RoB-2) to assess the included studies, and the results are detailed in Multimedia Appendix 1. The overall risk of bias was judged as moderate. The analysis revealed a distinct pattern: the most prominent sources of bias pertained to the randomization process and deviations from intended interventions. In these domains, a notable proportion of studies were rated as “high risk,” accompanied by a substantial number with “some concerns,” marking them as the core contributors to the overall risk of bias.

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The selection of the reported result emerged as a prevalent area of potential bias; while fewer studies were "high risk" in this domain, the majority raised "some concerns," indicating a widespread methodological limitation. In contrast, risks in the domains of measurement of the outcome and missing outcome data were relatively lower, with assessments predominantly being "low risk" and only sporadically "some concerns," suggesting these aspects were better controlled.

Furthermore, we used the CINeMA framework to rate the confidence in the NMA evidence of social and communication skills, which was very low in all comparisons. The results are detailed in Multimedia Appendix 1. This rating was driven by serious concerns about within-study bias (moderate risk of bias in included trials), nontransitivity (clinical and methodological heterogeneity), imprecision (very wide CIs), and sparse data (a small number of studies forming the network). This very low confidence rating formally emphasizes the high uncertainty of the quantitative estimates and rankings.

Other Exploratory Analyses

Meta-regression did not indicate the significant effects of region, intervention form, intervention duration, and intervention cycle on social and communication skills. Meanwhile, the subgroup analysis showed significant heterogeneity among different regions and different intervention form groups. The research results are presented in Multimedia Appendix 1. The source of this heterogeneity might be due to the insufficient sample size of the included original studies. Furthermore, in a single intervention, a treatment course of more than 40 minutes showed significant heterogeneity, which might be attributed to methodological differences, individual differences among participants, publication bias, among other factors. In Multimedia Appendix 1, the sensitivity analysis demonstrated that excluding studies with a high risk of bias generally yielded results consistent with the original findings. The funnel plot in Multimedia Appendix 1 shows that the scattered points are mainly located at the top of the funnel and demonstrated bilateral symmetry, indicating that the studies using the Social Functioning Assessment Scale as the outcome measurement have the least publication bias. However, 3 studies were located outside the funnel and were rather scattered, indicating that there might be a certain degree of publication bias, which could be due to the small sample size and low accuracy.

Discussion

Key Findings

This is the first study to apply the NMA to compare VR technologies for social skills in children with ASD. The most salient finding, however, is not a comparative effect estimate or ranking but rather a negative one: the existing evidence base is too heterogeneous, sparse, and methodologically inconsistent to support any valid quantitative synthesis. The critical findings are not comparative effect sizes or intervention rankings but rather (1) extreme and irreducible statistical heterogeneity (I^2=91.9%, P<.001), reflecting profound clinical and methodological diversity; (2) a sparse and disconnected evidence network in which most intervention nodes are supported by single studies and the majority of pairwise comparisons lack any direct evidence; (3) clear violations of the transitivity and consistency assumptions required for a meaningful NMA; and (4) "very low" confidence in all comparative estimates as rated by the CINeMA framework. In essence, the attempt to perform an NMA "failed"—and this failure is itself the most robust and clinically informative result of this study. Therefore, this discussion will first critically examine these limitations and then, within the framework of the existing evidence, cautiously explore the potential value and challenges of different VR technologies and point out directions for future research.

Why Did the NMA Fail? Limitations and Sources of Heterogeneity in the Existing Evidence

Although the NMA provides a theoretical framework for comparing multiple interventions, the reliability of its results depends on the internal consistency of the evidence base [48]. The extreme heterogeneity observed in this study (I^2=91.9%) is not accidental but stems from fundamental, irreconcilable differences at multiple levels that directly violate the transitivity and consistency assumptions of NMA.

First, in terms of outcome measurement tools, various studies employed a range of tools, such as from the Autism Behavior Checklist and Psychoeducational Profile to the Vineland Adaptive Behavior Scales, each assessing social functions in different dimensions, with varying degrees of sensitivity and scoring methods. The direct combination of their data assumes conceptual equivalence that does not hold, and this alone renders any pooled effect size uninterpretable [49]. Second, in terms of intervention protocols, even within the category of "head-mounted displays," there are significant differences in core elements, such as the specific content of virtual scenarios, interaction logic, duration of each session, total intervention period, and whether therapist guidance is included, making them essentially different "intervention packages." Third, in terms of study subjects, key characteristics, such as the age range of children, severity of ASD, and cognitive function levels, vary. These clinical and methodological diversities make it difficult to directly compare the study results and are the main reasons for the wide range of effect sizes observed. These clinical and methodological diversities are not merely nuisances to be statistically adjusted; they represent fundamental violations of the assumption that studies are sufficiently similar to be synthesized for comparative inference. Consequently, the primary robust conclusion from this quantitative exercise is the profound inability of the existing data to support stable or credible comparative effect estimates using the NMA.

The Potential Value and Implementation Considerations of Different VR Technologies

While acknowledging the aforementioned limitations, a descriptive synthesis of existing research can still offer valuable insights. Various forms of VR technologies, including HMDs, desktop VR, and augmented reality, have all reported positive improvements in social skills in their respective studies [50]. Among them, HMDs have shown outstanding potential in multiple studies due to their ability to provide highly immersive, controllable, and customizable virtual social environments [51]. This sense of immersion may help attract the attention of children with ASD and allow them to practice social interactions

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in a safe and highly repetitive environment, which aligns with the views presented in the systematic review by Bradley and Newbutt [52]. However, this does not imply that HMDs are superior to other modalities; they are simply the most intensively studied to date. For instance, desktop VR, with its lower sensory load and higher operational convenience, may be more suitable for some sensitive individuals or as an initial adaptation tool [53]. Meanwhile, CAVE systems, despite being limited to fixed locations, offer a unique shared space experience and are suitable for group training that requires close guidance from therapists [23].

At the same time, we must confront the practical challenges that VR intervention, especially immersive devices, faces in clinical translation. Although initial data suggest that children with ASD have a good acceptance of HMDs, the collection of safety data regarding sensory hypersensitivity, anxiety induction, or cybersickness is still neither systematic nor sufficient [54]. In addition, equipment costs, the need for professional technical support, and the integration of intervention programs with existing rehabilitation systems are all key obstacles to their wide promotion [55]. Future intervention frameworks should include a structured "transition from virtual to real" phase and actively explore the combination with mature paradigms, such as natural developmental behavior intervention [56].

Implications for Future Research

Given the current weak and inconsistent evidence base, research in this field urgently needs to move from exploring feasibility to building high-level evidence. However, the path to high-level evidence does not begin with head-to-head trials; it begins with methodological standardization.

First and foremost, methodological standardization is an indispensable prerequisite. We strongly advocate that future research studies adopt a consensus-based core outcome set and report the specific parameters of the intervention protocol in detail to enhance comparability among studies. Without this foundational step, even large-scale comparative trials will remain nonsynthesizable and will not advance the field. Second, there is a need to design and implement head-to-head RCTs—but only after the above standardization has been achieved. Such trials should directly compare the efficacy of different VR technologies in the same population and with the same measurement tools, rather than only comparing them with passive control groups. However, until outcome measures and intervention descriptors are harmonized, the results of such trials will remain context-bound and difficult to replicate or generalize. Third, the research perspective needs to go beyond immediate effects and incorporate long-term follow-up evaluations to examine the retention and generalization of skills to real-world situations and systematically monitor and report adverse events. Finally, exploring personalized intervention matching based on individual characteristics will be an inevitable path to achieving precise rehabilitation.

In conclusion, VR offers a promising new toolkit for social skills intervention in autism. This review indicates that various forms of VR hold potential, but current research is still in its early stages, with limited and heterogeneous evidence quality. We cannot, and should not, claim any specific technology as the "best" choice based on the existing data. Future efforts should focus on strengthening the evidence base, improving technical solutions, and promoting the safe, effective, and equitable integration of VR into multimodal ASD intervention systems.

Limitations

This study has several important limitations that must be fully taken into account when interpreting its results.

First, the sparsity of the evidence network is the fundamental factor that restricts the explanatory power of this NMA. Although 11 studies were included, there were as many as 8 intervention measures being compared, resulting in many comparison nodes being supported by only a single study. This "broad but shallow" evidence structure means that, for most comparisons between technologies, the effect estimates are highly dependent on indirect evidence, thereby increasing the instability and uncertainty of the results. The ranking probability results generated under this sparse network should be regarded as extremely preliminary exploratory hints rather than conclusive efficacy rankings.

Second, this study observed significant and unexplained heterogeneity. Although we attempted to explore the sources of heterogeneity through the subgroup analysis and meta-regression, the clinical and methodological diversity among studies in terms of population characteristics, intervention details, and core outcome measurement tools constituted irreducible systematic differences. Particularly, the standardization and combination of scale scores based on different theoretical constructs and measurement units, although a methodological convention, might have obscured the specific impact of the intervention on different dimensions of social function. Therefore, the large effect size intervals and fluctuations in the combined estimates reported mainly reflect this fundamental heterogeneity, suggesting that simple quantitative synthesis may not accurately describe the complex reality. In contrast, sensitivity analyses confirmed that the extreme effect estimates were an intrinsic product of the evidence structure and not the result of individual outliers. Thus, the core value of this study lies not in the numerical results it generates, but in the fact that it clearly reveals that current evidence is insufficient for reliable quantitative comparisons. Furthermore, the classification of interventions and comparators, while necessary for quantitative synthesis, itself introduces a source of heterogeneity. This clinical and methodological diversity directly challenges the similarity assumption required for a robust NMA and is a primary reason for the high statistical heterogeneity observed and the wide confidence intervals in our effect estimates.

Third, there may be language and search biases. To ensure the feasibility of the search, the language of the literature in this review was limited to Chinese and English, which might have resulted in missing relevant studies published in other languages, thereby affecting the comprehensiveness of the evidence base.

Fourth, the depth and breadth of outcome measures are insufficient. All included studies focused on the immediate postintervention effects and generally lacked medium- and

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long-term follow-up data, thus making it impossible to assess the sustainability of VR intervention effects and their generalization to real-life scenarios. Additionally, for the ASD population, which is sensitive to sensory stimuli, only a few studies systematically reported adverse reactions or reasons for dropout, leaving a gap in the comprehensive assessment of the safety profile of VR technology, especially immersive devices.

Finally, the risk of bias in the included studies should be treated with caution. Nearly half of the studies had "some concerns" or "high risk" in the randomization process or blinding implementation, which might have affected the internal validity of the effect estimates to some extent. Although the sensitivity analysis showed that the direction of the main conclusion remained unchanged after excluding the high-risk studies, this risk indicates that more methodologically rigorous studies are needed in the future to strengthen the evidence base.

Conclusion

This is the first NMA to quantitatively compare diverse VR technologies for improving social and communication skills in children with ASD. The most salient finding is not about the superiority of any specific technology but rather about the current state of the evidence base: it is too limited, heterogeneous, and methodologically inconsistent to support reliable conclusions regarding comparative effectiveness.

The core value of this study lies in systematically reviewing the current evidence, highlighting the key gaps that need to be addressed and demonstrating that the evidence is not yet ready for comparative synthesis. Future research must make breakthroughs in the following areas: first, more high-quality, large-sample RCTs should be conducted, especially those directly comparing different VR technologies, to provide more reliable data on therapeutic efficacy. Second, efforts should be made to standardize outcome measurement tools and use consensus-based core sets of indicators to enhance comparability among studies and the accumulation of evidence. Third, long-term efficacy and safety must be emphasized, including the assessment of skill maintenance, generalization, and potential risks associated with technology use. Fourth, individualized intervention plans based on personal characteristics should be explored to determine which technologies are most suitable for different types of children with autism.

In conclusion, VR shows promising potential as an intervention tool, but its evidence base is still in its infancy. The current research findings should be regarded as generating hypotheses about which technologies merit further investigation, not as validating conclusions about their comparative effectiveness. We call on the academic community to work together to advance methodological harmonization as the essential foundation for all subsequent comparative research studies.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategies, risk-of-bias assessment, exploratory quantitative synthesis, meta-regression, subgroup analysis, sensitivity analysis, funnel plot, and Confidence in Network Meta-Analysis assessment.
[DOCX File, 16680 KB - pediatrics_v9i1e82814_app1.docx]

Checklist 1
PRISMA checklist.
[PDF File, 134 KB - pediatrics_v9i1e82814_app2.pdf]

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Abbreviations

ASD: autism spectrum disorder
CAVE: cave automatic virtual environment
CINeMA: Confidence in Network Meta-Analysis
DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
HMD: head-mounted display
NMA: network meta-analysis
PICOS: population/patient, intervention, comparator, outcome, and study design
PRISMA: Preferred Reporting Items Statement for Systematic Reviews and Meta-Analyses
PROSPERO: International Prospective Register of Systematic Reviews
RCT: randomized controlled trial
RoB-2: revised Cochrane risk of bias assessment tool
SMD: standardized mean difference
VR: virtual reality

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Screen Time, Child Depression, and Anxiety During the COVID-19 Pandemic: Systematic Review and Meta-Analysis

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Abstract

Background: In response to the COVID-19 pandemic, governments around the world enforced stay-at-home orders and social distancing guidelines that amplified the use of screen time among pediatric populations. Excessive screen time may negatively impact mental health by increasing depression and anxiety.

Objective: The first aim was to conduct a systematic review of articles examining screen time and mental health outcomes among children and adolescents during the COVID-19 pandemic from 2020 to 2023. The second aim was to determine the combined effect sizes for the associations of screen time and depression and/or anxiety among children and adolescents during the COVID-19 pandemic from 2020 to 2023 and whether gender or age influenced outcomes.

Methods: Bibliographic databases were searched including MEDLINE (Ovid), Embase (Elsevier), Cochrane Library (Wiley), CINAHL Complete (EBSCO), and PsycINFO (EBSCO). There were a total of 6462 nonduplicate studies that were screened. Study inclusion criteria included children ages 0 to <18 years, the effects of screen time on children during the COVID-19 pandemic, screen time and depression and/or anxiety, articles written in English, and articles, including quantitative and qualitative studies, published between 2020 and 2023. A total of 452 articles underwent full-text review with 23 articles meeting criteria for final article extraction.

Results: A total of 23 studies totaling 29,581 children and adolescents were included in the study. Results showed that most studies reported a positive association between screen time and depression and/or anxiety (r=0.175, 95% CI 0.124-0.226, P<.001 and r=0.157, 95% CI 0.0994-0.214, P<.001, respectively) during COVID-19. Meta-regression revealed that screen time measured in problematic use of electronic devices had a 0.15 higher correlation with anxiety compared to screen time measured in duration of electronic device use.

Conclusions: During the COVID-19 pandemic, children and adolescents with higher levels of screen time had increased depression and/or anxiety. Findings suggest the need for ongoing parent, professional, and self-monitoring of youth screen behaviors and habits as well as activities that promote social connectedness during global or national health emergencies.

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KEYWORDS

screen time; anxiety; depression; COVID-19 pandemic; children; adolescents; mental health

Introduction

The global COVID-19 pandemic impacted children's screen time. As numerous restrictions were put on children and adolescents during COVID-19, regular screen usage increased due to the closure of regular outdoor activities and increase in online learning. A meta-analysis of over 29,000 children showed a 52% increase in screen time, particularly for those aged 12 - 18 years [1]. Excessive screen time increased, with adolescents reported to have almost 6 hours per day of screen use, mainly spent on watching shows, movies, and playing games [2]. One-third of adolescents aged 13 - 17 years reported using social media "almost constantly" [3]. Children at 9.5 years of age who were surveyed during the COVID-19 pandemic

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reported an average increase in recreational screen time of 11 hours per week compared to the 1 hour per week increase reported in prepandemic surveys conducted at ages 5 and 8 years [4].

The COVID-19 pandemic also exacerbated the preexisting mental health challenges of children and adolescents [5]. A meta-analysis covering over 80,000 youths globally found that the prevalence of anxiety and depression doubled during the COVID-19 pandemic to 20% - 25% [6]. In the United States, emergency visits for children due to mental health problems rose drastically by 31% - 50% since the beginning of the pandemic [7]. Globally, depression and posttraumatic stress disorder were significantly more prevalent among children aged 7 to 15 years [8] due to the separation from classmates and friends. Overall, distancing measures during the pandemic were harmful to adolescent mental health [9].

The opportunity for excessive screen use during the COVID-19 pandemic also impacted mental health outcomes among children and adolescents. Social media and media addiction were associated with ill-being among adolescents [9]. The US Surgeon General released a report [10] indicating potential risks of social media use on the mental health of children and adolescents and called for more evidence. During the pandemic, a greater duration of screen time (such as television viewing [10] or digital media time [10], including social media use [11,12]) was associated with higher levels of depression and anxiety [12]. The associations between screen time and poor mental health outcomes have been found in individual studies; however, to our knowledge, there have not been meta-analyses of screen time using standardized or validated measures of depression and anxiety during the pandemic.

Thus, this review aims to fill this gap by examining the mental health effects of screen time in children and adolescents throughout the COVID-19 pandemic. First, the purpose was to conduct a systematic review of articles examining screen time and depression and anxiety among children and adolescents during the COVID-19 pandemic from 2020 to 2023. Second, the purpose was to determine the combined effect size for the association of screen time and depression and anxiety among children and adolescents during the COVID-19 pandemic from 2020 to 2023. We additionally explored the influence of gender and age on the relationship between screen time and mental health outcomes.

Methods

Eligibility Criteria

Studies identified through database searches were screened for the following inclusion criteria: (1) children ages 0 to <18 years, (2) examination of the effects of screen time on children during the COVID-19 pandemic (eg, video games, smartphone use, or computer use), (3) examination of screen time and anxiety and/or depression, (4) articles were written in English, and (5) studies, including quantitative and qualitative studies, published between 2020 and 2023. Studies were excluded if they did not describe the effects of screen time on children during the COVID-19 pandemic (eg, provider-led and provider-care interventions; telehealth) or did not meet the inclusion criteria listed above.

Information Sources and Search Strategy

We initially searched the following bibliographic databases: MEDLINE (Ovid), Embase (Elsevier), Cochrane Library (Wiley), CINAHL Complete (EBSCO), and PsycINFO (EBSCO). A MEDLINE search strategy was created using a combination of Medical Subject Headings (MeSH) and keywords for the concepts of COVID-19, screen time, and pediatrics. All team members reviewed the strategy and results; with team approval, the search was customized using controlled vocabulary (when available) and keywords in Embase, Cochrane Library, and PsycINFO (Multimedia Appendix 1). As of November 2021, all resulting citations were exported into an EndNote 20 (Clarivate Analytics) library with duplicates removed [13]. The resulting collection of citations was then imported into Covidence for screening. In August 2022, the search was run again in all bibliographic databases and any unique citations were imported into Covidence. Finally, in February 2023, the search was rerun given the refinement of the research question to include validated measures of depression and anxiety and to capture new studies that had been recently published. This was done again in MEDLINE and PsycINFO and also included CINAHL. All articles were imported and screened in Covidence.

Data Collection Process

Two reviewers independently extracted data from each article and the extracted data were sent to the research team for consensus. The following data were extracted from each study: the first author, the date and place of publication, the number of participants enrolled, participant demographics, measures/assessments used, study start and end date, inclusion criteria, findings summary, and effect sizes. The extracted data were collected in Covidence. Any disagreements were resolved in discussions with the research team.

Screen time during the COVID-19 pandemic, including problematic use that was excessive or disordered (eg, video games, smartphone or computer use, social media use), was defined through self-reports of screen time duration. Anxiety was defined using self-report standardized questionnaires as well as standardized parent report measures on anxiety symptoms. Depression was defined using self-report standardized questionnaires as well as standardized parent report measures on depressive symptoms.

Study Risk of Bias Assessment

The STROBE (Strengthening the Reporting of Observational studies in Epidemiology) checklist was used to assess the quality of included studies on a scale from 0 to 21 (Table 1) [14]. Two reviewers assessed each study independently and then met to achieve consensus.

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Table . STROBE (Strengthening the Reporting of Observational studies in Epidemiology) checklist for bias assessment.

	Introduction		Methods				Results		Discussion		
ID	Back-ground	Objec-tives	Partici-pants	Variables	Data/mea-sures	Statistical methods	Descrip-tive data	Outcomes	Results	Limita-tions	Total
1 [15]	2	2	2	2	2	2	2	2	2	2	20
2 [16]	2	2	2	2	2	2	2	2	2	2	20
3 [17]	2	2	2	2	2	2	2	2	2	2	20
4 [18]	2	2	2	2	2	2	2	2	2	2	20
5 [19]	2	2	2	2	2	0	2	2	2	2	18
6 [20]	2	2	2	2	2	2	2	2	2	2	20
7 [21]	2	2	2	2	2	1	2	2	2	2	19
8 [22]	2	2	2	2	2	2	2	2	2	2	20
9 [23]	2	2	2	2	2	2	2	2	2	2	20
10 [24]	2	2	2	2	2	2	2	2	2	2	20
11 [25]	2	2	2	2	2	1	2	2	2	2	19
12 [26]	2	2	2	2	2	2	2	2	2	2	20
13 [27]	2	2	2	2	2	2	2	2	2	2	20
14 [28]	2	2	2	2	2	2	2	2	2	2	20
15 [29]	2	2	2	2	2	2	2	2	2	2	20
16 [30]	2	2	2	2	2	2	2	2	2	1	19
17 [30]	2	2	2	2	2	2	2	2	2	2	20
18 [11]	2	2	2	2	2	2	2	2	2	2	19
19 [31]	2	2	2	2	2	2	2	2	2	2	20
20 [32]	2	2	2	2	2	2	2	2	2	2	20
21 [33]	2	2	2	2	2	2	2	2	2	2	20
22 [34]	2	2	2	2	2	1	2	2	2	2	19
23 [35]	2	2	2	2	2	1	2	2	2	2	19

Effect Measures, Synthesis Methods, and Analyses

Fisher *r*-to-*z* transformation was used as the effect measure to quantify the relationship between screen time, anxiety, and depression, and results were converted back to Pearson correlations for interpretation. Studies were excluded if they were missing sufficient summary statistics and/or were unconvertible into appropriate effect sizes. Studies reported in other effect measures were converted to correlations using the conversion formulas proposed by Borenstein et al [14]. If a study assessed the same outcome with more than one measure, the average effect size was used in the analysis [36].

A random-effects model was used for all meta-analysis to account for heterogeneity across studies. Pooled correlations of r=0.10, r=0.30, and r=0.50 were considered as small, medium, and large effect sizes, respectively [37]. Heterogeneity (ie, $\tau 2$) was assessed using the restricted maximum-likelihood estimator. In addition to the estimation of $\tau 2$, the Q test for heterogeneity and the I^2 statistics are also reported [38]. Forest plots were generated for each outcome to visualize individual study effects and pooled estimates. Funnel plots were used to detect potential publication bias. Meta-regression analysis was performed to assess the impact of age, gender, and the definition of screen time (duration of use vs problematic use) on the effect sizes [39]. To evaluate the robustness of the results, sensitivity analysis was conducted by excluding studies identified as potential outliers or exerting excessive influence on the pooled effect using studentized residuals and the Cook distance [40]. All statistical analyses were performed using RStudio (version 4.4.1; Posit PBC) and the *metafor* package [41].

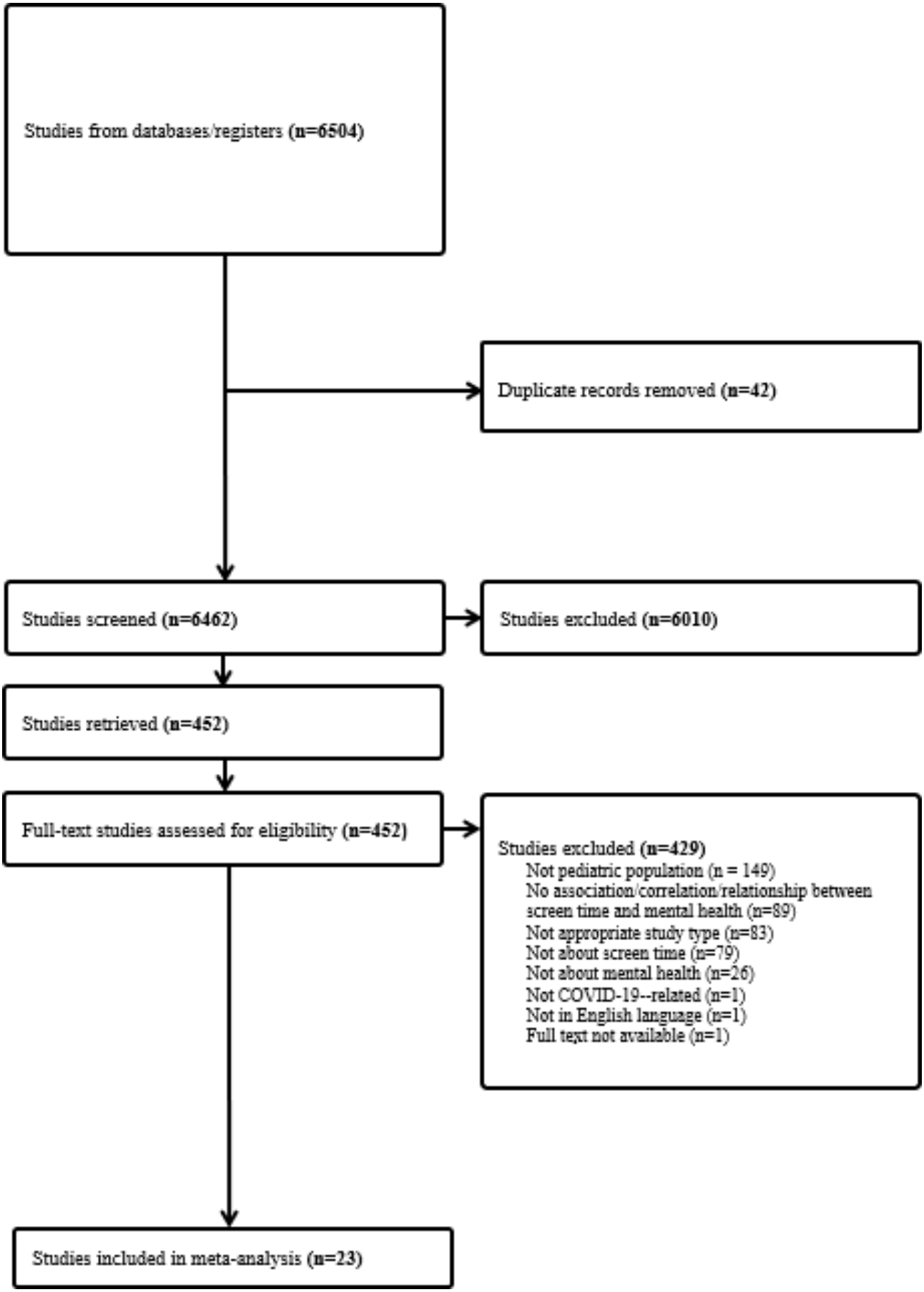
Results

Search Results and Included Studies

In the initial database search, 6504 records were obtained. After duplicate removal, the titles and abstracts of 6462 records were screened independently by 7 coders based on the predefined eligibility criteria. After the title and abstract screening, 452 articles were retained. Following full-text screening, 429 articles were excluded from the systematic review, and 23 articles totaling 29,581 children and adolescents were retained in the systematic review and meta-analysis. See Figure 1 for the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram of observational studies.

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Figure 1. PRISMA flowchart for studies of screen time during the COVID-19 pandemic and pediatric mental health. PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses.



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Study Characteristics

Across the 23 studies (Table 2), children and adolescents were 8 to <18 years of age, with a mean age of 13.54 (SD 0.43) years; in addition, 49% (n=14,390) were male and 51% (n=15,191) were female. Of the 23 studies, 39% (n=9) were from North America, 44% (n=10) were from Asia, and 17% (n=4) were from Europe. Studies were published globally in the following countries: United States (n=6), China (n=6), Canada (n=3), Hong Kong (n=1), Hungary (n=1), Italy (n=2), India (n=1), Iran (n=1), Poland (n=1), and South Korea (n=1). Of the 23 studies, 96% (n=22) examined depression, 83% (n=19) examined anxiety, and 78% (n=18) examined both depression and anxiety.

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Table . Characteristics of studies.

ID	Author	Country	Sample size (N)	Male (%)	Age (years)	Screen time	Depression	Anxiety
1a	Alves et al, 2021 [15]	United States	30	43	11.7	Duration	PANAS-C[a]	STAIC[b]
1b	Alves et al, 2021 [15]	United States	34	32	11.9	Duration	PANAS-C	STAIC
2	Berki et al, 2021 [16]	Hungary	705	37	15.9	Duration	CDI[c]	N/A
3	Charmaraman et al, 2022 [17]	United States	900	47	12.53	Duration	CESDR-10[d]	SADS[e]
4	Chen et al, 2021 [18]	China	1357	50	10.71	Duration	DASS-21[f]	DASS-21
5	De Pasquale et al, 2021 [42]	Italy	162	48.2	9.4	Problematic use	N/A	CAM-S[g]
6	Ellis et al, 2020 [19]	Canada	1054	21.9	16.68	Duration	BSI[h]	N/A
7	Fazeli et al, 2020 [20]	Iran	1512	56.4	15.51	Problematic use	DASS	DASS
8	Lee et al, 2021 [21]	South Korea	264	100	17.57	Problematic use	CES-D[i]	N/A
9	Liu et al, 2022 [22]	China	5581	48.5	13.8	Problematic use	SDS[j]	SAS[k]
10	McArthur et al, 2021 [23]	Canada	846	52.8	9.85	Duration	BASC-3[l]	BASC-3
11	Moitra et al, 2021 [24]	India	1298	53.3	13.2	Duration	PHQ[m]-2	N/A
12	Mousavi et al, 2022 [25]	United States	215	51.2	15.63	Duration	DASS	DASS
13	Murata et al, 2021 [26]	United States	583	20	15.8	Duration	PHQ-9	GAD[n] -7
14	Muzi et al, 2021 [27]	Italy	62	37	15.43	Problematic use	YSR[o] 11 - 18	YSR 11 - 18
15	Ren et al, 2021 [28]	China	1771	51.8	N/A	Duration	PHQ-9	GAD-7
16	Sikorska et al, 2021 [29]	Poland	370	32.7	15.38	Duration	DASS-21	DASS-21
17a	Tandon et al, old, 2021 [30]	United States	500	50.5	14	Duration	SDQ[p]	SDQ
17b	Tandon et al, young, 2021 [30]	United States	500	52.6	8	Duration	SDQ	SDQ
18	Tao et al, 2021 [11]	United States	407	17.7	16.47	Duration	CES-D	GAD-7
19	Tardif-Grenier et al, 2021 [31]	Canada	895	26.3	14.69	Duration	CES-D	SCARED-R[q]
20	Teng et al, 2021 [32]	China	1778	50.7	N/A	Duration	CES-D	STAI[r]
21	Xiang et al, 2022 [33]	China	2423	51.2	10.5	Duration	DASS-21	DASS-21
22	Zhang et al, 2022 [34]	China	3471	51.6	14.1	Duration	PHQ-9	GAD-7

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ID	Author	Country	Sample size (N)	Male (%)	Age (years)	Screen time	Depression	Anxiety
23	Zhu et al, 2021 [35]	Hong Kong	2863	59	12.6	Problematic use	PHQ-9	GAD-7

[a]PANAS-C: Positive and Negative Affect Scale - Child Form.
[b]STAIC: State-Trait Anxiety Inventory for Children.
[c]CDI: Children's Depression Inventory.
[d]CESDR-10: Center for Epidemiologic Studies Depression Scale Revised.
[e]SADS: Social Avoidance and Distress Scale.
[f]DASS-21: Depression Anxiety Stress Scale.
[g]CAM-S: Child Anxiety Meter-State.
[h]BSI: Brief Symptom Inventory.
[i]CES-D: The Center for Epidemiologic Studies Depression Scale.
[j]SDS: Self-Rating Depression Scale.
[k]SAS: Self-Rating Anxiety Scale.
[l]BASC-3: Behavior Assessment System for Children-Third Edition.
[m]PHQ: Patient Health Questionnaire.
[n]GAD-7: Generalized Anxiety Disorder 7-item.
[o]YSR: Youth Self-Report.
[p]SDQ: Strengths and Difficulties Questionnaire.
[q]SCARED-R: Screen for Child Anxiety Related Disorders-Revised.
[r]STAI: State Trait Anxiety Inventory.

Risk of Bias in Studies

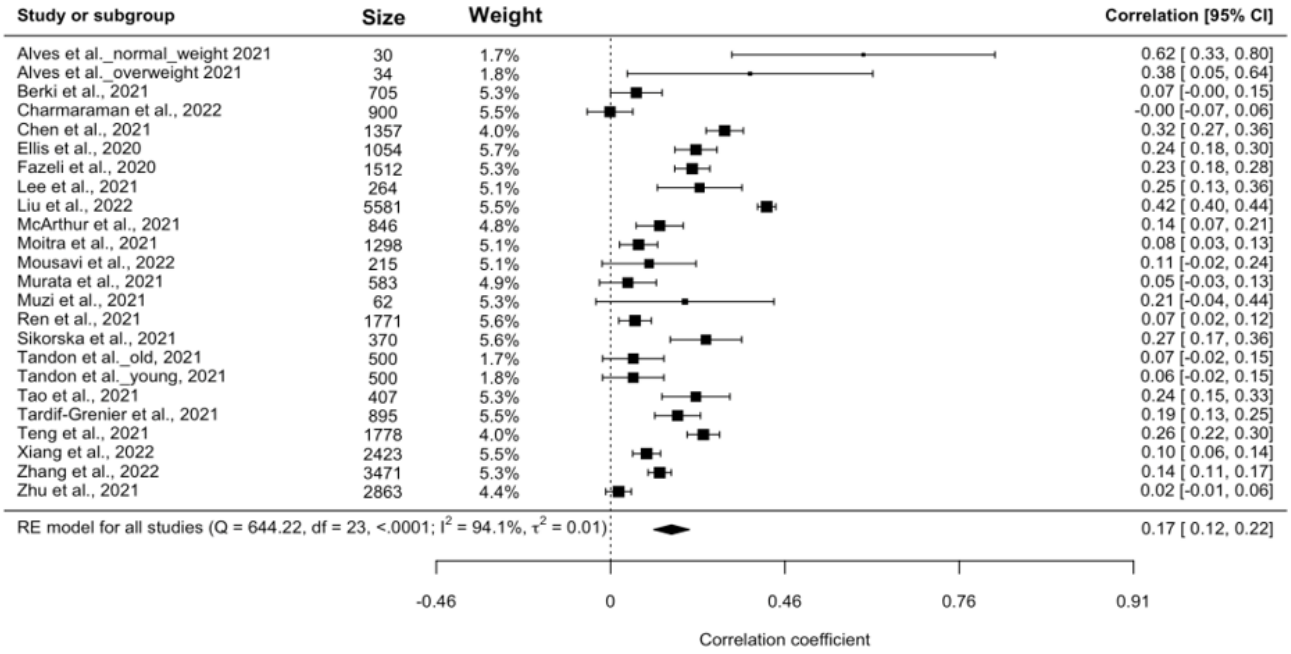
The STROBE checklist [14] was used to assess the quality of studies and any potential bias as seen in Table 1. Two independent reviewers assessed each study, resulting in a possible score from 0 to 20. Each section of the STROBE checklist had a potential score of 0 to 2, with 0 meaning criteria were not met, 1 meaning criteria were partially met, and 2 meaning criteria were fully met. Two reviewers ranked the scores, and any disagreements were discussed with a third reviewer to achieve consensus. All studies used validated questionnaires for depression and anxiety. McArthur et al [23] used a large longitudinal cohort, which allowed for examination of differences over time. The majority of studies were cross-sectional and were conducted during the global pandemic, which did not allow for examination of causal relationships. The following studies were found to have a lower quality assessment. De Pasquale et al [42] did not provide any information on the statistical tests that were conducted in the methods. Fazeli et al [20] had limited information on the statistical methods. Moitra and Madan [24] conducted a mediation analysis on a cross-sectional study but did not indicate the temporal order in their survey methods. Zhu et al [35] imputed more than 25% of missing data. Sikorska et al [29] did not adequately address potential limitations.

Screen Time and Depression

Twenty-two of the 23 included studies (all except [42]) reported comparable effect sizes for screen time and depression. Two studies [15,30] presented results only for stratified subgroups rather than an overall sample. Therefore, we treated the stratified groups as separate studies in the analysis and increased the sample size to 24 for the analysis. The observed correlation coefficients ranged from −0.00160 to 0.620. The random-effects model revealed a significant, positive, small estimated pooled correlation (r=0.175, 95% CI 0.124-0.226; P<.001; I^2=94%). According to the Q test, the true estimates appear to be heterogeneous (Q_{23}=644.22, P<.001, τ2=0.0138, I^2=95%). A forest plot showing the observed and the estimated correlation is shown in Figure 2 [11,15-31,33-35]. Meta-regression showed no significant associations of depression with age and gender.

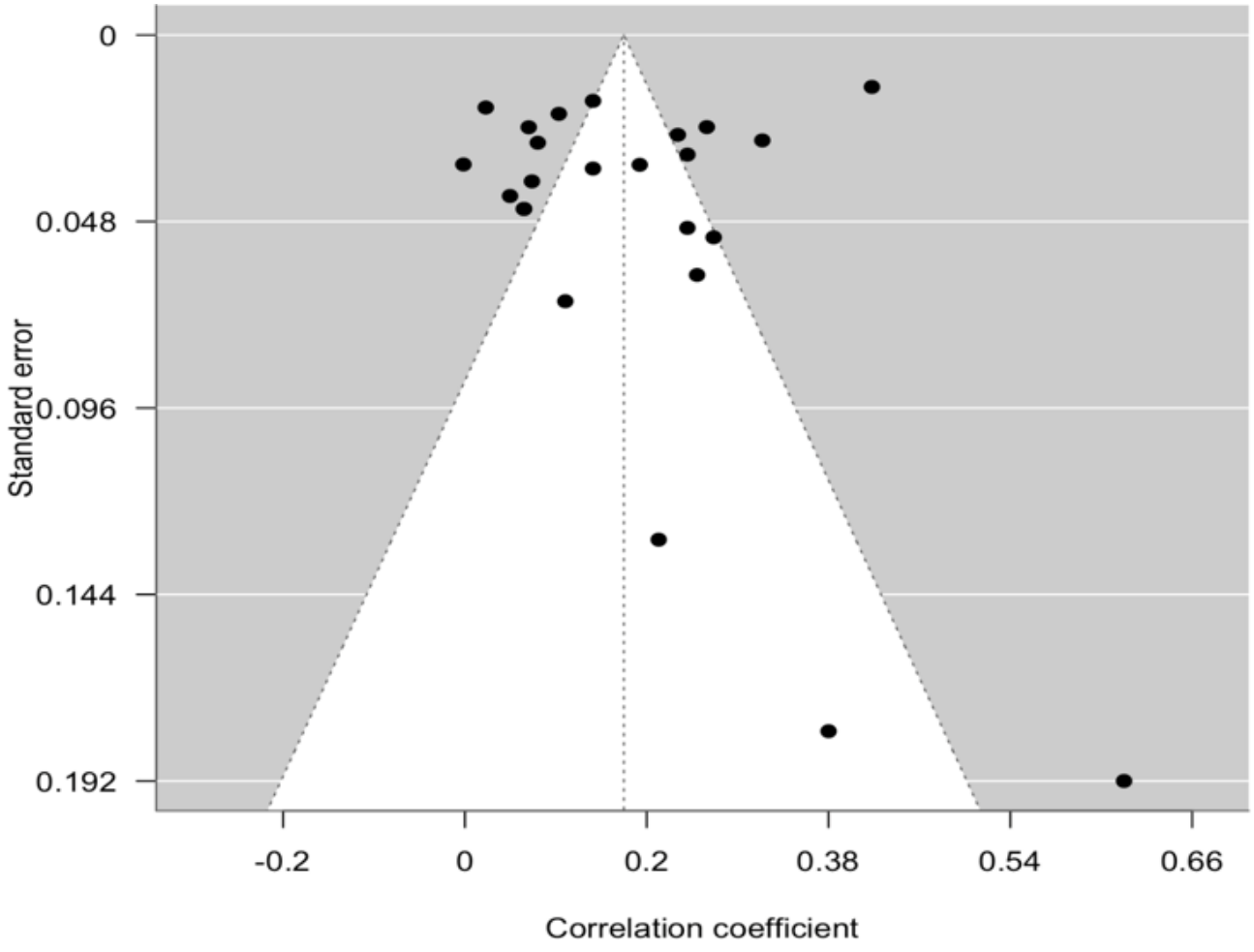
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Figure 2. Forest plot for depression.



A funnel plot of the estimates is shown in Figure 3. The plot is reasonably symmetrical around the pooled estimate, indicating no strong evidence of publication bias or small-study effects. Both the Cook distance and studentized residuals showed that one study [22] could be overly influential. Sensitivity analysis was conducted by removing the study. The result from the sensitivity analysis remained stable after removing the potential outlier (r=0.158, 95% CI 0.114-0.202; P<.001), supporting the result from the main analysis. Although I^2 decreased from 95% to 90%, heterogeneity remained high across studies.

Figure 3. Funnel plot for depression.

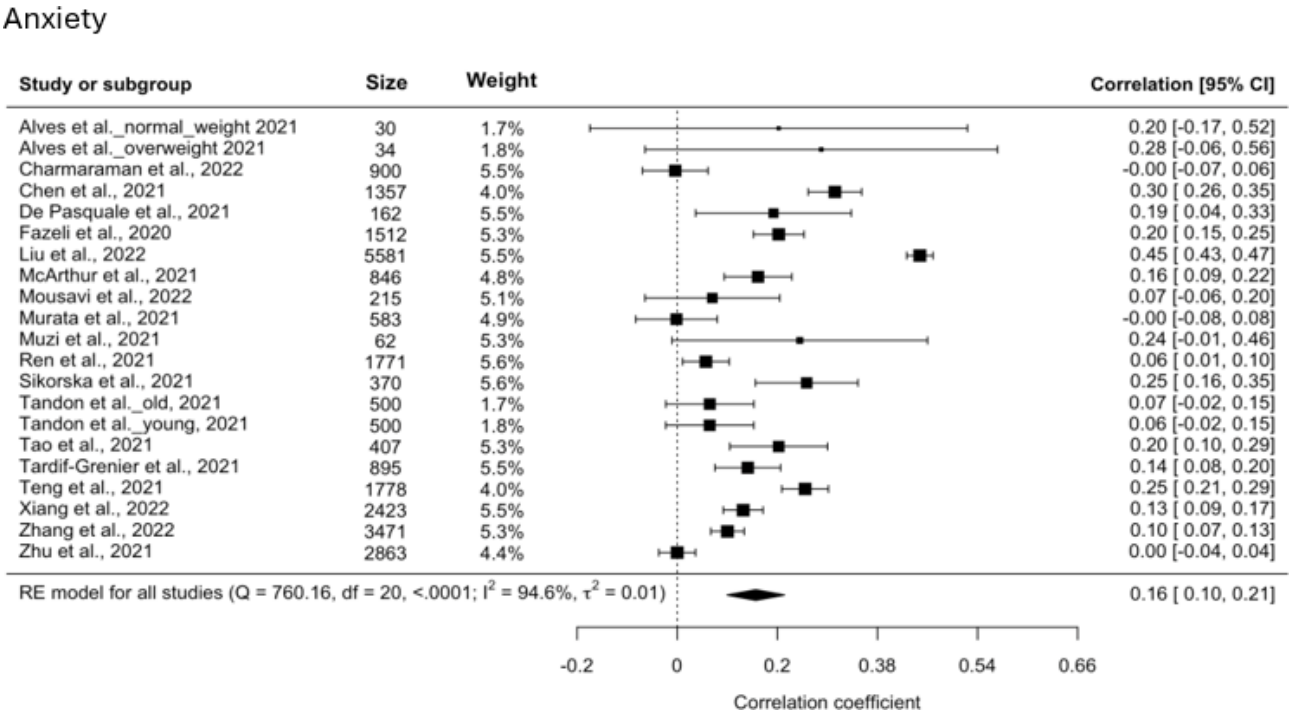


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Screen Time and Anxiety

A total of 19 studies reported correlation coefficients for screen time and anxiety, ranging from −0.00390 to 0.450. Since the results from Alves et al [15] and Tandon et al [30] were reported as two stratified subgroups, it increased the total sample size to 21 for the analysis. A random-effects model for screen time and anxiety again indicated a significant yet small estimated pooled correlation (r=0.157, 95% CI 0.0994-0.214; P<.001), with a Q test (Q_{20}=760.16, P<.001,τ2=0.0150, I^2=95%) demonstrating high heterogeneity. A forest plot showing the observed and estimated correlations is shown in Figure 4 [11,15,17,18,20,22,23,25-30,33-35,42]. Meta-regression revealed that compared to studies where screen time was measured as duration of use, those defining it as problematic use have an average 0.1585 higher Fisher z score for the correlation between screen time and anxiety. In terms of correlation, this translates to roughly a 0.15 increase, indicating a stronger correlation with anxiety in studies with problematic use.

Figure 4. Forest plot for anxiety.

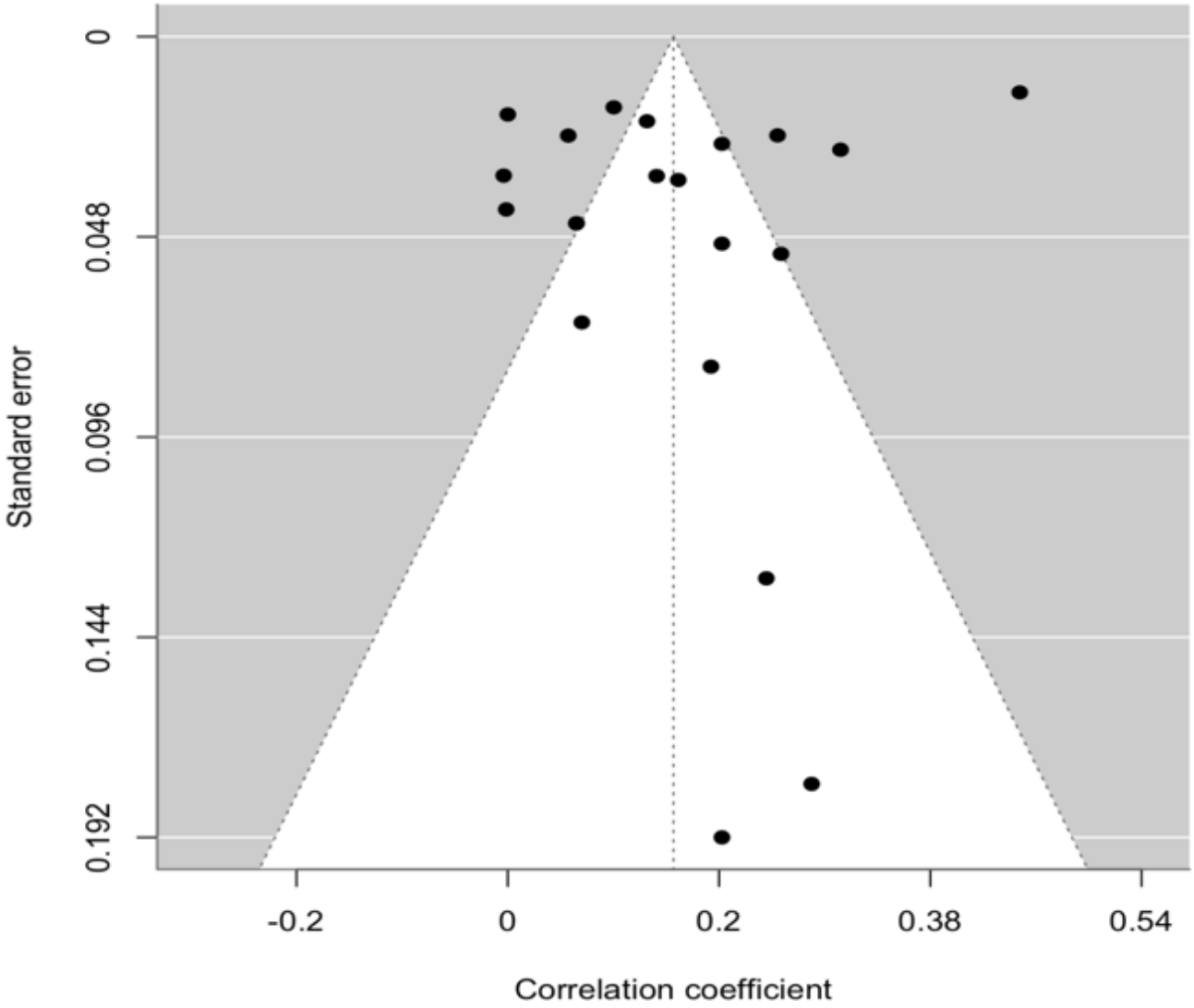


Certainty of Evidence

The funnel plot in Figure 5 was fairly symmetrical around the pooled effect size visually, with no indication of publication bias or small-study effects. The same study [22] was considered to be an outlier based on the Cook distance and studentized residual. The result from the sensitivity analysis yielded a slightly lower but still significant correlation (r=0.135, 95% CI 0.0890-0.181; P<.001), supporting the result from the main analysis. Although I^2 decreased from 95% to 89%, heterogeneity remained high overall, suggesting the true effect varies across different studies.

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Figure 5. Funnel plot for anxiety.



Discussion

Principal Findings

This meta-analysis of a total of 23 global studies examined screen time and mental health outcomes among 29,581 children and adolescents during the COVID-19 pandemic. Screen time had a significant, positive, small estimated pooled correlation with increased depression (22 studies) and increased anxiety (19 studies). Problematic screen use that was excessive or disordered had a stronger correlation with anxiety than average screen use. Age and gender did not influence mental health outcomes; most youth were adolescents and gender was equally distributed. Sensitivity analyses for studies with outliers for depression and anxiety supported the results from the main analysis.

Although various studies examined different types of screen time during the pandemic, results remained the same. Studies reported greater time spent on social media was associated with higher depressive [11,19] and anxiety symptoms [11]. Zhu et al [35] reported pathological gaming behavior (as compared to excessive, leisure, and none) was associated with increased depression and anxiety. Berki et al [16] reported that more hours of daily screen time (time spent using electronic devices such as a computer, tablet, or smartphone) were associated with higher depressive symptoms. Studies also found that a greater number of hours spent on video games and social media predicted higher depressive [18,26,43] and anxiety [18] symptoms and negative perceived well-being [44].

Strengths

There were various strengths in this meta-analysis. A rigorous process was implemented, with multiple reviewers using a systematic approach to achieve consensus when screening studies for eligibility and extracting data from studies that met eligibility criteria. Additionally, depression and anxiety were measured using validated questionnaires, and the meta-analysis methodology provided precision in the estimate of the effect size, which increased the validity and generalizability of the findings. Extracted studies included pooled data from 10 countries in North America, Europe, and Asia, further increasing the generalizability of the findings. Sensitivity analyses demonstrated the robustness of the study results. Finally, the COVID-19 pandemic was a global emergency that served as a natural experiment and magnified the conditions to allow youth to participate in excessive screen time, providing a rare

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opportunity with high statistical power to examine the impact on mental health outcomes.

Limitations

There were limitations in this study. Most studies examined the negative impact of screen time, which may have introduced some bias. Given the unprecedented nature of the global pandemic, most studies were cross-sectional, allowing for the examination of the relationship between screen time and increased depression or anxiety at one point in time. The results are not generalizable to all age groups as the cohort mostly consisted of adolescents, with a mean age of 13.54 years. More information is needed about how the COVID-19 pandemic impacted school-age (6 - 12 year olds) and young children (0 - 5 year olds). Screen time was also measured through youth self-reports or parent reports, which may not accurately reflect the amount of time spent on screens due to recall bias. It is possible that other factors aside from screen time, such as the adjustment to the online schooling format and/or cybervictimization, may have impacted anxiety and depression. Since this study included data from multiple countries, there may have been different methods for collecting and tracking data, and it is possible that some mental health data could have been underreported.

Clinical Implications

During the pandemic, children and adolescents with increased screen time were negatively impacted in terms of depression and anxiety due to higher levels of screen time. These findings suggest the need for ongoing assessment of children and adolescents' quality and quantity of screen behaviors to identify risk factors to prevent or treat mental health outcomes, especially in the event of another global or national emergency. More research is needed to develop a validated tool to assess screen time [45,46]. Given the significance of screen time in the lives of youth, it is important to consider how to address unhealthy media habits that may increase during a pandemic. The American Academy of Pediatrics recommends the 5 Cs of Media Use to promote healthy media habits [47]. This includes Child, Content, Calm, Crowding Out, and Communication. Practitioners should work with families to develop family media plans that address rules around screen time, balancing family and media time, conversations around responsible social media use, teaching emotion regulation strategies, parental modeling of screen use, and monitoring content for quality, developmental appropriateness, and privacy. Additionally, pediatricians can provide anticipatory guidance to help children and families prepare for emergencies, such as a global pandemic [48]. Children and adolescents should learn from an early age about the benefits and risks of screen use, with an emphasis on developing healthy screen habits that maximize positive social interactions, learning, and recreation; increasing awareness of safety factors such as the protection of privacy; and creating self-awareness that will guard against the negative impacts on mental health related to screen overuse. Finally, promoting positive childhood experiences during a global emergency may help to buffer negative impacts of excessive screen time on mental health outcomes by nurturing healthy social-emotional development.

Conclusion

This meta-analysis includes the evidence from 23 studies on screen time and mental health. During the COVID-19 pandemic, children and adolescents with higher levels of screen time had increased depression and/or anxiety. These data suggest the need for ongoing parent, professional, and self-monitoring of youth screen behaviors and habits as well as activities that promote social connectedness during global or national health emergencies.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategies by database.
[DOCX File, 21 KB - pediatrics_v9i1e83228_app1.docx]

Checklist 1
PRISMA checklist.
[DOCX File, 275 KB - pediatrics_v9i1e83228_app2.docx]

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Abbreviations

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
STROBE: Strengthening the Reporting of Observational studies in Epidemiology

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Virtual, Augmented, Mixed, and Immersive Technologies for Prenatal and Childbirth Education: Scoping Review

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Abstract

Background: Virtual, augmented, mixed, and other immersive technologies, collectively referred to as extended reality (XR), are increasingly used to enhance experiential learning in health education. By creating interactive 3-dimensional or 360° environments, these technologies allow expectant parents to engage in realistic prenatal and childbirth scenarios, promoting emotional preparedness, knowledge acquisition, and confidence. Although XR has been widely studied in clinical training, its application in prenatal and childbirth education for parents remains less systematically explored.

Objective: This scoping review aims to map and synthesize the current evidence on the use of virtual, augmented, mixed, and immersive technologies in prenatal and childbirth education, highlighting their educational benefits, methodological approaches, and implementation challenges.

Methods: A comprehensive search was conducted across Scopus, Web of Science, PubMed, CINAHL, IEEE Xplore, APA PsycINFO, and APA PsycArticles from inception to October 16, 2025. Search terms included “virtual reality,” “augmented reality,” “mixed reality,” “extended reality,” and “immersive technology,” combined with prenatal and childbirth education descriptors. Studies were included if they applied immersive or XR technologies to deliver prenatal or childbirth education for expectant parents. Screening and data extraction were performed independently by 2 reviewers following PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) guidelines. The review was registered on Open Science Framework (OSF).

Results: From 1861 records, 11 studies from 8 countries were included, spanning randomized controlled, quasi-experimental, feasibility, and qualitative designs. Interventions comprised head-mounted display–based virtual reality, 360° video, and mixed reality simulations. Outcomes covered psychological, physiological, educational, and experiential domains. Most studies reported feasibility and high engagement, with encouraging signals for reduced anxiety and improved birth preparedness and, in some cases, reductions in pain and intrapartum indicators. No serious adverse events were reported; nausea and discomfort were infrequent and transient. Thematic analysis identified 5 recurring themes: enhanced birth preparedness, realism and presence as a key mechanism, usability barriers and the need for guided facilitation, motivational and educational potential, and limited partner inclusion. Methodological quality was heterogeneous, with small samples, nonstandardized measures, and short follow-up.

Conclusions: Evidence for XR in prenatal education is promising yet preliminary. Rigorous multicenter studies with standardized outcomes, longer follow-up, and greater partner involvement, alongside attention to equitable access and digital literacy, are needed to support integration into maternity care pathways.

Trial Registration: OSF Registries osf.io/4uzy7; https://osf.io/4uzy7/overview

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KEYWORDS

extended reality; immersive technology; augmented reality; mixed reality; 360° video; virtual reality; childbirth education; parental education; prenatal education; breastfeeding

Introduction

Background and Importance of Prenatal Education

Prenatal education plays a pivotal role in preparing expectant parents for childbirth and early parenthood. Traditionally, such education has been delivered through in-person classes, with the goal of fostering confidence and informed decision-making during pregnancy [1-3]. Improving parental emotional readiness has also been associated with better neonatal outcomes, including reduced complications at birth, underscoring the indirect benefits of prenatal education on child health [4,5].

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Beyond knowledge acquisition, prenatal programs aim to enhance emotional preparedness, self-efficacy, and engagement, factors that can significantly influence maternal and neonatal well-being [6].

Limitations of Traditional Approaches

Despite its recognized importance, participation in conventional prenatal education programs may be complicated and at times impeded due to time constraints, work demands, and logistical or transportation barriers [7]. Traditional didactic formats often provide limited experiential engagement and may fail to adequately address psychological aspects such as fear of childbirth (FOC) and anxiety; a randomized controlled trial (RCT) evaluates an 8-week integrated childbirth education program that combines labor simulations with mindfulness practices to better target these needs. Compared with standard prenatal care, the program significantly reduced FOC, anxiety, and depressive symptoms and increased dispositional mindfulness through early postpartum, suggesting that integrative approaches (such as mindfulness) can improve the impact of the traditional prenatal education programs, for example, improving perinatal mental health in women with high FOC [8]. Pregnancy is widely recognized as a sensitive period in which psychological distress, including fear, anxiety, and depression, can negatively affect both maternal and neonatal outcomes [5,9]. Common concerns include miscarriage, fetal abnormalities, labor pain, and the perceived ability to be a "good mother." Studies have shown that FOC, particularly in late pregnancy, may contribute to avoidance behaviors such as elective cesarean section [9,10]. Nonpharmacological interventions, including hypnosis, physical activity, and cognitive-behavioral strategies, have been trialed to mitigate childbirth-related anxiety with mixed but promising results [11-13]. Overall, prenatal education remains a widely accessible and effective strategy to empower parents and promote positive maternal and infant outcomes [14-16].

The Use of Virtual, Augmented, Mixed, and Immersive Technologies in Prenatal Education

With the growing digitization of health care and the evolving needs of diverse parent populations, innovative approaches to prenatal education are increasingly being explored.

Extended reality (XR) is an umbrella term encompassing virtual reality (VR), augmented reality (AR), and mixed reality (MR) technologies, which collectively enable users to interact with digital environments and objects beyond traditional screen-based media. XR systems differ in the degree of immersion and integration between virtual and physical elements, including (1) VR, which provides full immersion in a computer-generated environment, typically via a head-mounted display (HMD) that occludes the physical world; (2) AR, which overlays digital information or objects onto the real environment, maintaining users' awareness of their surroundings; and (3) MR, which allows real and virtual elements to coexist and interact in real time, creating a seamless hybrid environment. These immersive systems leverage high-resolution audiovisual displays, motion tracking, and multisensory feedback (eg, haptic or spatial audio) to generate a sense of presence and involvement, key dimensions of the immersive experience [17,18]. In this review, XR and immersive technologies are defined as digital simulation environments, ranging from fully immersive VR headsets to semi-immersive 360° video and mobile-based apps, designed to support experiential learning and emotional engagement during prenatal and childbirth education [19,20]. By providing immersive, interactive simulations, XR could enable users to experience realistic childbirth environments in a safe and controlled setting, potentially enhancing understanding, emotional preparedness, and engagement, especially among first-time parents or those with limited access to conventional resources [21]. While the use of XR in clinical training for health care professionals is well established [22], its application for patient-facing prenatal education remains relatively understudied. Early studies suggest that immersive interventions, administered in different phases of the childbirth process, may reduce childbirth-related anxiety, improve systolic blood pressure, decrease maternal heart rate, and even increase fetal movement acceleration [23,24]. Furthermore, XR-based interventions can offer increased flexibility and accessibility, potentially reducing geographic and socioeconomic barriers to participation [25].

Recent randomized trials and systematic reviews have begun to consolidate the evidence base for immersive technologies in perinatal care. VR used during labor or cesarean birth has been associated with reductions in pain and anxiety and improvements in birth satisfaction, without major safety concerns for mothers or newborns [21,26,27]. In parallel, VR-based prenatal education and broader programs for pregnant women have reported gains in childbirth knowledge, self-efficacy, and pregnancy-related anxiety, suggesting that immersive tools can strengthen both cognitive and emotional preparation for birth [24]. These developments highlight the need for a focused synthesis of XR specifically in parent-facing prenatal and childbirth education, beyond the more established literature on clinician training.

Public Health and Psychosocial Context

Beyond technological innovation, prenatal education is a key component of global maternal health policy. The World Health Organization (WHO) has emphasized the importance of high-quality, integrated maternity services that ensure a positive pregnancy and childbirth experience [28]. Within this framework, addressing maternal emotional well-being, particularly anxiety and FOC, is considered a central priority. Immersive technologies can contribute to these goals by providing emotionally engaging and accessible educational experiences, supporting both knowledge acquisition and psychological resilience during pregnancy [29,30].

Pedagogical Frameworks Supporting the Use of Immersive Technologies

The educational value of immersive technologies is supported by several pedagogical models. The Interaction Model of Client Health Behavior (IMCHB) emphasizes the role of emotionally resonant and individualized learning experiences in shaping behavior change [31]. Likewise, constructivist learning theory posits that experiential and interactive simulations facilitate understanding through active, context-based engagement, allowing learners to integrate new information with prior experiences [32]. The Cognitive Load Theory offers a

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complementary framework, suggesting that well-designed XR content can enhance learning by minimizing extraneous cognitive demands and improving retention through multimodal cues such as narration, interactivity, and visual emphasis [33]. Together, these models support the potential of XR-based prenatal education to foster active, meaningful, and self-directed learning.

Challenges and Research Gap

Despite its promise, XR-based prenatal education faces several challenges, including usability issues (eg, cybersickness, device discomfort, and limited digital literacy), ethical concerns about replacing human interaction, and potential inequalities in access. Existing research is also limited by methodological heterogeneity, small sample sizes, and a lack of longitudinal follow-up, making it difficult to generalize findings or establish best practices (eg, [34,35]). As prenatal care becomes increasingly hybrid and digitally mediated, particularly after the COVID-19 pandemic, it is essential to understand how, when, and for whom XR interventions are most effective, and to identify key design and implementation features.

Aim of the Review

This scoping review aims to explore and map the evidence on the application of immersive technologies in prenatal course programs, focusing on their benefits, challenges, and potential for enhancing learning and emotional preparedness among expectant parents. By synthesizing key findings and trends, the review aims to inform educators, clinicians, designers, policymakers, and researchers. It supports evidence-informed use of immersive technologies to improve maternal and perinatal outcomes and fosters a shared understanding of the state of the art and next research steps in partnership with stakeholders involved in childbirth preparation. This scoping review begins with a comprehensive search of academic peer-reviewed literature. By grounding the review in scientifically validated evidence, it lays a basis for later examining broader practical implications and innovations within the gray literature. The following key research questions (RQs) guided the search strategy and data extraction process in the academic literature:

- RQ1: what are the primary applications of virtual, augmented, mixed, and immersive technologies in prenatal education programs?
- RQ2: what benefits have been reported regarding their use in enhancing learning, emotional preparedness, and engagement?
- RQ3: what challenges and limitations are identified in implementing XR-based interventions in prenatal education?
- RQ4: what methodologies and technological approaches are most used in studies on XR in prenatal education?
- RQ5: what research gaps exist in this area, and what future directions are recommended?

The findings will provide a thorough overview of how XR is used in prenatal education, offering insights for researchers, educators, and policymakers on effectively integrating innovative technologies to enhance maternal health outcomes.

Methods

Study Design

This scoping review followed a five-step process: (1) formulating the research question, (2) identifying relevant studies, (3) selecting studies for inclusion, (4) organizing the data, and (5) synthesizing and presenting the findings [36]. The final search strategy was refined through an iterative approach to optimize database searches and improve search terms. To ensure methodological rigor and clarity, the study design and manuscript preparation adhered to the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) framework [36,37].

A scoping review was chosen to provide an overview of the available evidence, not a formal critical synthesis or a definitive answer to a specific research question [38].

Protocol and Registration

The scoping review protocol is registered a priori with the Center for Open Science (OSF; registration type: OSF Preregistration, date registered: March 5, 2025 [39]).

Selection of Sources of Evidence and Eligibility Criteria

The selection of evidence sources was conducted in 4 sequential and distinct phases: “First Round,” “Second Round,” “References Inclusion Round,” and “Third Round” (Table 1). To systematically identify a comprehensive set of papers that contribute to addressing our research questions, we established a set of eligibility criteria to be applied iteratively through several rounds. The criteria aim to minimize false negatives and false positives, ensuring that only studies meeting the defined standards are included in the review. Table 1 provides an overview of the criteria used to filter and select the studies.

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Table . Description of the eligibility criteria.

Selection sources phase	Eligibility criteria applied
First round	• Inclusion criteria • Original papers published in English. • Articles published in peer-reviewed journals or credible conference proceedings. • Focused on the use of XR[a] technologies (VR[b], AR[c], MR[d], or 360° video) in prenatal or childbirth education for pregnant women and expectant parents. • Addressed outcomes such as learning, emotional preparedness, anxiety reduction, or partner engagement. • Involved expectant parents and/or stakeholders. • Exclusion criteria • Non–English-language • Article types: book, book chapters, dissertations, abstracts, posters, interviews, protocols, and reports. • Nonoriginal articles: meta-analysis and reviews, including reviews without original data or studies with insufficient detail. • No full text available. • Not focused on prenatal or childbirth education for parents. • Addressed XR in clinical obstetric care but not in an educational context. • Studies primarily describing XR-based training for health care professionals or clinical skills education. • Studies based solely on remote learning, online courses, or mobile messaging without immersive interaction.
Second round	• Exclusion criteria • Studies without participants. • The article does not report any qualitative or quantitative participant involvement results.
References inclusion round	• This step focused on identifying additional studies by screening the reference lists of the previously included papers.
Third round	• This phase consisted of an additional verification of all previously screened files to ensure consistency and completeness. Furthermore, we extended the search to include the SciSpace database, which allowed us to identify and incorporate additional relevant papers not captured in earlier rounds.

[a]XR: extended reality.

[b]VR: virtual reality.

[c]AR: augmented reality.

[d]MR: mixed reality.

Information Sources and Search Strategy

A comprehensive search strategy was developed to identify relevant literature on the use of XR in prenatal education. The search process included both database searches and gray literature exploration to ensure thorough coverage of the topic.

The search was conducted from January 30 to October 16, 2025. To ensure comprehensive coverage across health sciences, psychology, and technology, the following databases were systematically searched:

1. APA PsycArticles and APA PsycINFO: capture psychological and behavioral science research, including mental health, anxiety, and parental preparedness relevant to prenatal education.
2. PubMed: offers broad biomedical coverage, including maternal health, obstetrics, and digital health, making it critical for identifying studies on physiological and emotional outcomes.
3. Web of Science (WoS), Cumulative Index to Nursing and Allied Health Literature (CINAHL)**,** and Scopus**:** provide wide-reaching coverage of peer-reviewed, multidisciplinary research, ensuring inclusion of various study designs (eg, RCTs and pilot studies).
4. IEEE Xplore: specializes in technology and human-computer interaction (HCI), essential for identifying studies on VR systems, usability, and digital learning tools.

The gray literature was explored using the following sources: Google Scholar**,** WHO Reproductive Health Library, and SciSpace.

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The search strategy combined three main concept blocks: (1) immersive technologies ("virtual reality," "augmented reality," "mixed reality," "extended reality," and "immersive technology"); (2) prenatal and childbirth education ("prenatal education," "antenatal education," "childbirth education," "prenatal classes," "parenting classes," "expectant parent education," and "childbirth training"); and (3) participant and facilitator roles ("pregnant women," "expectant parents," "midwife," "childbirth educator," "parent educator," "perinatal educator," "healthcare provider," and "health professional").

Boolean operators ("AND"/"OR"/"NOT") were applied appropriately, and syntax was adapted to each database (PubMed, Scopus, Web of Science, IEEE Xplore, CINAHL Ultimate, APA PsycINFO, and APA PsycArticles). The final search was rerun on October 16, 2025, and full database-specific queries are reported in Multimedia Appendix 1. Studies focusing exclusively on professional training, without a direct patient-facing component, were excluded. This approach balances inclusivity in the initial search with relevance during study selection, helping to identify interventions co-designed or delivered by professionals but intended for parents. The search strategy, including the keywords and search strings used, is summarized in Table 1. The research team supplemented the sources identification process by including references cited within the full texts of publications included as a result of the database search. This approach was guided by the selection strategy detailed in the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 flow diagram (Figure 1).

Data Items

For each included study, we extracted the following variables: (1) bibliographic information: authors, year of publication, country, and journal or conference; (2) study characteristics: design (eg, RCT, quasi-experimental, and qualitative), setting (hospital, university, and online), and sample size; (3) participant characteristics: demographics (age, sex, and gestational stage), inclusion of partners or caregivers, and specific eligibility criteria; (4) intervention details: type of VR technology (eg, immersive headset, 360° video, and mobile app), educational content (childbirth, breastfeeding, prenatal exercise, and mental health), frequency, and duration of sessions; (5) comparator (if applicable): conventional prenatal education, standard care, or no intervention; (6) outcomes: (a) psychological features and symptoms (anxiety, depression, fear of childbirth, and perceived stress); (b) physiological during intrapartum and postpartum outcomes (pain, uterine activity, perineal trauma, and postpartum hemorrhage); (c) educational outcomes (knowledge acquisition, memory retention, and preparedness); and (d) user experience outcomes: usability, satisfaction, immersion, and engagement; (6) main results: direction of outcomes, qualitative themes, and feasibility and acceptability measures; and (7) other relevant information: inclusion of partner or family support, equity considerations (digital literacy and access), and reported methodological limitations (Tables 2-6).

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Table . General information summaries of selected studies.

References	Database	Country	Study design	Background	Objectives
Xie and Zeng [23]	PubMed	China	Randomized clinical trial with a 2-group intervention design	• With the implementation of the 2-child policy in China, childbirth rates have increased. Many women experience fear and anxiety about childbirth, which can prolong labor and increase complications. VR[a] has been increasingly used in health care settings, offering immersive and interactive experiences. This study investigates the effectiveness of VR combined with moderate perineal protection during childbirth.	• To explore the effects of VR-based prenatal health education combined with moderate perineal protection on childbirth outcomes, pain management, self-efficacy, anxiety, and perineal trauma in primiparous women.
Lee et al [34]	Google Scholar	Korea	Prospective interventional study	• Pregnant women face significant physiological and psychological changes, increasing the risk of mental health disorders, including depression and anxiety. • Mental health disorders in pregnancy can negatively impact both the mother and infant, increasing risks such as low birth weight and preterm birth. Existing mental health programs for pregnant women are insufficient in terms of accessibility and effectiveness.	• To prospectively investigate the efficacy of a VR-assisted mental health promotion program in pregnant women. • To assess its impact on depression, anxiety, perceived stress, and quality of life. • To evaluate the program's effectiveness in high-risk subgroups of pregnant women.

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References	Database	Country	Study design	Background	Objectives
Caballero-Galilea et al [40]	Web of Science, Scopus, and PubMed	Spain	Single-group pre-post quasi-experimental study based on the Transparent Reporting of Evaluations with Nonrandomized Designs (TREND) guidelines	• Anxiety affects up to 1 in 4 pregnant women and is associated with adverse obstetric, neonatal, and psychological outcomes. FOC[b] occurs in 5% - 15% of cases and contributes to higher cesarean rates and reduced maternal well-being. While traditional prenatal education and psychological interventions can mitigate these effects, evidence on the use of VR for improving mental health and reducing childbirth-related anxiety remains limited but promising.	• To assess the effectiveness of immersive VR exposure to the childbirth process in reducing anxiety among women in the third trimester of pregnancy.
Siivola et al [41]	CINAHL Ultimate, PubMed, and Google Scholar	Finland	Pilot study with a user-centered design process	• The COVID-19 pandemic led to the cancellation or transition of CBE[c] to online formats in Finland. There was a need for an alternative method to provide immersive and engaging CBE. FOC has been increasing in Finland, necessitating better education tools.	• To develop a VR childbirth education program with 360° videos. • To test the program's usability, motion sickness, effectiveness, and potential impact on FOC. • To investigate which end-user devices are preferred (eg, VR headset, computer, tablet, and smartphone). • To make CBE accessible across multiple devices, including VR headsets, computers, tablets, and smartphones.
Siivola et al [42]	Scopus and Google Scholar	Finland	User-centered design study		• To evaluate the effectiveness of a VR CBE program in improving learning outcomes, usability, and user experience, while also assessing its impact on FOC.

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References	Database	Country	Study design	Background	Objectives
				• CBE in Finland has deteriorated, with many expectant parents lacking access to hospital tours or comprehensive prenatal education. VR presents an opportunity to enhance CBE by offering immersive and realistic childbirth experiences.	
Tang et al [43]	IEEE Xplore	Belgium	Qualitative user study	• Breastfeeding has well-documented health benefits, yet many new parents face difficulties during the early postnatal stage. Traditional antenatal education often fails to convey the complexity of real-life breastfeeding experiences. VR has the potential to provide an immersive and interactive way for parents-to-be to explore these challenges.	• To assess the potential of a VR breastfeeding simulation ("Virtual Feed") in conveying the lived experience of breastfeeding and to explore user expectations related to playful technology in health care.
Tang et al [44]	Scopus, Web of Science, and Google Scholar	Belgium (participants from various backgrounds including Western, Eastern, and Southern Europe, as well as South and Southeast Asia)	Qualitative co-design	• Breastfeeding offers numerous benefits but remains challenging for many parents. Antenatal education often presents breastfeeding as a natural and straightforward process, which can lead to unrealistic expectations. • The study aimed to address this gap by designing an immersive VR breastfeeding simulation to help parents experience common breastfeeding challenges.	The study sought to answer 2 primary research questions: • What design considerations are needed to create interactive simulations for breastfeeding experiences? • How do parents and parents-to-be perceive such simulations, and what is their potential in antenatal education?
Noben et al [45]	Google Scholar	Netherlands	Randomized controlled trial		

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References	Database	Country	Study design	Background	Objectives
				• Previous research demonstrated that the level of anxiety and FOC is known to be associated with the incidence of postpartum depression. Women who deliver by a CD[d] are at risk for both increased fear of childbirth and postpartum depression. It is essential to minimize preoperative anxiety for these patients because lower preoperative anxiety has been shown to lead to greater maternal satisfaction with CD and thus a more positive birth experience.	• To investigate the effect of VR in addition to conventional information provision on the preoperative anxiety levels of women undergoing a planned CD.
Setiawan et al [46]	Google Scholar	Indonesia	Pilot feasibility study; Semiexperimental study	• There are still many pregnant women who are less interested in exercising during pregnancy, due to heavy workload during the working day and a dense schedule of daily activities in her career or as a housewife. Some women assume that attending a pregnancy exercise course in hospitals or health care centers is time-consuming and too formal because they have to follow the prenatal personal trainer schedule. The technology that allows helping pregnant women in exercise during pregnancy is virtual reality.	• To develop a VR app for pregnant women to easily perform an exercise during pregnancy with no limited space and time.
Park and Kim [47]	Google Scholar	Korea	Quasi-experimental study		

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References	Database	Country	Study design	Background	Objectives
				• Hospitalized women with threatened preterm labor often experience psychological and physical distress, which may exacerbate uterine activity and cervical changes, necessitating targeted prenatal care. VR-based prenatal education may improve engagement and support. Guided by the Cox IMCHB[e], this study developed and evaluated a VR prenatal education program to address these complex needs.	• To design, administer, and assess the impact of a VR-based prenatal education program for pregnant women hospitalized due to preterm labor.
Montoya-Moncada et al [48]	PubMed	Colombia	Noninferiority randomized controlled trial		• To test whether mixed reality + standard counseling improves maternal self-efficacy (BSES-SF) and satisfaction (MBFES) versus standard counseling alone, 1 week post partum.

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References	Database	Country	Study design	Background	Objectives
				• Breastfeeding is natural but requires learned skills and is shaped by social and psychological factors. The World Health Organization and the United Nations Children's Fund recommend 6 months of exclusive breastfeeding and continued breastfeeding with complementary foods for at least 2 years, yet rates remain low worldwide. Traditional counseling is mostly theoretical and rarely uses modern technology; motivation and confidence help success, while stigma, aggressive formula marketing, and poor guidance hinder it. This study tests whether a mixed-reality educational approach, compared with standard counseling, improves mothers' satisfaction and confidence.	

[a]VR: virtual reality.

[b]FOC: fear of childbirth.

[c]CBE: childbirth education.

[d]CD: cesarean delivery.

[e]IMCHB: Interaction Model of Client Health Behavior.

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Table . Demographic characteristics of participants in the experiments.

Study (year)	Single or multicenter	Inclusion and exclusion criteria	Recruitment methods	Sample size	Sex, n (%)	Age (years)[a]
Xie and Zeng [23] (2023)	Single center	Inclusion criteria: (1) singleton full-term pregnancy, (2) normal external pelvic measurement, (3) no obvious cephalopelvic disproportion, (4) no complications during pregnancy or labor, and (5) age 20 - 34 years. Exclusion criteria: (1) estimated fetal weight≥4000 g, (2) fetal biparietal diameter>9.7 cm, (3) presence of mental illness or communication disorders, and (4) use of analgesia during labor.	Pregnant women receiving routine antenatal care at the hospital between June 1, 2018 and December 31, 2018, were invited to participate. Participants and their families provided informed consent before enrollment.	N=200: primiparous women were randomly assigned to either the treatment group (n=100) or the control group (n=100).	Female=200 (100%)	Treatment group: 30.29 (1.14) Control group: 30.35 (1.07)

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Study (year)	Single or multicenter	Inclusion and exclusion criteria	Recruitment methods	Sample size	Sex, n (%)	Age (years)[a]
Lee et al [34] (2025)	Single center	Inclusion criteria: (1) pregnant women, (2) able to understand and use the Korean language, and (3) willing to participate in the study. Exclusion criteria: (1) intellectual disability preventing VR[b] training, (2) visual impairment making VR use impossible, and (3) illiteracy.	Advertisements in the obstetrics and gynecology unit.	N=56 (participants were grouped using cluster analysis based on their mental health characteristics before the VR intervention. The study identified three clusters: (1) Cluster 1 (Healthy Mental State): 19 (33.9%) participants with low depression and anxiety. Higher quality of life. No significant need for intervention. Cluster 2 (Treatment-Required Group—High-Risk): 9 (16.1%) participants with high depression and anxiety scores. Low quality of life. Required active mental health support. Cluster 3 (Intermediate Group): 28 (50%) participants with moderate depression and anxiety. NB: High-risk participants were also defined using standard clinical cutoff scores: (1) PHQ-9[c] cutoff for depression:≥8; (2) GAD-7[d] cutoff for anxiety:≥5. From this, two additional high-risk groups were analyzed separately: (1) high-risk for depression (PHQ-9≥8); n=20 (35.7%); (2) high-risk for anxiety (GAD-7≥5); n=8 (14.3%).	Female=56 (100%).	34.3 (4.0)

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Study (year)	Single or multicenter	Inclusion and exclusion criteria	Recruitment methods	Sample size	Sex, n (%)	Age (years)[a]
Caballero-Galilea et al [40] (2025)	Single center	Inclusion criteria: (1) aged 18 years or older, (2) nonmultiple pregnancy, and (3) be either primiparous or multiparous in the third trimester of gestation. Exclusion criteria: (1) women with visual or hearing impairments that prevent effective participation in virtual reality experiences, (2) those with neurological, otorhinolaryngological, or mental health conditions that could be exacerbated using VR devices.	Pregnant women attending a prenatal education program in a health center in Madrid (Spain) between February 2023 and October 2024.	N=73 pregnant women.	Female=73 (100%).	Median 34.0 (IQR 5.0)
Siivola et al [41] (2023)	Single center	Inclusion criteria: (1) women who had recently given birth but were not currently pregnant. Exclusion criteria: (1) pregnant women (for the initial pilot), (2) individuals with a prior diagnosis of FOC[e] (not included in the first phase).	Participants were recruited through an online survey and invited to test the program in a research facility. A second phase allowed participants to test the program remotely.	First phase: N=3 women who had recently given birth. Second phase: open to more participants, allowing home testing.	Female=3 (100%)	Not explicitly stated in the document.
Siivola et al [42] (2024)	Single center	Inclusion criteria: (1) pregnant individuals fluent in Finnish who had received CBE[f] from public prenatal clinics but had not been offered a hospital tour. Exclusion criteria: (1) individuals not pregnant, non-Finnish speakers, or those unable to participate in the research location for initial testing.	Participants were recruited through social media.	N=5 pregnant women.	Female=5 (100%)	37 (SD not reported); 31 - 41 years

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Study (year)	Single or multicenter	Inclusion and exclusion criteria	Recruitment methods	Sample size	Sex, n (%)	Age (years)[a]
Tang et al [43] (2022)	Single center	Inclusion criteria: (1) breastfeeding parents, parents-to-be, and partners interested in antenatal education. Exclusion criteria: (1) not explicitly mentioned but likely excluded those with significant VR interaction limitations or lack of consent.	Snowball sampling. Flyers at a local daycare, university campus, and social media outreach.	N=10: Breastfeeding parents (n=6) Parents-to-be (n=3) Partner (n=1)	Female=9 (90%) Male=1 (10%)	25 - 45 years (n=8); 36 - 45 years (n=2)
Tang et al [44] (2022)	Single center using online and in-person methodologies	Inclusion criteria: (1) participants included breastfeeding parents, partners, and parents-to-be who planned to breastfeed. Exclusion criteria: (1) no specific exclusion criteria mentioned apart from not having relevant breastfeeding experience or interest.	Participants were recruited through snowball sampling with advertisements on social media and word-of-mouth referrals.	N=19: Breastfeeding mothers (n=11), Partners (n=5), Parents-to-be who planned to breastfeed (n=3), and they had 1 child (n=11), 2 children (n=2), and 3 children (n=3). The youngest child was 15 months old (SD 9.45), and the breastfeeding duration of the youngest child was up to 1 month (n=1), up to 3 months (n=2), up to 6 months (n=2), up to 9 months (n=1), and up to one year or longer (n=10). Participants resided in Western Europe, but grew up in Western Europe (n=6), Eastern Europe (n=5), Southern Europe (n=4), South Asia (n=1), Southeast Asia (n=1), East Asia (n=1), South America (n=1).	Female=13 (68%) Male=6 (32%)	26 - 45 years (n=13); 36-45 years (n=6)

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Study (year)	Single or multicenter	Inclusion and exclusion criteria	Recruitment methods	Sample size	Sex, n (%)	Age (years)[a]
Noben et al [45] (2019)	Single center	Inclusion criteria: women aged 18 years or older, had planned for elective CD[g] after 37 weeks of gestation, and had sufficient knowledge of the Dutch language. Exclusion criteria: prematurity (gestational age<37 weeks), placenta previa, pre-eclampsia, and a suspected congenital anomaly.	Patients were recruited from the outpatient clinic at our hospital, enrolled from November 2016 to January 2018, (who were scheduled for elective CD at Máxima Medical Center in Veldhoven).	N=97: Virtual reality group=49 and control group=48 The partners also participated, but it is not indicated how many of them collaborated in the study.	Female=97 (100%)	VR group 32.6 (3.9); Control group 33.12 (4.3)
Setiawan et al [46] (2019)	Single center	(Inclusion and exclusion criteria are not labeled explicitly) Inclusion criteria: provide voluntary consent to engage with the VR system. Gestational age starts from the age of 16 - 18 weeks.	(Not labeled explicitly) Convenience sampling ; voluntary participation ; prescreening for medical eligibility.	N=6 women	Female=6 (100%)	27.7 (2.3)
Park and Kim [47]	Multicenter study (2 hospitals of South Korea were involved. One hospital was assigned to conduct the experimental intervention, while the other was used to collect control group data)	Inclusion criteria: pregnant women hospitalized for preterm labor.	Convenience sampling.	N=31: n=15 (VR group); n=16 (control group).	Female=31 (100%)	VR group: 30.26 (3.63); Control group: 31.43 (2.50)

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Study (year)	Single or multicenter	Inclusion and exclusion criteria	Recruitment methods	Sample size	Sex, n (%)	Age (years)[a]
Montoya-Moncada et al [48] (2025)	Single center	Inclusion criteria: third-trimester pregnant women≥18 years, hemodynamically stable, oriented, and intending to breastfeed. Exclusion criteria: neonatal malformations or conditions affecting breastfeeding, and maternal contraindications (eg, HIV+, oncologic treatment), NICU[h] or ICU[i] need.	Eligible women attending prenatal care; consent obtained during prenatal sessions; intervention delivered within maternity and/or paternity preparation courses.	N=58 randomized (MR+ standard training group: n=29; control group: n=29); 76 screened; no loss to follow-up reported.	Female=58 (100%)	Not reported; eligibility≥18 years

[a]Age data are reported as mean (SD), median (IQR), range, or categories, as available.

[b]VR: virtual reality.

[c]PHQ-9: Patient Health Questionnaire-9.

[d]GAD-7: Generalized Anxiety Disorder-7.

[e]FOC: fear of childbirth.

[f]CBE: childbirth education.

[g]CD: cesarean delivery.

[h]NICU: neonatal intensive care unit.

[i]ICU: intensive care unit.

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Table . Characteristics of experimental methodology.

Study	Experimental procedure	Health operator involvement	Measures	Variables investigated
Xie and Zeng [23]	• Treatment group: prenatal education with VR[a]-based health education. • Control group: traditional prenatal education.	• Midwives trained in moderate perineal protection. • Nursing staff provided VR-based health education.	• Delivery outcomes: time of second-stage labor, postpartum hemorrhage within 2 hours, neonatal Apgar scores, and neonatal weight. • Pain levels: VAS[b] (0 - 10). • Anxiety levels: VAS-A. • Self-efficacy: general Self-Efficacy Scale. • Quality of life satisfaction: self-reported scale (0 - 100).	• Pain. • Anxiety. • Delivery outcomes (labor duration, hemorrhage, and perineal trauma). • Self-efficacy and quality of life.

Lee et al [34]	• Experimental procedure: VR-assisted mental health promotion program designed specifically for pregnant women.	• Health care professionals were involved in the recruitment process and monitoring participant safety.
		  • VR procedure was self-administered
		  • Assessment and monitoring: the mental health state of participants was assessed before and after the VR intervention using self-reported measures.
			• Standardized scales and questionnaires:
			  • PHQ-9[c]
			  • GAD-7[d]
			  • PSS[e]
			  • WHOQOL-BREF[f]
				• Depressive and anxiety symptoms.
				• Stress-related symptoms
				• Quality of life.

Caballero-Galilea et al [40]	• Participants experienced a 60-min immersive VR simulation of eutocic childbirth after standard education. Anxiety (PRAQ-20[g]) was assessed pre- and postintervention.	• Developed and supervised by midwives and obstetricians, midwives facilitated sessions and ensured participant safety during the VR simulation.	• Pregnancy-Related Anxiety Questionnaire–Revised (PRAQ-20) administered pre and post VR; sociodemographic and obstetric data collected.	• Pregnancy-related anxiety • VR adverse effects.

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Study	Experimental procedure	Health operator involvement	Measures	Variables investigated
Siivola et al [41]	• Participants used VR headsets and other devices to test the childbirth education program.	• The project involved midwives, childbirth educators, and researchers. • A real midwife played the role in the videos to ensure authenticity.	• Pretest Questionnaire: a structured online questionnaire was administered before participants engaged with the VR program. • During the VR experience, observational measures, and a cognitive walkthrough were conducted to assess usability. • After the VR experience: semistructured interview to gain qualitative feedback. • Posttest Questionnaire: to evaluate their experiences. • Usability and interaction tracking (during home use phase).	• Usability of the VR program. • Motion sickness occurrence. • User preference for different devices. • Impact on FOC[h]. • Variables measured: • Demographics: name, age, number of previous births, last childbirth year, current pregnancy status. • Previous childbirth education exposure: participation in childbirth education (CBE) at a public prenatal clinic, attendance at a hospital birth ward tour, enrollment in additional childbirth education classes • Preferred learning methods for childbirth. • FOC history • Experience with virtual reality. • Engagement with the VR program. • Motion sickness symptoms. • Usability and learning curve. • Time spent in the VR experience. • Duration of headset use. • Physical comfort. • Device preference. • Perceived value of VR components. • Effectiveness of different media formats in learning. • Impact on fear of childbirth.
Siivola et al [42]	• Participants used the VR childbirth education program with a headset under researcher observation.	• A Lamaze-certified childbirth educator was involved in study design, data analysis, and participant support.	• Usability: PSUS[i] • Engagement: observational data on VR session length and content consumption • Learning outcomes: self-reported understanding of childbirth-related topics. • Emotional impact: FOC	User engagement and experience with VR childbirth education. Usability of the VR program Improvement in childbirth knowledge and preparedness. Impact on FOC.
Tang et al [43]	• Participants engaged with the VirtualFeed VR breastfeeding simulation.	• None reported; study focused on self-guided user experiences.		User perceptions of breastfeeding simulation realism. Impact of interactivity and game-like elements. Potential application of VR for antenatal education.

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Study	Experimental procedure	Health operator involvement	Measures	Variables investigated
			• Qualitative thematic analysis of interview transcripts. • User feedback on realism, effectiveness, and engagement with the simulation.	
Tang et al [44]	Participants engaged in (1) visualizing and discussing breastfeeding settings; (2) exploring challenges and social influences on breastfeeding; (3) expressing design preferences for the VR environment; and (4) describing ideal and challenging breastfeeding scenarios.	• The study did not involve direct medical professionals.	• Thematic analysis of participant responses. • Visual and interactive engagement through VR and design workshops. • Reflections on breastfeeding experiences based on user feedback.	User perception of the breastfeeding simulation Immersion and realism of the VR experience Potential impact on antenatal education Challenges and facilitators of breastfeeding.
Noben et al [45]	• VR group: VR video was shown using the Infor-Med app on the participant's smartphone, and VR glasses were supplied by the researcher at the outpatient clinic.	• Physician and researcher	• Anxiety: VAS-A. • Simulation Sickness: SSQ[j]. • Tilburg Pregnancy Distress Scale. • Childbirth Perception Scale (CPS). • Pregnancy and Childbirth Questionnaire (PCQ).	Preoperative anxiety, motion sickness symptoms, woman's perception of her pregnancy, perception of delivery and perception of the first postpartum week, preoperative information, participants in the VR group received an additional question if they felt more prepared for CD after seeing the VR video.
Setiawan et al [46]	• Doing vital sign check-up to the target user before practice with VR. • VR application implementation for the target user. • Doing a vital sign check-up after practice with VR and evaluation of the IVE[k] questionnaire.	• None reported.	• Simulator Sickness Questionnaire, User experience in the IVE.	Vital signs: heart rate (HR), blood pressure (BP), respiration rate (RR), and anemic conjunctiva (AC). Symptoms like vomiting, nausea, and dizziness.
Park and Kim [47]	• VR Group: 3 VR sessions. • Components: educational VR program and relaxation meditation VR. • Control Group: received usual care only without VR.	• 1 VR expert, 1 nursing professor, and 1 head nurse from a women's specialty hospital.	• Self-report questionnaire: STAI[l]. • Stress related to preterm labor. • Pregnancy health care practice behavior. • Self-efficacy in pregnancy health care. • Uterine contractions: frequency (times/min) and intensity (mm Hg). • Cervical length: transvaginal ultrasound.	State anxiety, stress related to preterm labor, frequency and intensity of uterine contractions, cervical length, practice behaviors in pregnancy health care, self-efficacy in health care.
Montoya-Moncada et al [48]		• Trained nurses, nursing assistants, and general practitioners delivered and facilitated sessions and provided real-time feedback.		Group assignment (MR+ standard vs standard) → maternal self-efficacy, maternal satisfaction, and EBF at 1 week.

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Study	Experimental procedure	Health operator involvement	Measures	Variables investigated
	• Intervention: a single facilitated session added to standard counseling, including a headset-based immersive video and hands-on practice using a silicone breast model, infant doll, and neonatal simulator. • Control: standard counseling only.		• Primary: BSES-SF[m] (14-70), MBFES[n] (30-150) at 1 week. • Secondary: exclusive breastfeeding (EBF) status and feeding categories per the World Health Organization.	

[a]VR: virtual reality.

[b]VAS: Visual Analog Scale.

[c]PHQ-9: Patient Health Questionnaire-9.

[d]GAD-7: Generalized Anxiety Disorder-7 Scale.

[e]PSS: Perceived Stress Scale.

[f]WHOQOL-BREF: World Health Organization Quality of Life–BREF.

[g]PRAQ-20: Pregnancy-Related Anxiety Questionnaire.

[h]FOC: fear of childbirth.

[i]PSUS: Pictorial System Usability Scale.

[j]SSQ: Speech, Spatial and Qualities of Hearing Scale.

[k]IVE: immersive virtual environment.

[l]STAI: State-Trait Anxiety Inventory.

[m]BSES-SF: Breastfeeding Self-Efficacy Scale-Short Form.

[n]MBFES: Maternal Breastfeeding Evaluation Scale.

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Table . Results, conclusion, and implications for future research.

Study	Results	Conclusions	Implications for future research
Xie and Zeng [23]	• No significant difference in second-stage labor duration between groups. • The treatment group had significantly lower postpartum hemorrhage (151.28 mL vs 248.95 mL; *P*=.008). • Pain scores were significantly lower in the treatment group (3.73±1.87 vs 5.97±2.66; *P*<.05). • No significant effect on neonatal Apgar scores or weight. • The treatment group had a higher rate of intact perineum and lower rates of severe perineal lacerations (*P*<.05). • Anxiety scores were significantly lower in the treatment group during labor (*P*<.001). • Self-efficacy and quality of life satisfaction were significantly higher in the treatment group (*P*<.001).	• VR[a] technology combined with moderate perineal protection can improve childbirth outcomes by reducing pain, anxiety, and perineal trauma. • This approach increases maternal confidence and promotes a better childbirth experience without adverse effects on newborns. • The intervention can be widely applied in clinical obstetric settings.	• Further studies should use standardized psychological scales to assess maternal mental health. • Future research should evaluate long-term maternal and neonatal outcomes. • Expanding VR health education to other aspects of maternal care, such as postpartum recovery, may be beneficial.
Lee et al [34]	• Significant reduction of depressive and anxiety symptoms comparing before and after VR program. • Quality of life scores significantly increased. • No significant change in perceived stress scores. • The program was particularly effective in the high-risk subgroup with severe depression and anxiety.	• The VR intervention was most effective for Cluster 2, which had the most severe mental health issues. • Depression, anxiety, and quality of life improved significantly in the high-risk depression group (PHQ-9[b]≥8). • Participants with high anxiety (GAD-7[c]≥5) showed improvements, but they were not statistically significant. • Perceived stress did not improve significantly in any of the high-risk groups.	• Future studies should customize VR interventions for specific high-risk subgroups. • A longer intervention period (more than 5 weeks) may be needed to show stronger effects. • VR programs should incorporate stress management techniques to improve perceived stress outcomes.
Caballero-Galilea et al [40]	• Significant postintervention decreases in PRAQ-20[d] anxiety scores (*P*<.001); greater effect among younger and primiparous women; no adverse effects; participants reported increased confidence and preparedness.	• Immersive VR childbirth simulation effectively reduced pregnancy-related anxiety, was well-tolerated, and perceived as supportive; results support VR as a complement to traditional prenatal education.	• Recommend RCTs[e] and longitudinal studies to confirm effects, assess long-term outcomes, explore emotional mechanisms, and adapt VR childbirth education for diverse populations.
Siivola et al [41]	• Users successfully navigated the VR program with minimal instructions. • No motion sickness was reported. • Users preferred using the program on personal devices rather than in research settings. The program was perceived as effective for childbirth education. Some improvements were suggested, such as adjusting camera angles and adding more immersive birth sequences.	• The VR CBE[f] program was well received and demonstrated potential for improving childbirth education. • It provided a realistic and immersive experience, making learning more engaging. • Further studies are needed to assess its impact on reducing FOC[g].	• Future studies should test the VR CBE with pregnant women and individuals diagnosed with FOC. • Evaluating the effectiveness of VR-based learning in improving childbirth preparedness. • Exploring further enhancements, such as interactive VR environments.

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Study	Results	Conclusions	Implications for future research
Siivola et al [42]	• Users watched an average of 33 minutes of VR content. 4/5 participants watched all 18 videos; one skipped a few due to prior knowledge. Usability scores were high (87 for VR and 76 for independent testing). VR improved learning outcomes compared to traditional CBE. Fear of childbirth impact varied; one participant's FOC increased, while another's FOC decreased.	• VR CBE provided a realistic, immersive learning experience. • The program was well-received, particularly for first-time parents.	• Testing with a larger and more diverse sample. Expanding VR content to include more childbirth scenarios (eg, medical pain relief and home births). • Investigating long-term retention of knowledge gained through VR CBE.
Tang et al [43]	• Participants found the simulation engaging and realistic. The simulated baby's behavior (delayed latching and hunger cues) effectively conveyed real breastfeeding challenges. Some participants felt frustrated by the lack of clear guidance and suggested integrating more explicit game elements, such as tutorial instructions and achievement notifications. The simulation was seen as a valuable tool for antenatal education, facilitating discussions between parents and health care providers.	• VR can effectively simulate breastfeeding challenges, promoting awareness and reflection. Participants expected game-like elements within the VR environment, raising questions about balancing realism and usability in health care simulations. The lack of explicit feedback within the simulation led to user frustration, suggesting the need for guided interactions.	• Investigate the optimal balance between realism and playfulness in VR health care simulations. Explore the impact of gamification on learning outcomes in antenatal education. • Assess the long-term effectiveness of VR breastfeeding simulations in improving breastfeeding success rates.

Tang et al [44]		• VR breastfeeding simulations can enhance antenatal education by providing immersive, realistic experiences.
		• The study highlighted challenges in VR design, such as managing uncertainty, realism, and user expectations.
		• In summary, the study's results indicate that interactive VR simulations can effectively communicate the complexities of breastfeeding by combining emotional engagement with experiential learning. Rather than providing explicit instruction, such systems may be most impactful when they offer opportunities for introspection and encourage users to reframe their expectations. The findings underscore the importance of designing with empathy, realism, and flexibility in mind—particularly when addressing sensitive and deeply personal aspects of early parenthood.
			• Future work should explore:
			  • Customization options to reflect diverse family structures and breastfeeding experiences.
			  • Incorporation of haptic feedback to simulate the physical aspects of breastfeeding.
			  • Longitudinal studies on the impact of VR simulations on breastfeeding success.

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Study	Results	Conclusions	Implications for future research
	• Thematic analysis revealed 2 dominant themes. The first theme highlighted the emotional and logistical imbalance often present in breastfeeding relationships, where one parent typically assumes the feeding role while the partner provides indirect support. Participants frequently emphasized the importance of practical and emotional presence from partners, such as preparing food, staying close during night feeds, or simply offering words of encouragement. • The second theme focused on parents' evolving understanding of breastfeeding. Many participants described the initial stages as marked by uncertainty, technical difficulties, and emotional strain. Public breastfeeding emerged as a significant source of stress, with participants reporting a lack of appropriate facilities and discomfort associated with social exposure. Nevertheless, some individuals reported that prior exposure to breastfeeding scenes, such as observing siblings or relatives breastfeed, had helped normalize the practice and reduced their own discomfort. • Participants expressed preferences for visually clean, aesthetically pleasing environments rendered in high-fidelity 3D graphics, along with gender-neutral color palettes and customizable avatars. Furthermore, they emphasized the value of including realistic but non-overwhelming challenges within the simulation. • Based on these findings, the researchers refined the VR simulation in the third phase. The updated version included 3 scenarios: breastfeeding in a home setting with a partner present, a public park environment populated with distant nonplayer characters and background noise, and a workplace scenario simulating a return to work, with social pressure and unexpected interruptions. The virtual baby was also redesigned to incorporate feeding behaviors, latching mechanics, and emotional states, represented through facial expressions and audio cues. A 9-state behavior model		

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Study	Results	Conclusions	Implications for future research
	was implemented to simulate the unpredictability of infant behavior during feeding. Thematic analysis of the interview transcripts revealed 2 overarching themes. The first described participants' deep affective engagement with the simulation. Many users, especially those with prior breastfeeding experience, reported that the simulation closely mirrored their own lived realities, triggering emotional recall, moments of joy and frustration, and a sense of bonding with the virtual baby. • The second theme referred to aspects of the simulation that disrupted immersion. These frictions stemmed from mismatches between the users' bodies and their virtual avatars, insufficient interactivity with nonplayer characters, overly pristine environments that did not reflect the reality of a household with a newborn, and the absence of tactile or haptic feedback. Additionally, several participants indicated a desire for more explicit feedback mechanisms, such as prompts or tutorials, to guide them through the feeding process. The simulation was generally perceived as nonthreatening and emotionally safe. None of the participants reported feeling discouraged or overwhelmed; rather, the VR experience facilitated nuanced reflection on breastfeeding and helped both parents and partners consider their roles more deeply.		
Noben et al [45]		• The study did not show a decrease in preoperative anxiety after VR information provision for patients undergoing elective CD. There was a trend toward decreased preoperative anxiety in the subgroup of women with a history of emergency CD who watched the VR video.	• Further research for identifying the characteristics of subgroups of patients who would potentially benefit from VR information provision is necessary.

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Study	Results	Conclusions	Implications for future research
	• There was an increase in the Visual Analog Scale for Anxiety (VAS-A) score between the first and second measurements of 1.5 cm for the women in the VR group compared to 0.8 cm for women in the control group (95% CI −0.1 to 2.0; *P*=.08). For their partners, there was an increase of 1.4 cm in the VR group compared to 0.9 cm in the control group (95% CI −0.5 to 1.6; *P*=.30). • The following variables showed a significant relation with ΔVAS-A: baseline VAS-A ($F_{1,75}$=8.4; *P*=.01) and history of CD[h] ($F_{1,75}$=6.0; *P*=.02). The increase in the baseline VAS-A score at time point 2 (at admission) in women in the VR group with a history of emergency CD was 1.7 cm smaller than that in women with a history of emergency CD in the control group, although this effect was not significant (*P*=.06). • Median scores on the SSQ[i] for motion sickness symptoms reflected the absence of discomfort caused by the VR video. • There was no significant difference in scores on the Tilburg Pregnancy Distress Scale subscales for both time points 1 and 2 between the VR group and the control group. • Individuals in the VR group without a history of emergency CD perceived a higher quality of care than the control group (10.2, SD 3.8 vs 12.9, SD 3.5; *P*=.02). 15% of women responded that they did not feel more prepared after seeing the VR video. 85% of women responded positively. From the partners, 79% responded positively. The 21% partners did not feel more prepared after seeing the VR video.		
Setiawan et al [46]	• The results of checking the vital signs after doing exercise with VR showed no sign of bad health conditions. • The average of all aspects of the IVE[j] questionnaire given is 4.26. (max 5)	• The average results of all aspects of the components in the IVE questionnaire showed positive results. That indicates the VR application for pregnancy exercise is feasible to use by pregnant women.	• In future research, it is possible to develop mixed reality applications for pregnancy exercise so that when doing exercise, pregnant women can still see the environment in the real world.
Park and Kim [47]			

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Study	Results	Conclusions	Implications for future research
	• State Anxiety: Experimental group: mean 44.53 (SD 7.58); Control group: mean 52.93 (SD 8.96); *P*=.009. VR intervention significantly reduced anxiety levels. • Stress Related to Preterm Labor: Experimental group: mean 48.66 (SD 4.82); Control group: mean = 55.87 (SD 6.91); *P*=.002. VR education significantly lowered stress scores. • Uterine contractions: frequency (times/min): Experimental: 1.00 (SD 0.75); Control: 1.84 (SD 0.76); *P*=.004. • Intensity (mm Hg): Experimental: 10.13 (SD 3.97); Control: 23.43 (SD 10.11); *P*<.001. Significant reductions in both frequency and strength of uterine contractions in the experimental group. • Cervical length: Experimental group: 33.93 (SD 5.33) mm; Control group: 31.62 (SD 7.38) mm; *P*=.009. Cervical length increased more in the experimental group, indicating a possible delay in labor progression. • Pregnancy health care practice behavior: Experimental group: 71.60 (SD 5.86); Control group: 67.37 (SD 5.47); *P*=.047; improved health-promoting behaviors in the experimental group. • Self-efficacy in pregnancy health care: Experimental group: 46.93 (SD 2.93); Control group: 40.81 (SD 4.98); *P*=.001. Higher confidence in managing pregnancy in the VR group.	• The VR-based prenatal education program was statistically and clinically effective in improving: • Psychological well-being (reduced anxiety and stress). • Physiological indicators (lower uterine activity and increased cervical length). • Behavioral outcomes (better self-care practices and self-efficacy).	• Future studies should: • Replicate the intervention across multiple institutions, diverse geographic areas, and larger sample sizes to confirm its effectiveness and improve external validity. • Use RCTs to strengthen causal inferences and minimize confounding factors. • Explore personalized VR content tailored to clinical severity (eg, cervical length, prior preterm labor) and educational needs. • Involve interdisciplinary collaborations (eg, obstetrics, psychology, digital health, and user experience design) to enhance both content relevance and technological usability. • Assess the sustained impact of VR-based education on: preterm birth rates, neonatal outcomes, maternal mental health postpartum, and long-term health behavior adherence. • Examine: barriers to use (eg, motion sickness and device usability); user interface improvements; low-cost and mobile-accessible versions for wider clinical implementation. • Include mediator and moderator analysis to isolate which components of the intervention are most impactful.
Montoya-Moncada et al [48]	• No between-group differences (BSES-SF[k] mean 63.31 vs 63.10; *P*=.87; MBFES[l] 133.48 vs 134.03; *P*=.84). Overall EBF[m] at 1 week = 93.1%; distribution by arm 50%/50%.	• MR adjunct not superior within 1-week window; very high early EBF suggests strong baseline supports.	• Larger samples, multiple sessions, longer follow-up; assess usability and accessibility and consider integration with postnatal supports.

[a]VR: virtual reality.

[b]PHQ-9: Patient Health Questionnaire-9.

[c]GAD-7: Generalized Anxiety Disorder Scale-7.

[d]PRAQ-20: Pregnancy-Related Anxiety Questionnaire.

[e]RCT: randomized controlled trial.

[f]CBE: childbirth education.

[g]FOC: fear of childbirth.

[h]CD: cesarean delivery.

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[i]SSQ: Speech, Spatial and Qualities of Hearing Scale.
[j]IVE: immersive virtual environment.
[k]BSES-SF: Breastfeeding Self-Efficacy Scale – Short Form.
[l]MBFES: Modified Breastfeeding Self-Efficacy Scale.
[m]EBF: exclusive breastfeeding.

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Table . Hardware and software equipment and virtual reality content.

Study	Hardware and software equipment	Virtual reality contents
Xie and Zeng [23]	• Hardware: desktop VR[a] system. • Software: SpaceMax VR software for interactive 3D labor room simulation.	• 3D interactive virtual labor room environment. • Virtual scenarios of delivery processes and perineal protection techniques. Realistic depictions of hospital settings, medical staff interactions, and childbirth procedures.
Lee et al [34]	• No specific details provided, but VR technology was used to create an immersive training and mental health promotion program.	• The VR program included 4 modules: • Module 1: Game-Based Cognitive Training. • Module 2: Advanced Game-Based Challenge. • Module 3: Psychoeducation and Emotional Support. • Module 4: Memory and Anticipation Training.
Caballero-Galilea et al [40]	• Hardware: Meta Quest 3 HMD[b]; obstetric props for kinesthetic immersion. • Software: custom Unity 3D simulation of eutocic childbirth with interactive hospital environment and soundscapes.	• Immersive VR simulation of eutocic childbirth in a virtual hospital setting, guiding participants through admission, monitoring, pain management, epidural, active labor, delivery, and immediate postpartum with multisensory cues and gaze-based interaction; aimed at realistically reproducing the childbirth experience, without a structured psychological or anxiety-focused educational component.
Siivola et al [41]	• Hardware: Insta360 Pro camera, Oculus Quest 2 VR headset, and Zoom H6 recorder. • Software: Adobe Premiere Pro, Pano2VR, and HandBrake.	• 360° multimedia childbirth program including panoramic and video-based labor scenarios, supportive audio clips, brief text and image content, and web resources covering the birth environment, pain relief options, labor positions, monitoring, comfort strategies, and birth preferences.
Siivola et al [42]	• Hardware: Oculus Quest 2 VR headset and Insta360Pro camera. • Software: • Editing: Adobe Premiere Pro and HandBrake (for video compression) • VR Development: Pano2VR • Accessibility: hosted on a website accessible via multiple devices (VR headsets, tablets, smartphones, and computers).	• 360° videos depicting hospital environments and birth scenarios. • Audio narration explaining childbirth procedures. • Interactive elements to explore different birthing techniques. • Additional multimedia content (text, images, and sound clips).
Tang et al [43]	• Hardware: Oculus Rift CV1, Leap Motion Controller, and tangible probe representing a baby (tracked using Oculus Touch controllers). • Software: unity-based VR simulation, SDKs from Oculus and Leap Motion, and FABRIK inverse kinematics.	• VR breastfeeding simulation across home, public, and workplace settings, using a self-avatar and responsive virtual baby to practice latching and feeding under realistic social and environmental conditions; interaction was minimally guided and deliberately nongamified to preserve realism.
Tang et al [44]	• Oculus Rift CV1 VR headset. • Oculus Touch controllers. • Leap Motion Controller. • Tangible baby representation (plush dolls weighted to simulate a newborn).	• The simulation included 3 scenarios: • Personal living space: a home setting for private breastfeeding. • Public park: outdoor breastfeeding experience with environmental influences. • Meeting room: breastfeeding in a workplace setting.

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Study	Hardware and software equipment	Virtual reality contents
Noben et al [45]	• Informed app and VR glasses	• The 360° VR video shows all the aspects of a CD, including the admission on the ward, the operating room, placement of spinal analgesia, and the birth of the baby when the gynecologist lifts the baby above the sterile environment.
Setiawan et al [46]	• Xiaomi Redmi Note 4 smartphone and VR Shinecon.	• VR prenatal exercise program with a preprogrammed virtual trainer delivering 10 sessions (warm-up, core seated pregnancy exercises, and cool-down) focused on safe stretching, pelvic movements, and breathing for childbirth preparation, with simple head-nod interaction in an immersive natural setting.
Park and Kim [47]	• VR head-mounted display: equipped with finger motion recognition for navigating menus and selecting content without the need for physical controllers. • 360-degree camera.	• VR intervention combining educational modules on preterm labor, prenatal care, symptom monitoring, hospitalization, and discharge with relaxation and meditation sessions using nature-based imagery, breathing guidance, and nurse-led narration to support knowledge, stress reduction, and emotional regulation.
Montoya-Moncada et al [48]	• MR headset; silicone breast model; infant doll; neonatal simulator; immersive video playback via VR Video Player.	• Immersive breastfeeding scenario videos shown via headset as part of the guided session.

[a]VR: virtual reality.

[b]HMD: head-mounted display.

Data Analysis

We conducted a thematic analysis following Braun and Clarke 6-phase framework [49] to synthesize qualitative and mixed methods insights across the included studies. This approach encompassed the phases of familiarization with the data, generating initial codes, searching for and reviewing themes, defining and naming themes, and producing the final report. Our main objective was to identify patterns related to participant experiences, perceived impacts, and implementation characteristics of XR-based interventions. More specifically, during the familiarization phase, 2 researchers (SP and ONM) thoroughly read the methodology, results, discussion, and conclusion sections of each included study. In the initial coding phase, we systematically labeled and coded relevant segments of the data, identifying features pertinent to our research focus. During the theme generation phase, the coded data were organized into candidate themes. In the reviewing themes phase, we refined and consolidated the themes through an iterative process of comparison, discussion, and evaluation of the coherence and distinctiveness of each theme against the preliminary coded data. Subsequently, in the defining and naming themes phase, we finalized the themes by articulating the scope and content of each one. Finally, in the reporting phase, we described the thematic findings and their relative prevalence across the dataset.

Throughout the analysis, we used an inductive, data-driven approach, allowing the themes to emerge organically from the data without reliance on preexisting theoretical models [50]. In parallel, we complemented this bottom-up strategy with a top-down perspective: the extraction and interpretation of findings were also guided by the research questions formulated during the scoping review process.

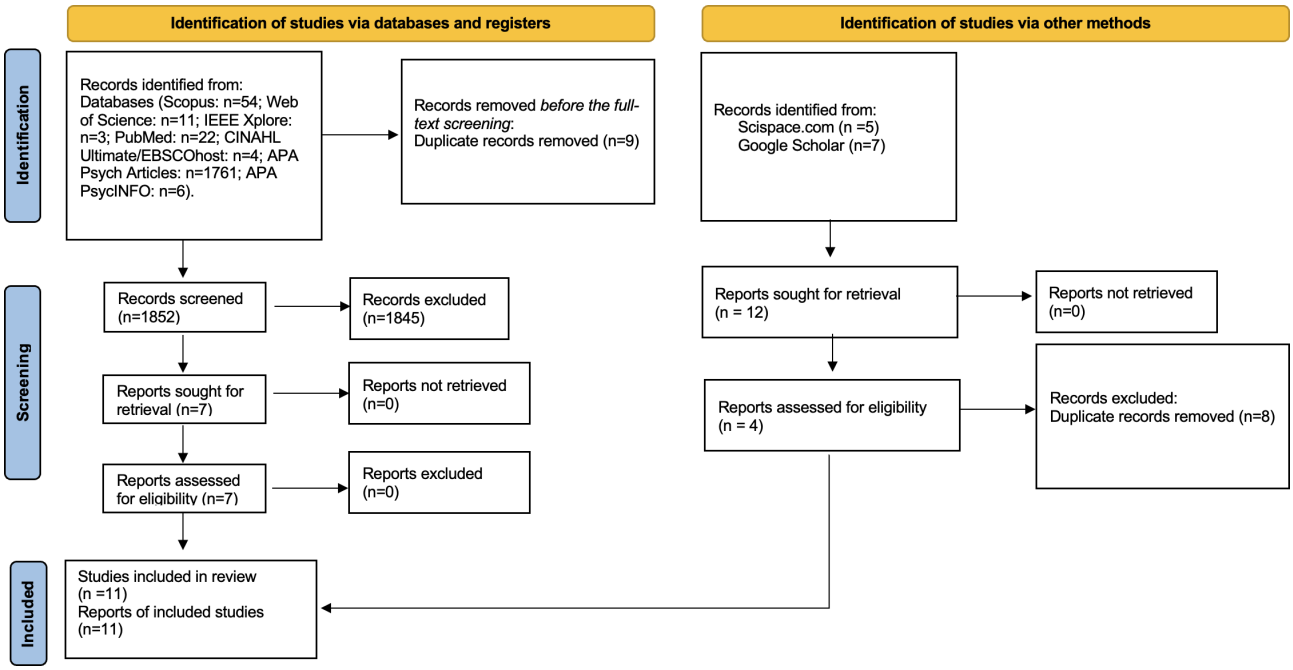
Results

Data Charting Process and Data Items

We included 11 studies [23,34,40-48] (Figure 1). A data extraction template has been deployed to outline the relevant data corresponding to the research objectives. The data, recorded either in narrative form or as nominal values, included the variables indicated in Tables 2-6.

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Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 flow diagram for new systematic reviews which included searches of databases, registers, and other sources [51]. Adapted from Page et al [51], which is published under a Creative Commons Attribution 4.0 International License (CC BY 4.0 [52]).



To provide a clearer overview of the findings, the "Results" are structured according to the 5 research questions defined in the "Introduction." Each subsection presents a synthesis of evidence addressing the corresponding question.

RQ1: What Are the Primary Applications of XR in Prenatal Education Programs?

To address RQ1, the included studies were analyzed to identify how virtual, augmented, mixed, and immersive technologies were applied within prenatal, childbirth, and early parenting education. The selected 11 studies included in the final review [23,40-48], from 2019 to 2025, and conducted across 8 countries (China [23], Korea [34,47], Spain [40], Finland [41,42], Belgium [43-45], Netherlands [46], Indonesia [47], and Colombia [48]). The works examined the use of XR technologies, mainly VR and 360° video-based simulations, for prenatal, childbirth, and breastfeeding education, as well as for promoting mental health, relaxation, and physical activity during pregnancy (Table 2). Most studies were single-center and focused on pregnant women as the target population, with 3 studies also involving partners [43-45]. Study designs included RCTs [23,45,48], quasi-experimental or interventional studies [34,40,46,47], pilot or feasibility studies [41,42,46], and qualitative user-centered design investigations [43,44]. Sample sizes ranged from small qualitative cohorts (from 10 to 25 participants) to larger controlled studies (from 60 to 200 participants). From a technological point of view, interventions used a range of immersive solutions: (1) fully immersive VR HMDs such as Oculus Quest, Rift, or equivalent [34,40-47]; (2) 360° or 3D video-based environments accessible through computers or mobile devices [23,41,42]; (3) hybrid setups integrating interactive elements, soundscapes, and guided relaxation content [40,43,47]; and (4) a MR headset used with a silicone breast model and infant doll to simulate breastfeeding [48]. Several studies applied structured instructional or design frameworks such as the Analyze, Design, Develop, Implement, and Evaluate model (ADDIE model) [47] and the IMCHB [47], or used user-centered and co-design methodologies [41-44].

RQ2: What Benefits Have Been Reported Regarding the Use of XR in Prenatal Education?

Overview

The included studies evaluated a range of psychological, physiological, educational, and experiential outcomes: (1) anxiety reduction and mental health promotion [34,40]; (2) childbirth education and fear-of-childbirth management [41,42]; (3) prenatal care for hospitalized or high-risk pregnancies [50]; (4) breastfeeding skill development and experiential learning [43,44,48]; (5) prenatal exercise motivation and maternal physical well-being [46]; (6) pain management and obstetric outcomes during labor [23]; and (7) reduction of preoperative anxiety before cesarean delivery [45]. More in detail, the reported outcomes were categorized into four main domains: (1) psychological outcomes (depression, anxiety, FOC, and perceived stress); (2) physiological outcomes (pain reduction, perineal trauma, postpartum hemorrhage, uterine contractions, and cervical length); (3) educational outcomes (knowledge acquisition, memory retention, and perceived preparedness); and (4) experiential outcomes (user experience, usability, acceptability, and immersion).

Psychological Outcomes

Anxiety reduction was consistently reported across multiple studies. Lee et al [34] conducted a 5-week VR-assisted mental health program for pregnant women, reporting significant reductions in depressive and anxiety symptoms (Patient Health Questionnaire-9 [PHQ-9] and Generalized Anxiety Disorder-7 [GAD-7]) and improvements in quality of life (WHOQOL-BREF [World Health Organization Quality of Life–BREF]). No statistically significant changes were observed

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in Perceived Stress Scale (PSS) scores, suggesting that while the VR program effectively enhanced emotional well-being, it may not directly influence stress-related factors. The intervention appeared particularly beneficial for participants at higher baseline risk for depression and anxiety. Similarly, Caballero-Galilea et al [40] found that controlled VR exposure to the childbirth process reduced pregnancy-related anxiety in third-trimester women. Noben et al [45] evaluated the use of 360° VR videos to prepare women and their partners for elective cesarean delivery. Although the intervention did not significantly reduce overall preoperative anxiety compared with standard information provision, most participants, both women and partners, reported feeling more prepared and less fearful about the upcoming procedure. Qualitative feedback indicated that the immersive visualization of the operating room and surgical process fostered familiarity and reduced uncertainty, particularly among those with prior emergency cesarean experience. Thus, while VR did not achieve a statistically significant decrease in anxiety scores, it enhanced perceived preparedness and satisfaction, suggesting potential benefits in specific subgroups. Xie et al [23] showed that women receiving VR-based prenatal education combined with perineal protection reported significantly lower anxiety. FOC was a specific target in 2 studies [41,42], both of which reported reductions in FOC levels and positive user feedback on emotional preparedness after participation in VR-based childbirth education. Park and Kim [47] conducted an experimental study targeting pregnant women hospitalized for preterm labor. The intervention group who received VR-based prenatal education demonstrated statistically significant improvements in self-efficacy, pregnancy-related knowledge, and emotional stability, along with a higher perceived usefulness of the training content compared to the control group. The VR program provided tailored content that addressed psychological well-being during hospitalization and included simulations of childbirth and newborn care. Importantly, participants in the VR group showed lower levels of anxiety and stress and greater readiness for labor and postpartum care.

To summarize, 9 out of 11 (81.8%) studies [23,34,40-48] assessed psychological or emotional dimensions such as anxiety, depression, perceived stress, or FOC. Among these, 7 [23,24,40-42,45,47] out of 11 studies [23,34,40-48] (63.6%) reported statistically significant or qualitatively positive effects on anxiety or related constructs. Specifically, studies [23,34,40,45] reported measurable anxiety reduction following exposure to immersive prenatal or perinatal experiences. Siivola et al [41,42] observed reductions in FOC and enhanced emotional readiness, while Park et al [47] found decreased stress and improved emotional stability in hospitalized women receiving VR-based prenatal education. One study [46] focused primarily on physical activity and did not measure mental health outcomes, whereas another [44] reported mixed results, some participants described VR breastfeeding simulations as “emotionally demanding” or “challenging,” suggesting that immersive realism can occasionally elicit discomfort alongside learning benefits. Overall, these findings suggest that immersive XR interventions could have an impact on enhancing psychological well-being, though emotional responses are related to the realism and sensitivity of the simulated content.

Physiological Outcomes

Some studies incorporated physiological or behavioral measures to complement psychological outcomes. VR-assisted prenatal preparation was associated with lower maternal heart rate, reduced pain scores, and higher rates of perineal integrity during childbirth [23]. Setiawan et al [46] monitored vital parameters before and after each VR-based exercise session, observing no adverse cardiovascular responses and confirming the feasibility of moderate physical activity guided through immersive environments. Similarly, Park et al [47] reported that VR relaxation modules stabilized uterine activity among women hospitalized with threatened preterm labor, contributing to improved comfort and adherence to treatment. Across all studies, no serious adverse effects were observed; minor discomfort, such as transient dizziness or eye fatigue, was infrequently reported and self-resolving. To summarize, 3 (30%) studies [23,46,47] reported physiological or obstetric indicators, either as primary or secondary outcomes. Among them, Xie et al [23] documented significant improvements in childbirth-related parameters, including reduced pain scores, higher rates of intact perineum, and shorter labor duration in the VR-assisted group. Park et al [47] observed stabilization of physiological stress markers such as systolic blood pressure, heart rate, and uterine activity. Setiawan et al [46] confirmed the safety and feasibility of VR-guided exercise, with no adverse cardiovascular responses. No study reported serious side effects, and among the few studies that assessed VR-related tolerability, adverse effects were generally absent or limited to minor, transient complaints. Noben et al [45] reported no discomfort or motion sickness, Setiawan et al [46] found no postsession nausea, vomiting, or dizziness, and Siivola et al [41] reported no motion sickness during testing. Minor transient adverse events were documented in only 2 studies (<20%): Siivola et al [42], in which 1 participant reported eye strain and another minor HMD-related discomfort, and Park et al [47], which reported 1 withdrawal due to HMD-related discomfort. Overall, most studies did not systematically assess VR-related side effects.

Educational Outcomes

Educational impact was evaluated through measures of knowledge acquisition, engagement, motivation, and self-efficacy. Siivola et al [41,42] developed and tested immersive childbirth education programs using 360° videos and VR headsets. Participants consistently rated the experiences as usable, realistic, and engaging, with reported improvements in childbirth knowledge and preparedness. However, evidence regarding the FOC reduction remains inconclusive. Tang et al [43,44] found that VR breastfeeding simulations supported experiential learning through embodied interactions, enabling users to visualize and practice realistic feeding challenges in a safe context. However, a subset of users reported frustration with the lack of explicit feedback or structured guidance during the simulation. Montoya-Moncada et al [48] found no statistically significant differences between the MR-based educational strategy and traditional breastfeeding counseling in terms of maternal self-efficacy and satisfaction. Park et al [47] highlighted that immersive prenatal modules improved engagement, comprehension, and emotional connection to content, aligning with the principles of the IMCHB model.

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Setiawan et al [46] demonstrated that VR exercise programs for pregnant women are feasible and could positively impact adherence to physical activity, suggesting behavioral reinforcement potential through gamified, self-paced environments. Overall, 6 [41-44,46,47] out of 11 studies [23,34,40-48] (54.5%) explicitly evaluated educational end points, such as knowledge acquisition, preparedness for childbirth, self-efficacy, or skill transfer. The studies [41-44,47] reported improvements in knowledge retention, confidence, and comprehension, particularly when interactive or 360° scenarios were used. Setiawan et al [46] found increased motivation and adherence to prenatal exercise programs, suggesting educational reinforcement through gamified feedback. Conversely, Caballero-Galilea et al [40] observed reductions in anxiety but did not detect significant changes in perceived knowledge, and one breastfeeding simulation study [44] noted that while participants valued the realism, they sought clearer instructional guidance. Approximately two-thirds of the included studies demonstrated enhanced learning or self-efficacy outcomes, though some highlighted the need for improved instructional design within immersive systems.

Experiential Outcomes

User-centered evaluations were prominent in at least 6 (60%) studies [41,42,44-47], which mainly investigated usability, comfort, and motion sickness. Most users reported high satisfaction and found the VR interfaces intuitive, with minor reports of motion discomfort. Studies reported user-centered or experiential metrics, including usability, acceptability, immersion, and motion sickness. Across these, most participants described immersive experiences as engaging, realistic, and emotionally meaningful. Some studies [41-44] emphasized the positive influence of interactivity and presence on emotional engagement. Other [44] noted occasional discomfort or cognitive overload among participants unfamiliar with VR interfaces. Reports of motion sickness were infrequent and mild.

Overall, user experience outcomes were favorable in the included studies, supporting the feasibility and acceptability of immersive prenatal and perinatal education.

When aggregated, 9 [23,34,40-42,45-48] of 11 studies [23,34,40-48] (81.8%) reported at least 1 positive outcome domain, and 6 [23,34,41,43,46,48] of 11 [23,34,40-48] (54.5%) demonstrated statistically significant improvements in at least one primary variable (eg, anxiety, pain, knowledge, or satisfaction). Psychological and educational benefits were the most consistent, particularly in anxiety reduction and learning engagement, although results were heterogeneous for FOC and preoperative anxiety. Physiological and experiential outcomes showed promising but preliminary evidence of safety and acceptability. Taken together, these findings reinforce the potential of XR technologies, especially VR, to enhance emotional readiness, experiential learning, and patient engagement during pregnancy and childbirth, while highlighting the need for larger, standardized, and multicenter studies to validate these early results. Tables 2-6 present a comprehensive overview of the included studies, summarizing study characteristics, participant demographics, methodological features, key results and implications, and details of the educational programs, including technological components and content design.

RQ3: What Challenges and Limitations Are Identified in the Integration of XR Into Prenatal Courses?

RQ3 examined the methodological diversity and implementation challenges reported in the included studies. As summarized in Table 3, methodological heterogeneity was observed across the included studies, reflecting the exploratory nature of research on immersive and XR technologies in prenatal and childbirth education. While some studies [23,34,40,45,47] adopted controlled or quasi-experimental frameworks to assess measurable outcomes, such as anxiety reduction or physiological responses, others relied on exploratory or design-based methodologies to examine user perceptions, usability, or content development processes. This diversity illustrates the coexistence of intervention trials and formative research, each contributing different types of evidence to the field. Differences also emerged in the exposure design and delivery parameters. The duration and frequency of immersive experiences varied considerably, from single brief sessions focusing on emotional regulation or preoperative preparation to multiweek interventions structured as comprehensive educational programs. The level of immersion also ranged widely, encompassing fully immersive VR headsets, semi-immersive 360° video environments, and hybrid configurations integrating soundscapes, narration, or limited interactivity. The measurement tools and outcome frameworks were equally inconsistent. Psychological outcomes such as anxiety, depression, or FOC were assessed with different validated instruments [eg, the State-Trait Anxiety Inventory (STAI), the Wijma Delivery Expectancy/Experience Questionnaire (W-DEQ), and the Edinburgh Postnatal Depression Scale (EPDS)], which hinders cross-study comparison. In contrast, educational and experiential outcomes were often measured through ad hoc questionnaires or qualitative interviews, limiting external validity but providing valuable insight into user engagement and emotional resonance. Some quantitative studies applied inferential statistics to compare intervention and control groups, whereas qualitative research emphasized thematic synthesis or user-centered evaluation frameworks. Follow-up assessments were infrequently conducted, reducing the capacity to assess long-term retention or behavioral impact. Most studies recruited only women, with sample sizes ranging from 10 participants in qualitative co-design studies [44] to 200 participants in randomized clinical trials [23]. Eligibility criteria were often highly restrictive, for example, targeting primiparous women without complications [23] or patients scheduled for elective cesarean delivery [45]. Such selectivity, while enhancing internal validity, reduces generalizability and further contributes to the methodological heterogeneity observed across the field. Intervention structures also differed markedly. For instance, Lee et al [34] implemented a progressive multimodule VR mental health program, Setiawan et al [46] integrated pre- and postsession physiological monitoring during VR exercise, and Park et al [47] developed a guided prenatal education model using the IMCHB framework for hospitalized women. This diversity of methodological orientations, ranging from structured trials to exploratory pilot studies, reflects both the experimental

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stage and the rapid evolution of immersive applications in prenatal education. Despite increasing recognition of coparenting and partner involvement, only 3 studies [43-45] explicitly included partners. This underscores an underexplored area for future research on shared learning and emotional coregulation during the perinatal period. Equity and accessibility were addressed in a limited number of studies. Barriers such as digital literacy, comfort, device availability, and motion sensitivity were acknowledged as potential obstacles to the equitable adoption of immersive education. Notably, the inclusion of multidevice access options (eg, VR headset, tablet, or smartphone [41,42,47]) was viewed positively by users, emphasizing the importance of flexible and inclusive design approaches for diverse populations. Overall, the methodological heterogeneity across studies underscores both the innovation potential and the fragmentation of current immersive technologies research in prenatal care. The field would benefit from shared methodological guidelines, standardized reporting criteria, and mixed methods designs that integrate psychological, educational, and experiential dimensions within unified evaluation frameworks.

RQ4: What Methodologies and Technological Approaches Are Commonly Used in Studies on XR for Prenatal Education?

RQ4 analyzed the technological and design characteristics of XR interventions, including hardware, software, and the structure of the immersive content. Technological diversity was substantial across studies, reflecting the evolving and experimental nature of immersive technological applications in maternal health. Most interventions used HMDs such as Oculus Rift, Oculus Quest, or smartphone-compatible VR viewers [34,41-44,46,47], allowing full or semi-immersive 3D visualization of childbirth or breastfeeding scenarios. Others implemented 360° panoramic videos accessible via computers, tablets, or mobile devices to broaden accessibility and minimize cybersickness [41,42,45].

Software environments were typically developed using Unity (Unity Technologies) or Pano2VR (Garden Gnome Software), integrated with supplementary editing tools such as Adobe Premiere Pro (Adobe Inc) and HandBrake (HandBrake Team) for video compression and cross-platform usability [41-43].

Across studies, immersive content was structured around thematic educational modules:

- Childbirth process simulations, including stages of labor, pain management, and hospital familiarization [23,41,42].
- Mental health and relaxation modules, focusing on stress reduction, guided breathing, and emotional resilience [34,47].
- Skill-based training, such as breastfeeding interaction scenarios and prenatal physical exercise routines [43,44,46,48].

Most interventions combined visual, auditory, and interactive cues to enhance engagement and learning transfer. Some included embodied tasks, for example, hand motion tracking, tactile interaction with a doll and/or silicone breast model [43,44,48], or guided voice-over narration simulating clinician or midwife presence [47]. User experience design was generally informed by user-centered frameworks and pedagogical models such as the IMCHB model and constructivist learning theory, emphasizing experiential learning through realistic simulation [47].

Overall, immersive technologies demonstrated versatility in integrating multisensory and interactive components adaptable to both clinical and home environments. However, variation in technical specifications and delivery platforms underscores the current lack of standardization in immersive maternal education tools.

RQ5: What Research Gaps Exist in This Area, and What Future Directions Are Recommended?

First, modest sample sizes and narrow eligibility criteria (eg, low-risk, primiparous women or inpatient cohorts) limit generalizability and constrain inferences about the applicability of XR. Only 3 studies enrolled partners [43-45], despite growing evidence in favor of shared parental education. Second, heterogeneity in study designs and measurement approaches hampers cross-study comparisons and meta-analytic synthesis. Psychological outcomes were often captured with validated scales, whereas experiential and usability outcomes frequently relied on ad hoc instruments. Standardized, validated tools tailored to XR-based maternal education remain lacking. Technologically, few interventions collected objective usability metrics (eg, engagement time and motion-tracking data), and accessibility testing for participants with low digital literacy or limited device access was rarely undertaken [41,42]. Moreover, ethical and equity considerations, including data privacy, the digital divide, and cultural adaptation of immersive content, were seldom discussed, despite their importance for global health implementation. Additional work should examine the suitability of mixed-reality tools across diverse populations, particularly in low- and middle-income countries where access to innovative educational strategies may be constrained yet potentially highly beneficial [48]. Future research should deploy RCTs that use more intensive educational strategies, incorporate multiple sessions, and extend follow-up to clarify long-term effects on maternal self-efficacy, satisfaction, and exclusive breastfeeding rates [48]. Finally, there remains a pressing need for longitudinal and comparative studies that evaluate behavioral and clinical outcomes beyond the immediate postpartum period. Researchers should explore scalable, low-cost immersive solutions and hybrid learning models that combine simulation with interpersonal support. Collaborative, interdisciplinary efforts, linking clinicians, designers, and educators, are essential to establish best practices and ensure safe, inclusive integration of XR technologies into prenatal and childbirth education.

Overall Summary of Findings

Overall, the synthesis across RQ1-RQ5 indicates that immersive and XR technologies are being increasingly integrated into prenatal and childbirth education with encouraging outcomes across psychological, physiological, educational, and experiential domains. Despite methodological heterogeneity and small sample sizes, most studies demonstrated positive effects on anxiety reduction, learning engagement, and emotional preparedness. However, limited standardization in

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design, measurement, and accessibility testing highlights the early developmental stage of this field. These results collectively support the feasibility and potential of XR as an innovative complement to conventional prenatal education, while underscoring the need for rigorous, inclusive, and longitudinal research to consolidate its evidence base.

Thematic Analysis

A total of 5 major themes and the related subthemes emerged from the analysis. To further contextualize these patterns, we have integrated responses to the 5 guiding research questions underpinning this review, supported by evidence from the included academic literature. Proportions refer to the 11 included studies [23,34,40-48].

Theme 1: VR as a Catalyst for Emotional, Cognitive, Physical, and Physiological Outcomes

This theme explores how immersive experiences promote emotional readiness, self-efficacy, and physiological comfort during pregnancy and childbirth. Across 8 [23,34,40,42,45-48] of 11 [23,34,40-48] (72.7%) studies, immersive or semi-immersive VR interventions demonstrated a measurable positive impact on participants' emotional regulation, childbirth-related self-efficacy, and perceived control during pregnancy and labor. Several studies explicitly reported reductions in anxiety, depressive symptoms, or FOC, particularly when VR was used to visualize the childbirth process or to simulate relaxation exercises [34-38,40-43,48-51]. Physiological parameters also improved in studies integrating biobehavioral monitoring: VR-based prenatal education combined with perineal protection lowered pain scores and postpartum bleeding [23]; VR-guided relaxation stabilized uterine activity in women with preterm labor [47]; and VR-assisted exercise programs showed no adverse cardiovascular effects [46]. Not all outcomes moved in the same direction: an RCT of a VR operating room walkthrough before an elective cesarean did not significantly reduce preoperative anxiety overall, although participants (and partners) reported feeling better prepared and no motion sickness was observed [45]. Overall, 9 [23,34,40-42,45-48] out of 11 [23,34,40-48] (81.8%) studies reported at least 1 beneficial psychological or physiological outcome, while 4 [23,34,40,47] of 11 (36.4%) [23,34,40-48] showed statistically significant improvement in at least 1 quantitative measure. These findings suggest that immersive experiences can promote emotional stability, physiological adaptation, and empowerment during pregnancy and childbirth.

- Enhanced self-efficacy, confidence, and perceived control among women during childbirth (9/11, 81.2%): immersive learning strengthened mothers' confidence and perceived control during childbirth [23,34,40-42,45-47].
- Distraction and emotional relief before and during childbirth (3/11, 27.3%): VR provided psychological distraction and emotional relief, reducing anxiety and stress through calming, immersive environments [34,40,45].
- Impact on physical or physiological parameters (3/11, 27.3%): immersive exposure was associated with reductions in pain and no adverse cardiovascular effects [23,46,47].

Theme 2: Customization, Sense of Presence, and Realism as Engagement Drivers

This theme captures how realism, presence, and adaptive learning features influence user engagement and satisfaction. Engagement was strongly shaped by audiovisual fidelity, a convincing sense of presence, and the possibility to tailor content. Users frequently described "being there" (eg, inside the birthing room) as key to relevance and motivation, and they valued options to progress independently [41,42]. At the same time, design tensions emerged when simulations looked or felt "game-like," creating unmet expectations for guidance, interactivity, or rewards; these microfrictions could chip away at immersion if not intentionally balanced [43,44].

Based on the contents, the following 3 subthemes emerged:

- Realism, immersion, and sense of presence (4/11, 36.4%): authentic audiovisual fidelity fostered emotional connection and meaningful engagement (eg, 360° hospital tours and realistic birthing scenarios) [41-44].
- Customization and personalization (2/11, 18.2%): users valued flexibility and the ability to tailor learning pace and content to personal needs [43,44].
- Participant satisfaction (4/11, 36.4%): overall satisfaction with VR experiences was high compared with traditional courses [40,42,46,47].

Theme 3: Technical and Usability Considerations

This theme synthesizes participants' feedback on the accessibility, usability, and technical limitations of immersive systems. Most users found VR interventions engaging, although minor barriers related to device comfort, navigation, or unfamiliarity with the technology were reported [44,46]. Feasibility and acceptability were generally good, with some device-related or interface hurdles. Multidevice access (HMD, computer, tablet, and smartphone) improved reach and scheduling flexibility, and HMDs often offered the best usability and presence [41,42].

The following subthemes are highlighted:

- Device flexibility and accessibility (5/11, 45.5%): VR allowed participation independent of place or schedule [34,40-42,44].
- Usability (ease of learning; 2/11, 18.2%): overall good usability, particularly with the headsets [41,42].
- Safety and tolerability: no serious adverse events reported (5/11, 45.5%) [23,34,40-42].
- Technological barriers (5/11, 45.5%): users occasionally experienced discomfort or interface issues [40-44].

Theme 4: VR as an Educational and Motivational Tool

This theme relates to cognitive learning, behavioral readiness, and social engagement facilitated by immersive tools. Most studies reported gains in knowledge, preparedness, and motivation. VR hospital tours about childbirth modules improved learning outcomes and provided concrete, realistic exemplars; VR-based programs also strengthened self-management and pregnancy care behaviors in higher-risk settings (eg, [42,47]). Immersive scenarios around breastfeeding surfaced lived challenges and promoted reflection and dialogue,

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complementing traditional didactics by addressing expectations and social or contextual barriers rarely covered in standard courses [43,44]. Preoperative VR for cesarean enhanced perceived preparedness in most women and their partners, highlighting motivational and informational value even when affective endpoints do not shift [45].

- Knowledge acquisition and retention (8/11, 72.7%): participants demonstrated improved understanding and recall of prenatal concepts [23,40-44,46,47].
- Ability to identify signs or symptoms of childbirth (5/11, 45.5%): VR improved recognition of early labor indicators and features related to breastfeeding experience [41,43,44,46,47].
- Coresponsibility and partner involvement (3/11, 27.3%): immersive education encouraged shared learning between partners [43-45].
- Recommendation to future parents (2/11, 18.2%): participants widely endorsed VR courses for peers [42,46].

Theme 5: Limitations

This final theme reflects methodological constraints and research priorities. Methodological constraints and implementation gaps temper generalizability. Several studies used small samples, single-group designs, or short follow-ups, and psychological outcomes were measured with heterogeneous tools. Selection biases and context-specific prototypes (eg, single-site pilots) were common, and partner or diverse-population representation was limited [40-43]. The main limits identified are the following:

1. Improving sample size (7/11, 63.6%) [34,40-42,45-47].
2. Lack of control group (3/11, 27.3%) [34,40,47].
3. Missing information (4/11, 36.4%): some studies pointed out the limited standardization especially about the measures used to assess psychological variables [23,40,42,45].
4. Selection biases (4/11, 36.4%) [34,41,45,46]: several studies point to the difficulty of accessing large and diverse samples, often having to resort to convenience sampling.
5. Confounding effect related to added intervention (VR and perineal protection [23]).
6. Inclusivity and contextual adaptation (4/11, 36.4%) [42-44,50].
7. Learning curve and technical literacy (4/11, 36.4%): limited familiarity with VR required orientation or staff support [42,43,46,47].
8. Lack of contextual and interactive cues and balanced gamification [42].
9. Lack of customization [34,44].
10. Lack of haptic feedback: the lack of perception of any type of pressure or vibration by participants may reduce their engagement with this technology [44].

Synthesis of Thematic Findings

Overall, from the thematic analysis, it emerges that immersive interventions primarily enhance emotional regulation, self-efficacy, and knowledge retention, reported in 70% - 80% of the included studies. Engagement is strongly linked to realism, presence, and personalization, while usability and equity remain key implementation challenges (eg, [23,34,40,47]).

Despite small samples and methodological variability, the findings collectively portray VR as a promising, user-accepted innovation for prenatal and childbirth education. The 5 themes identified were closely interrelated rather than independent. Realism and sense of presence appeared to be a central mechanism linking the technological features of immersive scenarios with users' psychological and educational outcomes. High levels of realism and immersion fostered emotional engagement and a stronger sense of preparedness, directly reinforcing confidence and learning outcomes. However, when the simulated experience became overly realistic or emotionally intense, participants occasionally reported discomfort, thereby connecting this theme to usability and instructional barriers. The need for structured guidance and emotional containment emerged as a mediating factor that shaped whether realism translated into positive or overwhelming experiences [41,44]. Similarly, the educational and motivational value of interventions was strongly influenced by the balance between realism and usability: participants were most motivated and confident when the immersive environment was both intuitive and emotionally manageable [42,43,47]. Finally, methodological and inclusivity limitations, such as small samples, short-term follow-up, and the underrepresentation of partners, acted as contextual moderators that constrained the generalizability of these interrelations [40,44,45]. Taken together, these interconnections suggest that the effectiveness of immersive scenarios in prenatal and childbirth education could be related to achieving equilibrium between immersion, usability, and emotional safety, ensuring that technological engagement consistently translates into meaningful learning and psychological benefit.

Discussion

Summary of Evidence

This scoping review underscores the growing importance of XR technologies in prenatal education, highlighting their diverse applications and potential benefits for expectant parents. Across heterogeneous designs and targets, XR (predominantly head-mounted VR and 360° video) emerged as a context-enabling technology that shapes expectations, self-efficacy, and preparedness.

The most consistently discussed mechanisms, warranting further investigation, were (1) presence and realism that situate users in concrete care pathways or lived scenarios (eg, birthing rooms and breastfeeding in public), aligning expectations with reality; (2) scaffolding (briefing, in-experience cues, and debriefing) to convert immersion into learning rather than overload; and (3) personalization and customization of pace, content, and intensity to match emotional readiness. These points recur in evaluations of childbirth education modules and breastfeeding simulations, which emphasize that simulations work best when they surface real-world complexity while remaining emotionally manageable [41-44]. Several included studies did not offer comprehensive VR-based childbirth training. Some interventions primarily targeted mental health promotion or general antenatal information, with childbirth skills training still provided via standard modalities; as a result, the evidence base appears

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stronger for preparedness and emotional regulation than for hands-on childbirth skills acquisition [34,40].

Not all affective end points shift uniformly. In the precesarean study using a 360° operating room walkthrough, overall preoperative anxiety did not significantly decline; however, participants felt better prepared and motion sickness was negligible, suggesting that VR may be more valuable for expectation setting and preparedness in this context [45]. By contrast, programs targeting mental health promotion during pregnancy reported reductions in depressive and anxiety symptoms and gains in quality of life, with stronger effects in higher-severity subgroups, consistent with VR acting as a precision amplifier when distress is greater [34,40]. This pattern aligns with broader VR evidence showing clinically meaningful anxiolytic and analgesic effects across nonobstetric contexts and robust efficacy for anxiety disorders in randomized trials [53-55].

In a recent noninferiority randomized trial evaluating an MR adjunct to standard prenatal counseling, there were no between-group differences in maternal self-efficacy or satisfaction at 1 week postpartum; however, exclusive breastfeeding reached 93.1% in both arms, indicating high baseline supports and potential ceiling effects [48].

Where VR was embedded alongside biobehavioral cointerventions (eg, perineal-protection techniques taught within a VR-supported prenatal program), studies discussed pragmatic benefits (eg, lower pain) while cautioning that future trials must disentangle the VR effect from the added clinical component [23]. From a design perspective, breastfeeding simulations repeatedly highlight a productive tension: when experiences feel game-like, users expect goals, feedback, and progression; if those are absent, microfrictions can erode engagement. Authors, therefore, advocate measured gamification (clear objectives and contextual feedback) and structured debriefs that channel emotional impact into reflection and action, principles that generalize to other perinatal VR modules [43,44]. Finally, implementation work converges on a practical message: HMDs maximize presence and usability for key sessions, but multidevice access (HMD plus PC or tablet or phone) broadens reach and equity for rehearsal and partner involvement. Brief sessions, seated posture, orientation, and clinician facilitation improve tolerance and learning transfer [41-44,47].

Findings converge with nonobstetric meta-analyses reporting consistent VR-driven reductions in pain and anxiety, and with clinical education studies where brief, expectation-aligned VR modules improve understanding when embedded in routine workflows [53-56]. In obstetrics, pooled analyses suggest state anxiety reductions during routine procedures without consistent maternal-fetal safety signals, albeit with reporting heterogeneity and short follow-up [24,57,58]. Overall, our results extend this literature by focusing on parent-facing prenatal education, emphasizing emotional preparedness, usability across digital literacy levels, and the value of facilitated debriefing, which are less central in clinician training research.

Implications for Clinical Practice

The findings of this scoping review suggest several concrete ways in which XR can be incorporated into prenatal care pathways. For parents scheduled for elective cesarean delivery, VR appears particularly useful as an informational and pathway-familiarization tool. Short, guided 360° tours of the operating theater and perioperative environment can strengthen perceived preparedness, even when mean anxiety scores do not change, and may be especially valuable for those with a history of emergency cesarean or heightened fear of surgery. Wherever possible, partners should be included so that both members of the dyad share a realistic understanding of the procedure and the perioperative setting [45].

Immersive programs that primarily target antenatal mental health, combining positive affect induction, psychoeducation, and relaxation or mindfulness elements, have shown reductions in depressive and anxiety symptoms and improvements in quality of life, with larger effects among higher-severity subgroups [34,41,42,46,47]. Clinically, this pattern supports the use of VR as an adjunctive component within stepped care models rather than as a stand-alone treatment. Brief, structured sessions can be embedded in routine antenatal visits to support emotional regulation, while more intensive psychotherapeutic strategies are likely to remain necessary when the aim is to modify stress appraisal and coping, which changed less consistently in the included trials [34,41,42,46,47]. Converging evidence from nonobstetric meta-analyses supports VR's adjunct role in reducing state anxiety in routine care pathways [53-55].

Within childbirth education and early parenting programs, headset-based, scenario-driven modules can be reserved for key sessions that introduce labor environments, decision points, and immediate postnatal routines, whereas remote 360° or video content can serve as refreshers to consolidate learning and allow parents to revisit material together at home [43-45].

For breastfeeding preparation, lived experience simulations that depict common technical and social challenges, such as latching difficulties or feeding in public, can help parents anticipate and normalize difficulties. Their impact appears greatest when VR sessions are framed and debriefed by midwives or lactation consultants, turning emotionally salient experiences into concrete action plans. Evidence from neonatal intensive care settings further suggests that VR may support lactation among mothers of preterm infants by reducing anxiety and enhancing expressed milk volume, although effects on self-efficacy and satisfaction depend on the quality of underlying counseling [43,44,48,59].

Across all applications, implementation choices shape both effectiveness and safety. The studies included in this review indicate that keeping sessions brief (around 10 - 15 min), using a seated posture, and allowing user-controlled pacing minimizes cybersickness and fatigue; no serious adverse events were reported, and obstetric meta-analyses likewise describe stable maternal and fetal parameters during short, guided uses [45,60].

When experiences adopt game-like conventions, it is important to make learning goals explicit and to provide light-touch feedback (eg, progress cues or hints), so that playfulness sustains

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engagement without trivializing care content [43,44]. Coviewing and partner involvement generally improve dyadic preparedness and adherence [45], and hybrid delivery models, combining clinic-based HMDs for high-presence moments with multidevice access (HMD, tablet, or smartphone) for rehearsal at home, may offer a pragmatic balance between fidelity, reach, and equity in diverse populations [41-44,47,61-64].

Implications for Future Research

Future research on XR-based prenatal education would benefit from greater methodological convergence. Across the included studies, outcome measures for anxiety, FOC, self-efficacy, and preparedness were highly fragmented, and reporting of presence, realism, and debriefing formats was inconsistent. Developing core outcome sets and agreed-upon reporting standards for VR "dose" (eg, frequency, duration, and hardware characteristics) and facilitation strategies would enhance comparability and support robust meta-analysis. Safety reporting should routinely include maternal hemodynamics, fetal heart rate patterns, and neonatal indicators, in line with emerging obstetric meta-analyses on intrapartum VR [24,40-44,47,50,57].

Several trials suggest that immersive programs may be particularly helpful for individuals with higher baseline distress, such as those with elevated depression or anxiety scores, or pronounced childbirth fear [34,41,42,46,47]. This pattern points to the need for studies that are prospectively powered for subgroup analyses, include prespecified interaction tests, and, where feasible, use adaptive designs to identify who benefits most and at what time point in pregnancy. In addition, family-centered outcomes, such as partner preparedness, dyadic coping, and coparenting adjustment, remain undermeasured despite growing evidence on paternal mental health and engagement. Future trials should therefore integrate these end points and draw on paternal-engagement frameworks when designing XR content [61-64].

Many of the interventions identified in the current review combined VR with additional components, including perineal protection techniques, structured counseling, or hands-on practice with task trainers, which makes it difficult to isolate the specific contribution of immersion. Future work should use active comparators or factorial designs to disentangle VR effects from cointerventions and to quantify how presence, guidance, and repetition relate to psychological and clinical outcomes [23]. Insights from rehabilitation science, where VR has been used extensively to structure motor learning schedules, could help specify dose-response relationships and practice parameters for perinatal education [65]. In parallel, design lessons emerging from breastfeeding simulations and co-design prototypes, such as embracing uncertainty while offering context-relevant feedback and enabling customization of family composition and environments, should be translated into testable design requirements and evaluated prospectively, even when initial prototypes fall outside strict effectiveness trial criteria [43,44]. Finally, implementation-focused and real-world research is needed to understand how immersive prenatal education can be scaled and sustained. Multicenter pragmatic trials should track uptake, completion rates, costs, and equity impacts, including representation of underserved groups and partner participation [41-44,47]. Given that early studies often restricted the use of headsets to clinic settings and resorted to nonimmersive devices for remote delivery, future work should evaluate models that provide loaner HMDs and home-based protocols with remote safety monitoring, comparing them with non-HMD approaches in terms of adherence, safety, user experience, and outcomes. Such implementation studies can inform guidelines for integrating XR into hybrid antenatal care pathways while safeguarding accessibility, inclusivity, and safety.

Limitations

Although our search spanned XR broadly, included studies were almost exclusively VR or 360°, with 1 MR trial, underscoring a modality gap [48]. Small samples, single-site prototypes, short follow-up, and heterogeneous measures limit generalizability and synthesis; some HCI-led prototypes caution that game-like framing can create normative expectations unless customization is provided [34-38,40-47,49-51]. Acceptability and safety were high overall, yet digital literacy and brief orientation remain prerequisites; where VR is embedded in multicomponent care, physiologic and clinical end points appear promising but attribution to VR alone is uncertain [23]. In obstetrics, evidence suggests anxiety reductions without consistent safety concerns, but reporting remains variable [24,57,58]. Finally, RCT work in breastfeeding points to targeted experiential benefits warranting replication and linkage to clinical end points [66].

Conclusions

For perinatal care, VR is most effective when high presence is matched with structured guidance and personalization, turning immersive exposure into meaningful preparedness and emotional regulation. Clinically, this translates into targeted use (eg, elective cesarean preparation and higher-severity mental health profiles) and hybrid delivery that balances fidelity with reach. For the field to mature, we need standardized outcomes, subgroup-powered pragmatic trials, and designs that separate VR's contribution from cointerventions while operationalizing HCI insights (uncertainty, feedback, and customization) as testable requirements. Integrating insights from broader VR meta-analyses and adjacent pediatric and rehabilitation domains strengthens the rationale for perinatal VR, while pointing to concrete design and implementation levers, partner inclusion, at-home HMD access, and safety-standardized reporting, that can accelerate translation into routine care.

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Data Availability

All data generated or analyzed during this study are included in this published article [and its supplementary information files].

Authors' Contributions

Conceptualization: SP
Data curation: SP
Formal analysis: SP, ONM
Methodology: SP, ONM
Project administration: SP
Resources: SP, ONM
Funding acquisition: OM
Supervision: OM
Writing – original draft: SP, ONM
Writing – review & editing: SP, ONM, OM

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search Strategy.
[DOCX File, 16 KB - pediatrics_v9i1e83621_app1.docx]

Checklist 1
PRISMA-ScR checklist.
[PDF File, 109 KB - pediatrics_v9i1e83621_app2.pdf]

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Abbreviations

ADDIE: Analyze, Design, Develop, Implement, and Evaluate
AR: augmented reality
CINAHL: Cumulative Index to Nursing and Allied Health Literature
EPDS: Edinburgh Postnatal Depression Scale
FOC: fear of childbirth
GAD-7: Generalized Anxiety Disorder-7
HCI: human-computer interaction
HMD: head-mounted display
IMCHB: Interaction Model of Client Health Behavior
MR: mixed reality
OSF: Open Science Framework
PHQ-9: Patient Health Questionnaire-9
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews
PSS: Perceived Stress Scale
RCT: randomized controlled trial
RQ: research question
STAI: State-Trait Anxiety Inventory
VR: virtual reality
W-DEQ: Wijma Delivery Expectancy/Experience Questionnaire
WHO: World Health Organization
WHOQOL-BREF: World Health Organization Quality of Life–BREF
WoS: Web of Science

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XR: extended reality

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Questionnaires Used to Explore the Perspectives of Parents and Health Professionals on Young Children's Use of Technology: Systematic Review

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Abstract

Background: Technology is integrated into many children's daily lives, with parents' and health professionals' perspectives shaping children's technology use. Measuring and understanding these perspectives are essential for developing strategies for supporting adults in decision-making that help children thrive in a digital world.

Objective: This systematic review aimed to investigate the psychometric properties of questionnaires used to assess parents' and health professionals' perspectives on young children's use of technology related to health, well-being, and development. The secondary aim was to synthesize findings on these perspectives.

Methods: Peer-reviewed papers published between January 2010 and September 2024 were identified through searches in 7 electronic databases. Studies were included if they examined parental or health care professionals' perspectives on technology use among children aged birth to 5 years. Two reviewers (CLR and IPHA) independently conducted the data extraction and study quality assessment. Reported psychometric properties of the questionnaires were synthesized. Deductive thematic analysis was used to explore the content focus of the questionnaire used in the included studies and synthesize the reported perspectives.

Results: In total, 85 studies were included, all involving parents. No study investigated health professionals' perspectives. The methodological quality of the studies was generally low, with 62 studies scoring below the threshold for acceptable quality. In total, 52 studies reported psychometric properties of the questionnaires used, of which, only 15 studies reported more than 1 measure of validity or reliability. A total of 75 studies reported participants' perspectives on children's technology use. Findings revealed that parents generally supported the role of digital devices in enhancing learning but expressed concerns about potential negative impacts on children's physical health, emotions, and behaviors.

Conclusions: Parents' perspectives on children's technology use were frequently assessed through questionnaires, though the validity of these questionnaires was often poor, with limited psychometric testing. Parental perspectives were mixed with educational benefits being recognized, while countered with concerns about the impact on children's physical health and development. High-quality questionnaires are needed to generate stronger evidence informing strategies to support families in technology use decision-making with and for children.

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KEYWORDS

measurement tools; questionnaire validation; early childhood; digital parenting; digital age

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Introduction

Technology is now an integrated part of many children's daily lives [1-3], encompassing both screen-based (eg, tablets, smartphones, and computers) and nonscreen-based (eg, smart toys and interactive learning tools) devices [4]. Recent survey data indicate a substantial increase in young children's technology use. For example, data from the United States suggest that children younger than 8 years of age spend ~2.5 hours per day on screen devices [3], while Australian children aged 2 - 6 years are estimated to spend ~25.9 hours per week [1]. The rise in young children's technology use has led to an increase in research, assessing its potential benefits and harms for children's health, well-being, and development [5]. Evidence suggests that technologies can enhance learning, language development, creativity, and support social connections [6-9]. However, excessive screen time has been associated with negative health effects, including sleep disturbances and obesity [10,11]. Moreover, exposure to inappropriate content has been linked to emotional and behavioral challenges such as attention issues and anxiety [7]. These mixed results highlight the complexity of technology's role in the health, well-being, and development of young children (birth to 5 years), and how factors such as content, context, and duration of use can influence technology's role [12].

Children's interaction with technology happens within a system, whereby multiple factors influence how children use technology [13,14]. One of these factors is the perspectives (ie, beliefs, attitudes, and viewpoints) of key adult figures in children's lives, including parents, educators, and health professionals. Parents are often primary mediators of children's technology use, as they play a central role in shaping technology use by setting rules, providing supervision, and coengagement. Thus, parent perspectives may influence children's use of technology and its impact on their health, well-being, and development [15,16]. Research suggests that parents hold mixed perspectives on children's technology use, mirroring broader public debates [17]. In total, 3 systematic reviews found that parents hold concerns about the negative impacts of screen time on children's physical health, social skills, exposure to inappropriate content, and development of addiction [18-20]. In contrast, the review by Choy et al [19] also found that parents perceived technology to be beneficial for learning, creativity, digital literacy, and social-emotional development. While these findings provide some insights into the complexity of parents' perspectives toward technology, the reviews by Chong et al [18] and Visier-Alfonso et al [20] only considered qualitative studies [18,20]. Moreover, Chong et al [18] did not investigate positive views on screen time, and the reviews by Visier-Alfonso et al [20] and Choy et al [19] only included studies that reported on technologies used to support physical activities or were internet-based.

Health professionals, such as medical doctors, child health nurses, and allied health professionals, are a trusted information source [16] who provide recommendations on healthy technology use, which parents often rely upon to make informed decisions about their children's digital engagement. However, their perspectives on children's technology use have not been systematically investigated and synthesized. Educators play a crucial role in enhancing learning experiences and digital literacy within the early learning and school environment and in supporting parents [15]. The perspectives of educators on children's technology use have been extensively discussed [15,21,22] and appear to reflect the broader community and parent perspectives. Specifically, educators have been found to hold positive views on the use of technology to support learning and engagement while also expressing concerns about exposure to inappropriate content and overuse. Given the substantial body of research on this topic, educators' perspectives will not be considered in this paper.

The perspectives of parents and health professionals may play an important role in shaping children's engagement with technology. For example, negative parental views on technology have been associated with more restrictive mediation strategies, whereas positive parental views have been linked to greater integration of technology into children's lives [23]. Likewise, health professionals with a positive view on technology may encourage parents to actively engage with their children's technology use, whereas those with a negative view may highlight the potential health risks associated with technology.

Perspectives can be captured through both qualitative and quantitative methods, such as interviews and questionnaires. While qualitative methods can provide a detailed understanding of perspectives, they are typically limited in sample size and generalizability. Given the low participant burden of questionnaires [24], this method enables large-scale data collection, which is essential for comparison of perspectives across different population groups. While questionnaires are useful tools, their validity is crucial for ensuring accurate and reliable high-quality evidence. However, no study has systematically investigated questionnaires that have been developed and used for assessing adults' perspectives on children's technology use and the validity of these tools. Thus, the focus of this study was on questionnaires. Having valid questionnaires available for capturing such perspectives can aid in developing evidence-based strategies for supporting adults in moving toward perspectives and practices that help children to thrive in a digital world.

Therefore, the primary aim of this systematic review was to investigate the psychometric properties of questionnaires that have been used to assess parents' and health professionals' perspectives on young children's use of technology related to health, well-being, and development. A secondary aim was to summarize the perspectives of parents and health professionals on young children's use of technology as measured by these tools.

Methods

Study Protocol

The study protocol was prospectively published on Open Scientific Framework [25]. This systematic review adhered to the PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analyses) [26] (Checklist 1).

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Ethical Considerations

This systematic review was exempted from ethics or institutional review board approval, as it did not involve human participants, and ethics approval was not required to review published or publicly reported literature.

Search Strategy

Searches were conducted in the following electronic databases: CINAHL, Embase, MEDLINE, ProQuest, PsycInfo, Scopus, SPORTDiscus, and Web of Science (Core Collection). These databases were selected to ensure coverage across multiple research disciplines relevant to the review topic, that is, health and medical sciences (MEDLINE and Embase), psychology and behavioral sciences (PsycInfo), nursing and allied health (CINAHL), as well as multidisciplinary sources (Scopus, Web of Science, and ProQuest). The search targeted papers published between January 1, 2010, and September 1, 2024, to capture contemporary technology and was conducted using a combination of search terms relating to adults' perspectives, technology use, target population (ie, parents, health professionals, and children), and method (ie, questionnaire). A full list of search strategies by databases is provided in Multimedia Appendix 1. Additionally, reference lists of included papers were searched for additional relevant studies.

Selection of Studies

All retrieved studies were exported into EndNote (version 20; Clarivate Analytics). Two reviewers (CLR and IPHA) independently screened titles and abstracts to identify potentially relevant papers using Research Screener, a software system that uses artificial intelligence to iteratively learn from screening decisions, reducing the need to review irrelevant papers [27]. Following title and abstract screening, full text screening of papers was completed independently by the same 2 reviewers. Any researcher disagreement on the eligibility of a particular study was resolved through discussion, with a third reviewer (JZ) to resolve discrepancies.

Inclusion Criteria

Studies were included if they explored parents' and health professionals' perspectives on young children's (aged birth to 5 years) technology use, including screen- and nonscreen-based devices, using questionnaires (eg, self-report survey instruments and diaries). Studies were included if they reported the use of a questionnaire relevant to the review aim, regardless of whether full details on the questionnaire and its development were reported. Only original peer-reviewed papers, published in English, were considered.

Exclusion Criteria

Review studies, expert opinions, editorial letters, and studies that focused on children with chronic health conditions (eg, cancer, diabetes, and epilepsy) were excluded.

Quality Assessment of Included Studies

The methodological quality of the included studies was assessed using the Quality Assessment Checklist for Survey Studies in Psychology (Q-SSP) [28]. The Q-SSP was selected, as it was specifically developed to evaluate the quality of survey-based studies, which aligned with the focus of this review. The Q-SSP was developed through a multistage process, which included reviewing existing quality assessment tools, establishing expert consensus on selected items, and refining the instrument based on validity assessments. The Q-SSP is a 20-item checklist that evaluates survey quality across 4 domains: introduction (4 items), participants (3 items), data (10 items), and ethics (3 items). Each item has the following response categories: yes (met criteria), no (did not meet criteria), not stated clearly, or not applicable. For each study, an overall quality score and a quality score for each domain were calculated as the percentage of "yes" out of the total applicable items. Depending on the number of applicable items, studies were required to achieve a set threshold score to be rated as "acceptable" in quality, while studies with scores less than this threshold were deemed to have "questionable" quality. Specifically, studies were classified as having "acceptable" methodological quality if they achieved an overall score ≥73% in accordance with the threshold defined in the Q-SSP [28]. The following were used as thresholds for "acceptable" quality for each domain as recommended: ≥75% for introduction, ≥67% for participants, ≥70% for data, and ≥100% for ethics. Of note, item 19 ("Were participants debriefed at the end of data collection?" ethics domain) was considered as not applicable, as debriefing could be argued as being impractical and that the data collection was harmless, given that all included studies were based on questionnaires. Study quality was independently assessed by 2 reviewers (CLR and IPHA), and any discrepancies were resolved by discussion without the requirement of a third reviewer.

Data Extraction and Synthesis of Studies Included in the Review

The following data were extracted from the included studies: study characteristics, questionnaire characteristics, questionnaire items, and perspectives from study participants. Study characteristics included author, year of publication, country where the study was completed, country setting (ie, country income classification), study aim and design, sample sizes, sample characteristics, and recruitment strategy. Sample characteristics included age, gender identity, and relationship to the child. Information on the following questionnaire details was extracted: questionnaire details (ie, title, number of items, and administration format), questionnaire development, number of items and scoring details, and questionnaire psychometric properties.

Reported psychometric properties of the questionnaires were descriptively synthesized. When available, this included evidence of validity (ie, face validity, content validity, construct validity, and criterion validity) and reliability (ie, internal consistency and test-retest reliability). Questionnaire items related to adults' perspectives on children's technology use and the reported perspectives were extracted from each study and entered into NVivo (version 14; QSR International) [29] to facilitate coding and identification of common themes related to the focus of the questionnaires and reported perspectives. All data were extracted independently by 2 reviewers (CLR and IPHA) and cross-checked for any discrepancies, which were resolved without requiring a third reviewer.

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A 2-level coding framework was developed to systematically assess (1) technology type, that is, technologies the questionnaire referred to, and (2) questionnaire content focus, that is, the focus of the items within the questionnaire regarding adults' perspectives on children's technology use. Following this framework, each questionnaire was first coded based on the technology type it referred to using the following codes (level 1): applications, computer, digital media or digital device, gaming, mobile touch screen devices, no specific hardware, screen time, and television. Next, a deductive thematic analysis [30] was used to investigate the content focus of each item and the reported perspectives, which were classified into 4 key dimensions based on the child-technology interaction model [14] to facilitate reader understanding:

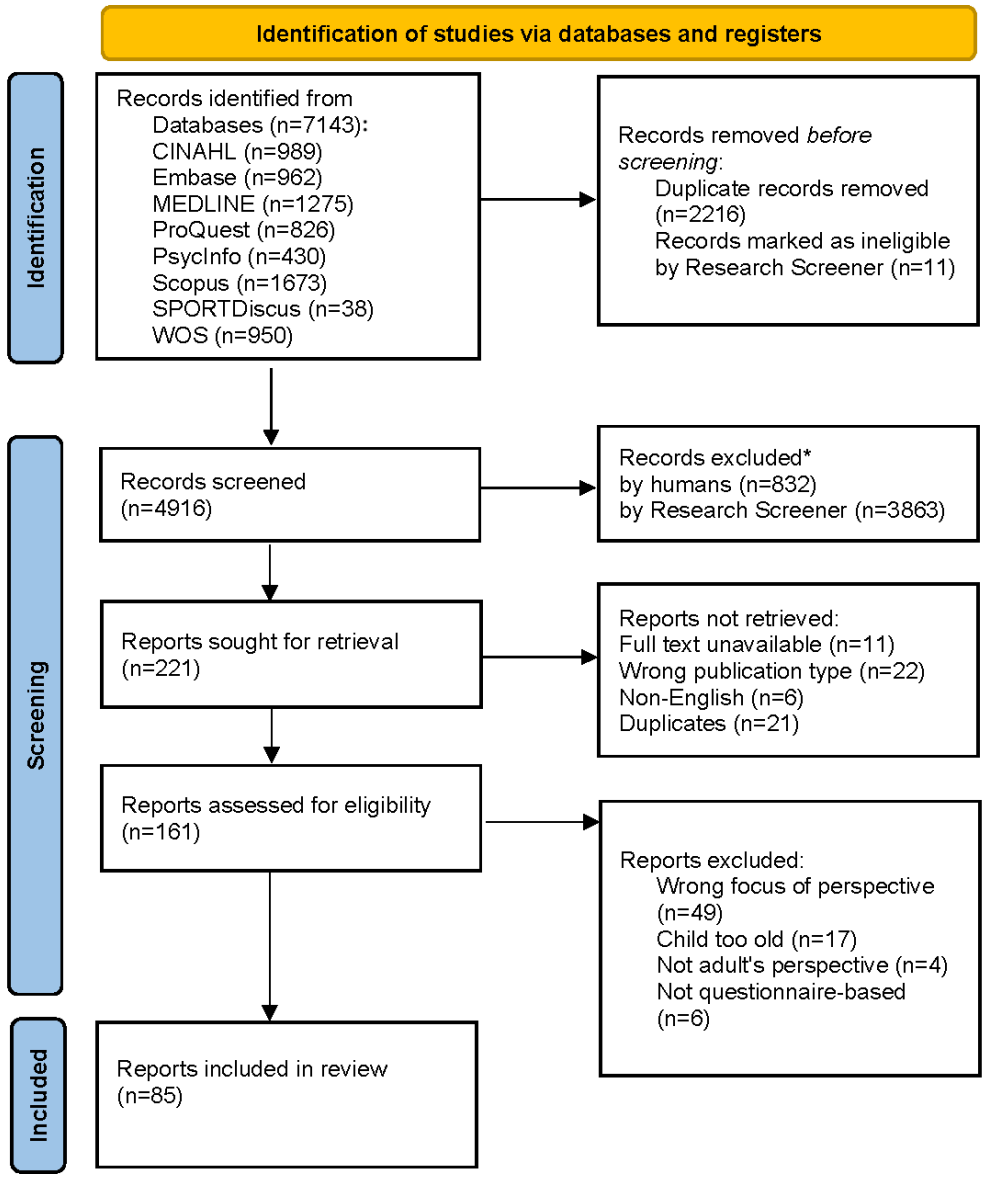
- Child: characteristics of the child, including demographic factors and individual capabilities (eg, age, physical health, and cognition);
- Other people: the role of family members or other social influences, such as peers and siblings, in children's technology use (eg, family interaction and coviewing);
- Tasks: the purpose for which the technology is used (eg, learning and entertainment); and
- Technology: the nature of the technology involved (eg, software and content).

Results

Study Inclusion

Figure 1 shows the PRISMA flowchart of search results and study exclusions. A total of 7143 records were identified based on the initial database search, of which 85 studies met the inclusion criteria for this review.

Figure 1. PRISMA flowchart of included studies. *Screening took place using "Research Screener," an artificial intelligence screening software. Four records were considered ineligible by Research Screener due to a lack of abstracts. In total, 21 rounds of screening (50 in each round) took place before the screeners determined that no further useful papers were being shown. PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses.



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Quality Assessment of Included Studies

Results of the quality assessment are presented in Table S1 in Multimedia Appendix 2 [31-115]. The average overall quality score was 61% (SD 15%; range 32% - 100%), with 62 studies scoring below the threshold for acceptable quality (ie, 73%), indicating questionable quality. Generally, studies had higher quality scores for introduction, as 84 studies scored above the threshold for acceptable quality (overall mean 98%, SD 8%; range 50% - 100%). In total, 47 and 17 studies, respectively, had acceptable quality related to information about study participants (mean 49%, SD 26%; range 0% - 100%) and data (mean 49%, SD 19%; range 10% - 100%). A total of 49 studies provided acceptable quality information related to ethics (mean 60%, SD 48%; range 0% - 100%).

Characteristics of Included Studies

The characteristics of included studies are provided in Table 1. Studies were published between 2012 and 2024, with most studies published in 2022 (11/85, 13%) and 2023 (22/85, 26%). Only 3 studies aimed to explicitly develop and validate questionnaires for measuring parents' perspectives on children's use of technology [33,39,112]. Among the remaining studies, most studies aimed to investigate adults' perspectives of children's use of technology (48/85, 56%) and/or determinants of children's technology use (19/85, 22%).

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Table . Characteristics of the included studies.

Author, year, country, country setting[a]	Aim of study	Study design and measurement type	Participants' characteristics (sample size; relationship to child; gender[b]; age)	Recruitment strategy
Akyol (2022) [31], Turkey, UMIC[c]	To investigate the effect of an online education program on parents' views on their children's technology use and online education.	Unclear if results are based on cross-sectional or longitudinal measurements. Mixed method (questionnaire and case study).	20; parents; 50% women; age NR[d].	NR.
Aladé and Donohue (2023) [32], United States, HIC[e]	To investigate the relationships between children's at-home technology use, their parents' attitudes toward technology, and their in-school tablet use.	Longitudinal. Mixed method (questionnaire and case study).	258; parents; 78% women; age NR.[d]	Parents were recruited from kindergartens that participated in a project where urban schools were given a tablet to use in the classroom.
Al-Balushi and Al-Shihi (2016) [33], Oman, HIC	To investigate parents' awareness of the risks of mobile devices on children and their happiness about their children's mobile device use.	Cross-sectional. Mixed method (explorative case study and questionnaire validity study).	10; parents; gender NR; age NR.	NR.
Alkalash et al (2023) [34], Saudi Arabia, HIC	To investigate parents' knowledge, attitudes, and practices of regulating screen exposure among their 6-year-old children in Saudi Arabia.	Cross-sectional. Questionnaire-based.	451; parents; 64% women; 35% aged between 25 and 34 years.	NR.
AlSamhori et al (2025) [35], Jordan, UMIC	To investigate parents' awareness of their 4 - to 10-year-old children's electronic device use and their perspectives on how screen time affects children's behavior in Jordan.	Cross-sectional. Questionnaire-based.	807; parents; gender NR; mothers' mean age was 35 (SD 5) years, fathers' mean age was 39 (SD 6) years.	Parents were recruited through various methods, including social media platforms and the distribution of the questionnaire in paper format at different locations in Jordan.
Amzalag (2021) [36], Israel, HIC	To investigate (1) parents' perceptions about digital learning games and 21st century skills and (2) parents' attitudes toward digital learning games instead of traditional homework.	Cross-sectional. Mixed method (questionnaire and semistructured interview).	198; parents; 71% women; age NR.	NR.
Arippin et al (2023) [37], Brunei Darussalam, HIC	To investigate parents' knowledge, attitude, practice, and experience of the screen time spent by their children younger than 5 years of age at home and to identify the common screen-based devices used, content type, and level of screen time spent by the children.	Cross-sectional. Questionnaire-based.	113; parents; 91% women; age NR.	Parents were recruited through health care facilities in 4 districts in Brunei Darussalam.

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Author, year, country, country setting[a]	Aim of study	Study design and measurement type	Participants' characteristics (sample size; relationship to child; gender[b]; age)	Recruitment strategy
Asplund et al (2015) [38], United States, HIC	To investigate (1) the rates of adherence to the American Academy of Pediatrics (AAP) screen time guidelines among Latino parents, (2) parental attitudes toward childhood electronic media use, and (3) the associations of child BMI, child and parent demographic characteristics, and household media environment with adherence to AAP screen time guidelines and with parents' attitudes toward childhood media use.	Cross-sectional. Questionnaire-based.	302; parents; gender NR; 47% younger than 30 years.	Families with an appointment at a clinic offering a nutrition program for women, infants, and children were contacted by study staff and asked to complete a survey.
Balaban Dağal and Bayındır (2019) [39], Turkey, UMIC	To develop a scale, "Effects of Digital Games in Early Ages Scale," which aimed to evaluate the effects of digital games on children during early childhood according to parental perception.	Cross-sectional. Questionnaire validation study.	777; parents; gender NR; age NR.	Families were recruited from 14 randomly selected schools with lower, middle, and upper socioeconomic status.
Bansal et al (2023) [40], India, LMIC[f]	To investigate the exposure of media and its influence among children.	Cross-sectional. Questionnaire-based.	405; parents; 63% mothers; age NR.	NR.
Barmomanesh et al (2017) [41], New Zealand, HIC	To investigate the use of touch screen devices in particular tablets or smartphones among 0 - to 5-year-old children and to ascertain parents' insights toward the use of these types of technologies by their children.	Cross-sectional. Questionnaire-based.	166; parents; 95% women; age NR.	Parents were recruited through a parenting Facebook page. An announcement containing a direct link to the survey was also sent by a manager at an education center to invite parents for participation in the survey.
Beyens and Eggermont (2014) [42], Belgium, HIC	To investigate predictors and consequences associated with the use of television as a "babysitter" for young children.	Cross-sectional. Questionnaire-based.	844; parents; 88% women; mean age 36 (SD 4.70) years.	Parents were recruited via invitation letters sent to 47 kindergartens and childcare centers.
Bleakley et al (2013) [43], United States, HIC	To investigate determinants and beliefs associated with parents' intention to limit their children's television viewing.	Cross-sectional. Based on telephone surveys.	516; parents; 67% women; mean age of 41 (SD 9.7) years.	Parents were selected using a random digit dialing from a publicly available list of households with a greater likelihood of containing a child between 3 and 16 years.
Boonmun et al (2023) [44], Thailand, UMIC	To investigate the effects of a training program on parents' planned behaviors and screen time reduction of their children.	Quasi-experimental study. Questionnaire-based.	67; parents; gender NR; mean ages were 27 years in the control group and 30 years in the intervention group.	Parents were recruited from 2 childcare centers in Thailand.
Bourha et al (2024) [45], Greece, HIC	To investigate parental perspectives on using digital technologies and the use of technology-enhanced toys among their 1 - to 4-year-old children.	Sequential explanatory study (dual phase: pre- and postinteraction with technology-enhanced toys). Questionnaire-based.	Prequestionnaire: 78; parents; 81% women; 59% were between 30 and 40 years. Postquestionnaire: 59; parents; 86% women; 66% were between 30 and 40 years.	Parents were recruited from 5 childcare centers.

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Author, year, country, country setting[a]	Aim of study	Study design and measurement type	Participants' characteristics (sample size; relationship to child; gender[b]; age)	Recruitment strategy
Brauchli et al (2024) [46], Switzerland, HIC	To investigate the roles of parenting stress and attitudes toward children's screen time throughout early childhood.	Longitudinal. Questionnaire-based.	462; parents; 93% women; mean ages were 36 - 37 (SD 4) years across 4 measurement time points.	Parents were recruited through newsletters from nonprofit organizations, posts in social media, advertisements in parenting magazines, and flyers distributed at daycare centers, pediatricians, and parental counseling centers.
Brown et al (2023) [47], United States, HIC	To investigate (1) parental knowledge and educational interests, (2) parental motivation or self-efficacy, and (3) parental beliefs about digital media use and determine how these vary based on children's age.	Cross-sectional. Questionnaire-based.	611; parents and grandparents; 77% women; mean age of 36.2 years (95% CI 35.4 - 37.1).	Parents from one of the pediatric practices associated with a statewide pediatric clinical trials and research network for their children's wellness appointment were offered to participate in the study by filling out a paper survey containing a description of the project.
Cardy et al (2023) [48] Canada, HIC	To investigate the patterns and purposes of technology use among autistic children compared to nonautistic children, explore how technology use affects children's well-being, and examine parents' attitudes toward children's technology use.	Cross-sectional. Questionnaire-based.	611; parents; gender NR; age NR.	Parents were recruited via hospital social media channels, newsletters and email distribution lists, and word-of-mouth.
Carson and Janssen (2012) [49], Canada, HIC	To investigate the influence of intrapersonal, interpersonal, and physical environment factors within the home setting on screen time among 0 - to 5-year-old children.	Cross-sectional. Questionnaire-based.	746; parents; 92% women; age NR.	Parents with children ≤5 years were recruited from licensed childcare centers and public health or community programs.
Carson et al (2013) [50], Canada, HIC	To investigate the proportion of 0 - to 4-year-old children meeting the new Canadian Sedentary Behaviour Guidelines for the Early Years and to describe parental attitudes toward and barriers to reducing screen time.	Cross-sectional. Questionnaire-based.	657; parents; gender NR; age NR.	Parents of preschool children were recruited from childcare centers and public health or community programs.
Chattha et al (2021) [51], Pakistan, LMIC	To investigate daily screen time among 2 - to 5-year-old children along with predisposing factors, quality of screen time, and parental perceptions of their children's screen time.	Cross-sectional. Mixed method (interview and questionnaire-based).	200; parents; gender NR; age NR.	Parents were recruited from general outpatient departments and pediatric outpatient departments of hospitals.
Chia et al (2022) [52], Singapore, HIC	To investigate the relationship between parent and child digital media use and to compare the characteristics of the top and bottom quartiles of children's daily digital media use.	Cross-sectional. Questionnaire-based.	1481; parents; 79% women; age NR.	Parents of children aged 2 - 5 years were recruited from preschools via invitation letters sent by the preschool operator.

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Author, year, country, country setting[a]	Aim of study	Study design and measurement type	Participants' characteristics (sample size; relationship to child; gender[b]; age)	Recruitment strategy
Chen and Tu (2018) [53], Taiwan, HIC	To investigate the impact on parents' attitudes toward internet use and their expectations of preschools to use internet-related applications.	Cross-sectional. Questionnaire-based.	483; parents; 71% women; 67% were aged 31 - 40 years.	NR.
Cingel and Krcmar (2013) [54], United States, HIC	To investigate how parent and child demographics, parental media-use motives, parental subjective norms, and parental attitudes toward preschool media use relate to actual media exposure among children.	Cross-sectional. Questionnaire-based.	168; parents; 85% women; age NR.	Parents were recruited from daycare centers, organized parent groups, and via an online snowball sample, where a link to an online version of the survey was sent to a number of parents who forwarded the link to others.
Covolo et al (2021) [55], Italy, HIC	To investigate (1) adults' opinions about mobile device use among 0 - to 5-year-old children, (2) if being parents of young children increased risk perception, and (3) the relationship between risk perception and parental attitudes to their children's mobile device use.	Cross-sectional. Questionnaire-based.	3115; parents; 86% women; mean age of 37.2 (SD 10.5) years.	Participants were recruited using a snowball sampling method by sharing a link of an online survey via social media and distributing the link through WhatsApp and Facebook groups dealing with children's health.
Dardanou et al (2020) [56], Norway, Portugal, and Japan, HIC	To investigate (1) parents' views on 0 - to 3-year-old children's use of touchscreen devices at home in Norway, Portugal, and Japan and (2) how dominant cultural discourses influence parents' perceptions and concerns regarding their 0 - to 3-year-old children's use of touchscreen devices.	Cross-sectional. Questionnaire-based.	552; parents; gender NR; age NR.	NR.
Dong et al (2022) [57], China, UMIC	To investigate (1) the average levels of young children's digital literacy and multimodal practices in central China, (2) the latent profiles of digital families in central China, and (3) the predictors of young children's digital literacy and multimodal practices in central China.	Cross-sectional. Questionnaire-based.	1953; parents and grandparents; 80% women; 39% aged between 31 and 35 years.	Online invitations were sent to all parents of children aged 0 - 8 years in a province in central China using an online survey platform. Furthermore, kindergarten principals, teachers, educators, and researchers advertised the online survey via social networks.
Eales et al (2021) [58], United States, HIC	To investigate (1) how children use screen media differently pre- versus post–COVID-19 and parent perceptions of their child's media use and (2) the parent and child factors that moderate trajectories of change in screen media use.	Longitudinal. Questionnaire-based.	129; parents; 98% women; mean age of 39.4 (SD 4.34) years.	Parents of children aged 2 - 11 years were randomly selected from a city-wide participant pool and sent an email with a survey link. Parents who indicated that they were willing to be recontacted were sent a follow-up mail with an invitation to complete another survey.

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Author, year, country, country setting[a]	Aim of study	Study design and measurement type	Participants' characteristics (sample size; relationship to child; gender[b]; age)	Recruitment strategy
Ebbeck et al (2016) [59], Singapore, HIC	To investigate (1) which technological devices are used by 0 - to 7-year-old children in Singapore, (2) the time duration spent on using different technological devices by 0 - to 7-year-old children in Singapore, and (3) parents' views of risks and benefits of their children accessing the emerging touch screen devices.	Cross-sectional. Questionnaire-based.	1058; parents; 72% women, 69% aged between 31 and 40 years.	Information letters were sent to parents or caregivers by email and hard copy to principals of 34 childcare centers.
Fan et al (2023) [60], China, UMIC	To investigate the parental perspectives of 2 - to 6-year-old children's use of short-video mobile apps.	Cross-sectional. Mixed method (questionnaire and interviews).	266; parents; 68% women; 73% were aged between 30 and 40 years.	Parents were recruited from an online survey service.
Farima et al (2023) [61], Moldova, UMIC	To investigate parents' knowledge, attitudes, and practices regarding the use of electronic devices by preschool children.	Cross-sectional. Questionnaire-based.	422; parents; 87% women; 63% were aged between 26 and 35 years.	NR.
Garcia-Conde et al (2020) [62], Spain, HIC	To investigate how parental attitudes toward sleeping, screen use, and feeding their child influence the child's body mass index.	Cross-sectional. Questionnaire-based.	908; parents; 84% women; age NR.	Parents were recruited from 21 primary schools in the main cities.
Gjelaj et al (2020) [63], Kosovo, UMIC	To investigate preschool teachers' and parents' attitudes and practices regarding digital technology use during preschool education.	Cross-sectional. Mixed method (questionnaire filled out by parents and teachers, and interviews).	100; parents; gender NR; age NR.	Parents and teachers were recruited from preschools by random sampling.
González-Sanmamed et al (2023) [64], Spain, HIC	To investigate families' perspectives on their children's use of mobile devices.	Cross-sectional. Questionnaire-based.	241; parents; 73% women; mean age was 39 (SD 7) years.	Parents were recruited from schools.
Grané et al (2023) [65], Spain, HIC	To investigate how and in what way families' perceptions and beliefs about digital technologies modulate children's use of screens at home.	Cross-sectional. Mixed method (questionnaire and interview).	46; parents; 76% women; age NR.	NR.
Griffith et al (2025) [66], United States, HIC	To investigate parents' experiences with remote schooling and technology-facilitated homework and how family characteristics, parent attitudes toward screen media, and parent digital skills relate to experiences with remote schooling and attitudes toward the use of digital technology for homework.	Cross-sectional. Questionnaire-based.	822; parents; 82% women; mean age was 36 (SD 9) years.	Parents were recruited from online panels via web-based advertising, customer loyalty web portals, and targeted email lists.

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Author, year, country, country setting[a]	Aim of study	Study design and measurement type	Participants' characteristics (sample size; relationship to child; gender[b]; age)	Recruitment strategy
Halpin et al (2021) [67], Australia, HIC	To investigate relationships between parenting style, self-efficacy, child behavior, parent distress, and screen time in young children, and to identify important variables predicting self-efficacy for managing children's screen time and actual screen use in young children.	Cross-sectional. Questionnaire-based.	106; parents; 95% women; mean age 33.76 (SD 5.35) years.	Parents were recruited via advertisements on social media, parenting forums and websites, and emails sent out to childcare centers.
Hamilton et al (2016) [68], Australia, HIC	To investigate the decision-making process and the beliefs underpinning parents' decisions to ensure that their child's screen time is limited according to the guidelines developed by the Department of Health, Australia.	Longitudinal. Mixed method (questionnaire and telephone interview).	207; parents; 67% women; mean age of 36.38 years.	Participants were recruited via online sources, face-to-face recruitment, and through their child's daycare facility.
Hatzigianni et al (2014) [69], Australia, HIC	To investigate parents' beliefs about how and why their young children use computers.	Longitudinal. Questionnaire-based.	51; parents; gender NR; age NR.	Parents were recruited from primary schools and childcare centers, where the teachers were willing to participate in a computer intervention.
Howie et al (2020) [70], Australia and United States, HIC	To investigate the reliability and validity of the "Parent report and Adult versions of Technology Use Questionnaire" and describe the technology use among young children and their parents.	Cross-sectional. Questionnaire-based.	96; parents; 89% women; mean age 36.9 (SD 5.0) years.	Parents were recruited from not-for-profit childcare organizations and childcare centers from 2 different cities.
Hutton et al (2018) [71], United States, HIC	To investigate attitudes and behaviors regarding shared reading and infant television viewing during the perinatal period among low socioeconomic status mothers.	Longitudinal. Questionnaire-based.	282; parents; 100% women; mean age 22.9 (SD 4.6) years.	All mothers were enrolled in a randomized controlled trial of safe sleep education.
Ihmeideh and Alkhawaldeh (2017) [72], Jordan, UMIC	To investigate the perceptions of preschool teachers and parents on how technology and digital media contribute toward developing child culture in Jordanian early years education.	Cross-sectional. Mixed method (questionnaire and interview).	480; teachers (n=170) and parents (n=310); gender NR; age NR.	Preschool teachers and parents of children were recruited randomly from a list of all private kindergartens.
Ilgar and Karakurt (2018) [73], Turkey, UMIC	To investigate the general attitudes of mothers of preschoolers toward the impact of computer games on children's development and behavior.	Cross-sectional. Questionnaire-based.	749; parents; 100% women; age NR.	NR.
Istenič et al (2023) [74], Slovenia, HIC	To investigate Slovene parents' opinions and perceptions of play and how they structure their child's play by offering them a set of toys.	Cross-sectional. Questionnaire-based.	306; parents; 90% women; age NR.	NR.

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Author, year, country, country setting[a]	Aim of study	Study design and measurement type	Participants' characteristics (sample size; relationship to child; gender[b]; age)	Recruitment strategy
Istenič et al (2023) [75], Slovenia, HIC	To investigate how parents (1) perceive digital technology and its role in a child's development and learning, (2) perceive characteristics of a child's play with traditional and digital toys, and (3) construct the home environment and play regarding a share of digital play versus traditional.	Cross-sectional. Questionnaire-based.	306; parents; 90% women; age NR.	NR.
Jain et al (2023) [76], India, LMIC	To determine the prevalence and predictors of excessive screen viewing time in children and its effect on physical or outdoor activity, sleep, and the prevalence of eye symptoms and headache in children in India.	Cross-sectional. Questionnaire-based.	Parents of 600 children answered a questionnaire when the children were younger than 10 years but unclear how many parents answered the questionnaire; parents; gender NR; age NR.	Households with children aged 3 - 15 years were identified during house-to-house visits in 36 urban wards and 36 villages using a 3-stage cluster sampling method.
Jin (2013) [77], Korea, HIC	To investigate (1) the relationship between 5 types of parental internet content filtering software (ICFS) adopters and the parents' adoption of ICFS, (2) how adoption type affects parents' perception of and satisfaction with ICFS, and (3) parental attitudes toward their children's internet use.	Cross-sectional. Questionnaire-based.	784; parents; 51% women; 69% aged 40 - 49 years.	Parents were randomly selected through consumer panel data on ICFS users. Active panel members were contacted by email and phone and asked to participate.
Joginder Singh et al (2021) [78], Malaysia, UMIC	To investigate (1) the amount of screen time reported by parents of 3 - to 5-year-old children, (2) how parental perception of screen time affects their children's language skills, and (3) the association between reported screen time and parental perceptions of how screen time affects their children's language skills.	Cross-sectional. Questionnaire-based.	340; parents; 85% women; 70% aged 31 - 40 years.	Parents were recruited online through WhatsApp, Telegram, and Facebook groups.
Konok et al (2020) [79], Hungary, HIC	To investigate whether parents' digital parenting style, general attitude, and beliefs regarding early mobile touch screen device use and role-modeling as indicated by their mobile attachment and use are associated with child digital activity.	Cross-sectional. Questionnaire-based.	1270; parents; 83% women; mean age 35.41 (SD 5.06) years.	Parents were recruited online through Facebook and the website of a Hungarian online magazine.
Kostyrka-Allchorne et al (2017) [80], United Kingdom, HIC	To investigate (1) media preferences and use among young children and (2) parental supervision methods and beliefs about media.	Cross-sectional. Questionnaire-based.	90; parents; 91% women; age NR.	Parents were recruited from 2 primary schools and 4 preschools.

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Author, year, country, country setting[a]	Aim of study	Study design and measurement type	Participants' characteristics (sample size; relationship to child; gender[b]; age)	Recruitment strategy
Lee et al (2022) [81], Korea, HIC	To investigate the association between young children's media use and parents' media use, attitudes toward media, and parenting style.	Cross-sectional. Questionnaire-based.	1020; parents; 50% women; age NR.	Parents were recruited from a national panel pool by a Korean survey company.
Lepicnik-Vodopivec and Samec (2013) [82] Slovenia, HIC	To investigate (1) how many types of information-communication technology (ICTs) the child's family owns, (2) the nature of the child's access at home, (3) how the child uses ICTs at home, (4) how often the child uses ICTs at home, (5) the influences on the child's use of ICTs at home, (6) the influence of the child's ICT use on their development, (7) the child's attitude toward ICTs at home, and (8) the parents' awareness about ICT use.	Cross-sectional. Questionnaire-based.	130; parents; 84% women; age NR.	NR.
Li and Chen (2015) [83], China, UMIC	To investigate how preschool children use tablets and the extent to which their parents' media behavior influences the children's tablet use.	Cross-sectional. Mixed method (questionnaire and interview).	161; parents; gender NR; age NR.	Parents were recruited from 3 kindergartens.
Liibaan et al (2023) [84], Scotland, HIC	To investigate parents' opinions of screen time, including impact on children's sleep, behavior, development, and underlying factors surrounding use and awareness of national guidelines.	Cross-sectional. Mixed method (questionnaire and interview).	9; parents; gender NR; age NR.	Parents were recruited via social media posts.
Little (2019) [85], United Kingdom, HIC	To investigate heritage language families' attitudes to using game-based digital technology for heritage language and literacy development, and how these attitudes are associated with children's self-awareness as heritage language speakers.	Cross-sectional. Mixed method (questionnaire and interview).	212; parents; gender NR; age NR.	Parents were recruited via social media posts, posted in 6 online parenting groups linked to heritage language or bilingualism.
Luo et al (2023) [86], Taiwan, HIC	To investigate parents' attitudes toward their young children's use of information communication technology, use patterns, and the relationship with socioeconomic status.	Cross-sectional. Questionnaire-based.	629; parents; 78% women; 40% were aged between 36 and 40 years.	Parents were recruited via kindergartens and elementary schools using a convenience sampling technique.

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Author, year, country, country setting[a]	Aim of study	Study design and measurement type	Participants' characteristics (sample size; relationship to child; gender[b]; age)	Recruitment strategy
Mansor et al (2021) [87], Malaysia, UMIC	To investigate parental barriers toward reducing a child's screen time and its predictors from sociodemographic, parental, child-related, and environmental factors among parents of children younger than 5 years of age who attended a child health clinic in Malaysia.	Cross-sectional. Questionnaire-based.	789; parents; 84% women, mean age 31.6 (SD 4.8) years.	Parents were recruited from 9 health clinics based on an attendance record from each clinic.
Matziou et al (2021) [88], Greece, HIC	To investigate (1) preschool children's sleeping and television viewing habits, (2) parents' perceptions about television viewing, and (3) potential correlation between the 2.	Cross-sectional. Questionnaire-based.	100; parents; gender NR; mean age of fathers 37.4 (SD 4.4) years, mean age of mothers 32.9 (SD 4.0) years.	Parents were recruited from randomly selected kindergartens.
Mikelić Preradović et al (2016) [89], Croatia, HIC	To investigate (1) perceptions of parents in Croatia toward computer use in general and their children's computer use and (2) parents' concerns and opinions about digital technology education in kindergarten.	Cross-sectional. Questionnaire-based.	152; parents; 72% women; 64.4% were aged 30 - 39 years.	Parents were recruited from a public early childhood educational institution.
Milford et al (2022) [90], Australia, HIC	To investigate how parents access information related to mobile media and their perspectives about the impact of mobile media on their child's behavior and executive functioning.	Cross-sectional. Questionnaire-based.	213; parents and other caregivers; 95% women; 45% were aged 31 - 40 years.	Parents or caregivers were recruited by posting advertisements on social media platforms including Facebook and Twitter and promoting within the community.
Nabi and Krcmar (2016) [91], United States, HIC	To investigate how perceived child characteristics influence parents' motives for allowing their children to use screen media.	Cross-sectional. Questionnaire-based.	151; parents; 82% women; age NR.	Parents were recruited from daycare centers, organized parent groups, and online snowball sampling, in which a link to the online version of the survey was sent to several parents, who then forwarded the link to others. The survey link was also posted on social networking sites.
Natsiopoulou et al (2013) [92], Greece, HIC	To investigate Greek parents' views on integrating computers into the preschool classroom and how they relate to family socioeconomic background.	Cross-sectional. Questionnaire-based.	280; parents; gender NR; age NR.	Parents were recruited from private and municipal preschool centers.
Nikken (2019) [93], Netherlands, HIC	To investigate whether parents see media devices as useful tools in child-rearing, and how parent-family characteristics and parental perceptions on parenting, media effects, and child development predict the acceptance of instructional media use.	Cross-sectional. Questionnaire-based.	516; parents; 68% women; age NR.	Parents were recruited online by a professional marketing research bureau.

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Author, year, country, country setting[a]	Aim of study	Study design and measurement type	Participants' characteristics (sample size; relationship to child; gender[b]; age)	Recruitment strategy
Nikken and Schols (2015) [94], Netherlands, HIC	To investigate if children's media skills and activities, parents' attitudes about media for children, and other child and parent characteristics predicted parental mediation practices.	Cross-sectional. Questionnaire-based.	896; parents; 47% women; mean age 37.3 (SD 6.1) years.	Parents were recruited from a large online panel.
Njoroge et al (2013) [95], United States, HIC	To investigate the associations between race or ethnicity, family socioeconomic status, and child television or DVD viewing, while assessing differences in ethnically diverse parents' beliefs and attitudes regarding the impact of television or DVD viewing on early childhood development.	Cross-sectional. Questionnaire-based.	596; parents; gender NR; age NR.	Parents were recruited from 2 metropolitan Seattle pediatric clinics and a pediatric practice network. Letters describing the study were sent to families with 3 - to 5-year-old children without regard to whether the child had been seen in their pediatric clinic recently.
Nwankwo et al (2019) [96], United Kingdom, HIC	To investigate the drivers of screen-related sedentary behavior within the home context and parents' attitudes in supporting children's associated behavior.	Cross-sectional. Mixed method (questionnaire and interview).	140; parents; 58% mothers; 49% were aged 36 - 45 years.	Parents were recruited by sending a survey link through emails or social media groups (Facebook, WhatsApp, and Twitter).
O'Connor and Fotakopoulou (2016) [97], United Kingdom, HIC	To investigate (1) what 0 - to 3-year-old children are doing with touch-screen devices in UK families, (2) what parents perceive as the advantages and drawbacks of their 0 - to 3-year-old children using new technology, and (3) the extent to which the justification of their practices appears to be aligned with dominant discourses around young children and technology.	Cross-sectional. Questionnaire-based.	226; parents and grandparents; 90% women; 67% were aged 31 - 40 years.	Parents were recruited by sending the online questionnaire to personal, parenting, and professional networks.
Ophir et al (2023) [98], Israel, HIC	To investigate the extent to which children's screen time increased during the COVID-19 lockdown and to evaluate mothers' consequent negative emotional reactions (study 1); and to investigate what could be contributing to the increases in screen time (study 2).	Cross-sectional with 2 independent cohorts. Questionnaire-based.	Study 1: 299; mothers; mean age was 41 (SD 5) years. Study 2: 283; mothers; mean age was 37 (SD 6) years.	Mothers were recruited from a survey company in Israel (study 1) and an Israeli college (study 2).
Van Petegem et al (2019) [99], Belgium, HIC	To investigate associations between parents' degree and style of restrictive mediation of children's digital gaming and parents' attitude about digital gaming, perceptions of children's defiance and problematic gaming, and their interest in social play.	Cross-sectional. Questionnaire-based.	762; parents; 83% women; mean age 35.27 (SD 5.65) years.	A large-scale survey was distributed through the mailing list of a child-oriented entertainment company. Parents with a child aged between 3 and 9 years were invited to participate.

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Author, year, country, country setting[a]	Aim of study	Study design and measurement type	Participants' characteristics (sample size; relationship to child; gender[b]; age)	Recruitment strategy
Raj et al (2022) [100], Malaysia, UMIC	To investigate the prevalence and determinants of excessive screen time among children younger than 5 years in Selangor, Malaysia.	Cross-sectional. Questionnaire-based.	489; parents; 48% women; mean age 32.2 (SD 0.2) years.	Parent-child dyads were recruited from 9 child health clinics.
Raj et al (2023) [101], Malaysia, UMIC	To develop, implement, and evaluate the effectiveness of a digital parental health education intervention to reduce excessive screen time among preschoolers from low socioeconomic families in Malaysia.	Randomized controlled trial. Questionnaire-based.	360; mothers; mean ages were 34 (SD 4.3) years in the intervention group and 33 (SD 5) years in the control group.	Mothers were recruited from preschools via electronic pamphlets containing information about the study. Interested mothers self-registered for the study using a Google Form link.
Rajalakshmi et al (2023) [102], India, LMIC	To investigate the burden of digital screen exposure and parental perceptions of its effects in children.	Cross-sectional. Questionnaire-based.	140; caregivers; 84% women; age NR.	Adults were recruited from tertiary health care centers using a random sampling technique.
Rosanda et al (2022) [103], Slovenia, HIC	To investigate (1) the use of digital technology by Slovenian infants and toddlers younger than 2 years of age, (2) what types of digital devices and apps young children use in their play, and (3) the parents' perspectives about their children's use of digital devices.	Cross-sectional. Questionnaire-based.	26; 25 parents and 1 aunt; gender NR; mean age 33.5 (SD 4.3) years.	NR.
Sada Garibay and Lapierre (2024) [104], Mexico, UMIC	To investigate what drives parents to use technical restriction tools offered by Subscription Video on Demand services.	Cross-sectional. Questionnaire-based.	1022; parents; 65%women; 44% were aged between 41 and 50 years.	Parents were recruited via Facebook, Instagram, student WhatsApp accounts, and other social media.
Peštaj et al (2024) [105], Slovenia, HIC	To investigate parental views on the characteristics of a quality children's program and its positive and negative effects on children's development and learning.	Cross-sectional. Questionnaire-based.	239; parents; 88% women; mean age was 34.9 (SD 5.24) years.	Parents were recruited via Facebook and emails by a counselor in the preschool where their children were enrolled.
Solomon-Moore et al (2017) [106], United Kingdom, HIC	To investigate whether parents' attitudes toward their young child's screen viewing behavior are associated with parents' sedentary time and screen viewing behaviors.	Cross-sectional. Questionnaire-based.	809; parents; 74% women; age NR.	Child-parent dyads were recruited from 57 primary schools in the greater Bristol area.
Stuckelman et al (2023) [107], United States, HIC	To investigate the inclusion of parent-directed suggestions or "nudges" in a touchscreen game app to promote positive shared family interactions during digital coplay.	Randomized controlled trial. Questionnaire-based.	77; parents; 92% women; control group mean age was 36.15 (SD 7.07) years, experimental group mean age was 35.45 (SD 6.74) years.	Parent-child dyads were recruited from social media posts, state birth records, and a university database of families interested in research participation.

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Author, year, country, country setting[a]	Aim of study	Study design and measurement type	Participants' characteristics (sample size; relationship to child; gender[b]; age)	Recruitment strategy
Suresh and Tiwari (2023) [108], India, LMIC	To investigate the parental knowledge, attitudes, and concerns toward media technology and screen time use by preschool children with autism spectrum disorder (ASD) and typically developing (TD) children in the Indian context.	Cross-sectional. Questionnaire-based.	182; parents (92 parents of TD children, 90 parents of children with ASD); 83% women in TD group, 86% women in ASD group; parents in both groups were aged between 20 and 49 years.	Parents in the ASD group were recruited from department clinics, regular schools, special schools, parent groups for children with ASD, and private speech therapy clinics. Parents in the TD group were recruited through regular primary schools, preschools, and day care centers.
Tanusha et al (2023) [109], Malaysia, UMIC	To investigate parents' perception of digital device use among their preschool children.	Cross-sectional. Questionnaire-based.	139; parents; gender NR; age NR.	Parents were recruited from their children's kindergartens. In total, 10 government kindergartens were randomly selected, and 15 children were selected randomly by computer from each school using the student registry.
Tay et al (2021) [110], Singapore, HIC	To investigate parents' attitudes and concerns toward their preschoolers' use of technology and digital media in Singapore.	Cross-sectional. Questionnaire-based.	3413; parents; gender NR; age NR.	Parents were recruited via letters, with a QR code to scan and complete the survey, sent out by the research team.
Vaala and Hornik (2014) [111], United States, HIC	To investigate (1) the relationships between American infants' and toddlers' television or video viewing time and their mothers' demographics, structural life circumstances, and cognitions and (2) the extent to which mothers' cognitions mediate relationships between the structural circumstances of mothers' lives and their infants' or toddlers' estimated television or video viewing.	Cross-sectional. Questionnaire-based.	698; mothers; 100% women; mean age 28.5 (SD 6.6) years.	Mothers were recruited through a national panel of around 1 million members. The panel sent recruitment emails to panel members who fit the criteria for study participation.
Vaiopoulou et al (2021) [112], Greece, HIC	To investigate (1) the psychometric characteristics of the Perceptions about Educational Apps Use-parents (PEAU-p) instrument and (2) explore parents' perceptions and attitudes toward using educational apps by implementing the PEAU-p instrument.	Cross-sectional. Questionnaire validation study.	435; parents; 96% women; mean age 36.88 (SD 5.21) years.	Parents were recruited using an electronic sampling process via social media groups.
Vittrup et al (2016) [113], United States, HIC	To investigate parental media attitudes and perceptions of their children's knowledge and engagement with various media technologies and to explore their actual knowledge and experience with these tools.	Cross-sectional. Mixed method (questionnaire and interview).	101; parents; gender NR; mean age 36 (range 25 - 53) years.	Parents were recruited from childcare centers, homeschool networks, and institutions of higher education via flyers with study information and packets of surveys.

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Author, year, country, country setting[a]	Aim of study	Study design and measurement type	Participants' characteristics (sample size; relationship to child; gender[b]; age)	Recruitment strategy
Vincent and Blot (2021) [115], France, HIC	To investigate (1) the proportion of parents who report having discussed the subject of their child's exposure to screens during a consultation with a health professional, (2) preschool children's exposure to television and mobile media devices, and (3) parents' views on the benefits and risks of exposing their children younger than 3 years of age.	Cross-sectional. Questionnaire-based.	451; parents; gender NR; median age was 34 (IQR 31 - 38) years.	Parents were recruited from 8 nurseries and a hospital's pediatric emergency room.
Wang et al (2024) [114], China, UMIC	To investigate Chinese intergenerational caregiving during the COVID-19 pandemic and different types of caregivers' beliefs, practices, and communication with children through various digital tools in the home environment.	Cross-sectional. Mixed method (questionnaire and semistructured interview).	264; parents and grandparents (185 mothers, 8 fathers, and 71 grandparents); 70% women; age NR.	Adults were recruited from preschools.

[a]Country income level was classified according to the World Bank income categories.

[b]Covers both gender and sex, depending on how this was reported in the study.

[c]UMIC: upper-middle-income country.

[d]NR: not reported.

[e]HIC: high-income country.

[f] LMIC: lower-middle-income country.

Among the 85 included studies, most were cross-sectional (74/85, 87%), 70 were based on questionnaire responses only, and 15 used a mixed methods approach of both questionnaires and interviews. The studies were conducted in a wide range of countries, but primarily in the United States (11/85, 13%), the United Kingdom (5/85, 6%), and Australia (5/85, 6%). The average number of study participants was 495 (SD 562; range 10 - 3413), of which, 82 studies only consisted of parents. In 3 studies, grandparents were also included [47,57,97]. No studies included health professionals. Accordingly, only parental perspectives are reported on in this paper. Among the 59 studies that reported participants' gender, most were women (mean 80%, SD 14%; range 47% - 100%). Participants' age was reported in 46 studies and mostly ranged between 30 and 40 years.

Characteristics and Psychometric Properties of Questionnaires Used in Included Studies

Multimedia Appendix 3 [31-146] provides the characteristics of questionnaires used among the 85 included studies. In total, 19 studies reported the title of the questionnaire, and 76 reported the item type. Among the studies describing questionnaire item type, 52 reported using questionnaires with closed-ended items, and 24 used questionnaires with a combination of closed- and open-ended items. A total of 63 studies provided information on administration format, of which most (n=42) used an online questionnaire. Information on how the questionnaire was developed was provided by 74 studies, most commonly (n=45) reported as being developed specifically for the study.

In total, 30 studies reported the total number of items in the questionnaire (mean 34; range 6 - 86), and 67 studies reported the number of items specifically related to parents' perspective of children's use of digital technologies (mean 11; range 1 - 33). Details on item scoring was reported in 61 studies, with a Likert-scale to measure level of agreement most commonly used (n=49).

Psychometric properties of questionnaires were reported by 52 studies. Among these, 14 studies conducted pilot tests to ensure face validity [33,34,47,52,55,71-73,76-78,93,100,109]. In total, 12 studies evaluated content validity by consulting experts within the field [39,44,52,53,64,65,72,73,76,86,108,110], of which, 3 studies reported content validity indexes, which ranged between 0.83 and 1.00 [44,76,108].

A total of 10 studies reported measures of construct validity based on results from a type of factor analysis [39,53,57,64,86,91,93,98,99,112]. Confirmatory factor analysis (CFA) was used in 4 studies [53,57,99,112], though the reported metrics varied. Chen and Tu [53] reported a root-mean-square error of approximation (RMSEA) of 0.06, a standardized root-mean-square residual (SRMR) of 0.05, a composite reliability of 0.88, and average variance extracted of 0.66. Dong et al [57] also performed a CFA and found that the model explained 43% of total variance, with eigenvalues ranging from 13.18 to 2.92, but no additional performance metrics were reported. Van Petegem et al [99] reported an RMSEA of 0.06 and SRMR of 0.02, while Vaiopoulou et al [112] found an

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RMSEA of 0.027 and SRMR of 0.07. Exploratory factor analysis was applied in 5 studies [39,64,86,93,112]. Balaban Dağal and Bayındır [39] used principal component analysis, reporting factor loadings of 0.54 - 0.87. González-Sanmamed et al [64] found loadings between 0.52 and 0.90, while Luo et al [86] identified a 2D structure with an internal reliability of 0.95 (specific metric not reported). Nikken [93] identified a 5D structure, with item loadings >0.45, and Vaiopoulou et al [112] used principal component analysis alongside CFA, reporting factor loadings of 0.54 - 0.89. In total, 2 studies conducted a factor analysis, but did not specify which type [91,98]. Nabi and Krcmar [91] identified a 2D structure, while Ophir et al [98] reported a 2D structure explaining 69% - 70% of variance, with factor loadings ranging from 0.69 to 0.81.

Cronbach α was predominantly reported (n=26 studies) as a measure of internal consistency reliability, ranging from 0.24 to 0.95 (mean 0.80), and one study used McDonald ω as a measure of internal consistency [46], which ranged between 0.62 and 0.69. A total of 7 studies reported a measure related to assessing reliability, but did not specify which metric this was based on [77,81,86,91,100,101,109]. One study reported a test-retest reliability based on intraclass correlation (ranging between 0.64 and 0.98) [87].

Taken together, these findings show that internal consistency reliability was the most frequently reported psychometric property (n=35), whereas fewer studies reported evidence of validity, including face validity (n=14), content validity (n=12), and construct validity [10]. Few studies (n=15) reported more than a single aspect of validity and/or reliability.

Focus of Questionnaires Used in Included Studies

A total of 67 studies reported either all or some examples of the questionnaire items used to measure parents' perspectives on children's technology use (Table S1 in Multimedia Appendix 4 [31-115]). When considering which type of digital technology each questionnaire covered (ie, results of the level 1 coding), most questionnaires focused on digital media or digital devices (n=22), where technology was broadly referred to without a particular hardware, software, or content type. In total, 12 studies focused on screen time, which either covered children's exposure to any screens or to specific device types (eg, television and smartphones) [37,40,44,49,50,67,76,78,87,98,106]. Among specific device types, 9 studies focused on children's exposure to mobile touch screen devices (eg, smartphones and tablets) [32-34,55,56,70,79,97,113], and 8 studies focused on television viewing [38,42,43,62,71,94,95,111]. A total of 7 studies did not specify a particular device (eg, referring to general internet use) [35,48,53,77,102,104,105]. Gaming and computer use were referred to in 4 [36,39,75,99] and 3 [73,89,92] studies, respectively. Finally, 2 studies focused on applications [60,112].

Table 2 provides an overview of the content focus of the questionnaire items according to the 4 overall dimensions of the child-technology interaction model. When considering the overall dimensions covered, most of the 437 reported items were related to the child dimension (n=187). Within this dimension, the most common content focus of the items was parents' perspectives on the potential impact of technology on children's physical health (n=48), including sleep issues and lack of physical activity, followed by the potential influence of technology on children's emotions and behaviors (n=47) and cognition (n=12). A total of 56 items could be considered as having a content focus under the other people dimension, of which, most items aimed to measure parental regulation of children's technology use (n=32). A total of 176 items were related to the task dimension, of which, most focused on parents' perspectives on the potential impact of technology use on how children learn (n=82) and how technology can be used for social aspects (n=40). Only 14 items could be considered as related to the technology dimension, of which, safety was the most common theme (n=16).

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Table . Classification of items according to the 4 dimensions of the child-technology interaction model, including codes used to classify each item.

Code[a]	Definition of code	Values (N=437), n (%)
"Child" dimension (n=187, 43%[a])		
Addiction	Item relates to child's addiction to technology.	12 (3)
Age of child	Item relates to the age of the child. Can either be mentioning a specific age (eg, 5 years) or range (eg, young children).	17 (4)
Attention	Item relates to technology's impact on children's attention.	10 (2)
Cognition	Item relates to technology's impact on children's cognition. Includes aesthetic (eg, order and beauty).	21 (5)
Creativity	Item relates to technology's impact on children's creativity.	12 (3)
Digital literacy	Item relates to children having the skills to use the technology.	8 (2)
Emotions and behaviors	Item relates to technology's impacts on children emotionally and/or their behavior (eg, makes child aggressive).	47 (9)
Physical health (including sleep issues)	Item relates to technology's impact on children's physical health.	48 (11)
Religion and culture	Item relates to technology's impact on children's religion and/or culture (eg, by helping children learn about religion or may influence cultural values).	3 (1)
Well-being	Item relates to technology's impact on children's overall well-being (eg, by influencing mental health or overall quality of life).	9 (2)
"Other people" dimension (n=56, 13%[a])		
Family interaction	Item relates to how children's technology use can promote or hinder family time or family interaction.	24 (5)
Parental regulation of technology	Item relates to regulations of technology use.	32 (7)
"Tasks" dimension (n=176, 40%[a])		
Displacement of activities	Item relates to time spent on digital technology instead of other activities such as normal or traditional play.	11 (3)
Entertainment and relaxation	Item relates to technology as being entertaining or a way of relaxation for children.	22 (5)
Keeping children occupied	Item relates to technology as being a way to "keep children occupied."	16 (4)
Learning	Item relates to children using digital technology for learning.	82 (19)
Preparing for adult life	Item relates to how technology can prepare children for adult life.	5 (1)
Social	Item relates to how technology can be used for or influences social aspects (eg, by influencing social skills or level and quality of social interactions).	40 (9)
"Technology" dimension (n=14, 4%[a])		
Internet and online	Item relates to children using the internet or being online.	2 (<1)

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Code[a]	Definition of code	Values (N=437), n (%)
Safety	Item relates to whether adults feel safe about their children using technology or to the age-appropriateness of content.	16 (4)

[a]Each item was only coded as belonging to one of the listed codes.

Perspectives From Included Studies' Participants

A total of 75 studies reported the study participants' perspectives on children's use of technology. Table S1 in Multimedia Appendix 5 [31-115] provides a full summary of study findings related to perspectives toward children's technology use based on questionnaire responses. Multimedia Appendix 6 shows the distribution of reported perspectives within each of the 4 dimensions of the child-technology interaction model (ie, child, other people, tasks, and technology) according to the classification codes represented in Table 2. Please note that perspectives were coded based on reported findings in Table S1 in Multimedia Appendix 5; thus, each study could contribute to multiple themes.

Across the 4 dimensions of the child-technology interaction model, parents expressed diverse perspectives on children's use of technology.

When considering the child dimension, 23 studies reported that parents were concerned about potential negative impacts of technology on their children's physical health. Commonly raised concerns were related to lack of physical activity, sleep issues, and poor eyesight. In total, 4 studies reported that parents believed that technology could have beneficial impacts on their children's physical health, such as improvement in movement skills [45,72,82,103]. A total of 13 studies reported that parents were concerned about technology leading to addiction [31,37,47,52,59,64,65,73,83,86,97,105,109]. Parents' perspectives on the impact of technology on children's emotions and behaviors were addressed in 11 studies [40,68,72-74,82,93,102,105,113,115]. While most of these studies (n=9) reported that parents had concerns about technologies leading to behavioral issues [40,68,73,74,93,102,105,113,115], some also reported that parents believe technology could have positive impacts on children's emotions and behaviors, for example, in supporting emotional regulation [72,82,93,105].

When considering the task dimension of the child-technology interaction model, a total of 41 studies reported perspectives related to the use of and/or potential influence of technology on children's learning. Among these studies, all participants reported positive perspectives, particularly in relation to the role of technology for enhancing children's academic performance. Mixed perspectives were found for the role of technology on children's social development. In total, 9 studies reported that the participants had concerns about technology negatively impacting children's social skills and development [47,56,70,73,81,93,105,108], while 4 studies reported that the participants believed technology had a positive impact, particularly in relation to social interaction [68,72,82,105]. A total of 9 studies reported that parents acknowledged technology as a positive source of entertainment and relaxation for children [32,38,47,50,56,62,92,105,110].

For the other people dimension, parents were concerned about technology interfering with family time [37,68,73,89]. Finally, for the technology dimension, a commonly held concern among the study participants was related to children's safety when using technology, particularly in relation to children being exposed to inappropriate content [47,51,52,59,60,64,70,80].

Discussion

Principal Findings

This systematic review aimed to investigate the psychometric properties of questionnaires that have been used to measure perspectives of parents and health professionals on young children's technology use and to synthesize these perspectives. Overall, the majority of the included studies were of questionable methodological quality (n=62, 73%), particularly in terms of describing the development and validation of the questionnaires used for measuring perspectives. Of the 85 included studies, 52 studies reported psychometric properties of the questionnaire used, but the psychometric evaluation was often limited and incomplete, often focusing on a single metric for validity. When assessing the questionnaires themselves, most items focused on asking participants about how technology could aid children's learning or how it could influence their physical health, emotions and behaviors, and social skills. As none of the studies recruited health professionals, we could only provide a synthesis of parental perspectives on young children's technology use. This synthesis indicated that parents generally had positive perspectives on the use of technology for academic and educational purposes, but concerns were expressed regarding the potential negative influences of technology on children's health and well-being.

High-quality methods for capturing the perspectives of parents and health professionals on children's technology use are essential for obtaining accurate, unbiased, and reliable data. The development of a valid and reliable questionnaire is an extensive process, in which several steps are taken to ensure face, content, and construct validity as well as internal reliability [147,148]. Overall, while many studies included in this review reported some acceptable validity and reliability metrics, gaps remained in the consistent use of metrics, with only 15 studies evaluating more than 1 measure of validity and/or reliability [39,52,53,57,64,72,73,76,77,86,93,99,100,108,109]. Moreover, only 3 studies specifically aimed to develop and validate a questionnaire for measuring parents' perspectives on children's technology use [33,39,112]. Among these, the study by Balaban Dağal and Bayındır [39] conducted the most detailed validity and reliability analysis, assessing content, construct, and internal validity as well as test-retest reliability. In contrast, the study

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by Al-Balushi and Al-Shihi [33] only evaluated face and content validity, and the study by Vaiopoulou et al [112] only evaluated construct and internal validity. Overall, these findings suggest that there is a need for further development of high-quality questionnaires within this research field.

When assessing the focus of questionnaire items used to measure perspectives, there was a lack of clarity and heterogeneity in the definition of technology adopted by studies. Most studies used the term "digital media" or "digital devices," which covered a range of hardware, software, and content. The lack of specificity could have influenced the responses from the study participants. For example, for the same item, some respondents may have thought of digital media as being social media, while others may have considered it to be television programs or learning apps. This could lead to inconsistent or even contradictory results and limit the accuracy and comparability of study findings. When considering the questionnaire items' focus, most items aimed to measure perspectives related to the potential impact of technology on how children learn, their physical health, emotions and behaviors, as well as social skills and interactions. It is worth noticing that the phrasing of the items themselves differed substantially both within and between studies, with some being negatively phrased (eg, "[computers] have a negative impact on children's socialisation" used in Ilgar and Karakurt [73]) and others being positively phrased (eg, "[digital media] help children communicate and interact with others" used in Ihmeideh and Alkhawaldeh [72]). This choice of item phrasing may stem from an implicit position of technological determinism, in which technology is believed to be socially causative [149]. It may be that the assumptions underlying the item development (eg, that technology use is harmful) and phrasing of the items directly influenced how participants interpreted the question and thereby how they chose to reply [150]. Specifically, negatively phrased items might have primed the respondents to focus on potential harms of technology use, whereas positively phrased items might have encouraged considerations of potential benefits. The framing of questions may also be influenced by the discipline context of the research team. As a result, the overall conclusions drawn about parental perspectives on children's technology use may be biased.

Despite the lack of construct clarity and large variability in phrasing of items, some general trends were found when synthesizing the parental perspectives reported among the included studies. In general, positive perspectives were reported in relation to how technologies can be used for enhancing children's learning, particularly in terms of academic skills and digital literacy. In contrast, concerns were often raised about technology's impact on children's physical health and emotions and behaviors. Mixed perspectives were found in relation to children's social skills. Such positive and negative perspectives on young children's use of technology have also been reported for early childhood educators [151]. Our results also concur with the findings of previous qualitative studies of parents [18-20]. The reviews by Choy et al [19], Chong et al [18], and Visier-Alfonso et al [20] reported parental concerns about technology negatively impacting their children's physical (eg, eyesight and sleep patterns), attention issues, and social development. However, Choy et al [19] also reported that parents believed that digital devices could positively contribute to children learning new skills. Taken together, the findings from previous qualitative studies and our results suggest that parents have mixed perspectives on the role of technology in their children's lives. These perceptions are likely influenced by a range of factors, including sociodemographic, cultural influences, parental age, age of their children, and parents' own experiences with technology [16]. Moreover, parental mixed perspectives may also be related to a lack of clear, evidence-based guidance on healthy technology use [17], although existing evidence does support parents' perspectives that technology use has potential risks and benefits [5].

Practical Implications

Based on our evaluation of questionnaires used for capturing the perspectives of parents on children's technology use, it is apparent that more work is required for developing high-quality questionnaires within this research field. The lack of validated questionnaires to capture the perspectives of health professionals also highlights a need. We encourage future research to prioritize the development of accurate, unbiased, and reliable questionnaires and propose that several steps are followed to support this. First, we would advise researchers to clearly define the research question, target population, their literacy level, and constructs aimed to be measured. Some of the key considerations include the type of technology, the age of children, the purpose of technology use, and the setting in which technologies are used, as these are likely to influence adults' perspectives. For example, gaming consoles could be more appropriate to ask parents of older children about who are commonly more exposed to this technology compared to younger children [3]. We would also encourage researchers to carefully consider which aspects of technology to measure, including not only the amount of time using technology (ie, quantity) but also the content and context in which it is used (ie, quality). Second, when developing the items and item response categories, we suggest using clear and concise language with balanced statements regarding potential benefits and risks associated with children's technology use to ensure that the respondents are not led toward a particular answer. Finally, we highly recommend that researchers thoroughly evaluate the validity and reliability of their questionnaire by using well-established approaches for measuring face, content, construct, and internal validity as well as assessing stability over time. Until further validated questionnaires are developed, we recommend the use of existing questionnaires with substantive validity evidence, such as the Balaban Dağal and Bayındır [39] questionnaire, if it matches the study's research question.

Our synthesis of perspectives revealed that parents have mixed views on the role of technology in their children's lives. While the potential benefits of technology, particularly for enhancing academic skills and social interactions, were acknowledged, concerns were often expressed about potential negative impacts on children's physical and mental health and overall development. These findings suggest that parents are cognizant of the complex role of technology in young children's lives, and this aligns with prior reports that parents are struggling to navigate conflicting narratives surrounding children's

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technology use [17]. These findings highlight several priorities for future research. Specifically, parents may be exposed to a broad range and, at times, controversial guidance from educators, health professionals, and media sources, making it challenging to make decisions regarding healthy technology use. We encourage future research to investigate the basis for parent perspectives, including what influences their perspectives. Moreover, prior research has reported sources parents use to gain information about health issues [16], but whether parents have the ability to independently develop a clear understanding of the evidence regarding the likely impacts of technology use on child outcomes is not known. Thus, this presents an important area for further investigation. Future research should also investigate the impact of social desirability on parental perspectives. Further, more work is required to understand whether perspectives are evidence-based or reflect parental views on ideal childhoods and other values. Addressing these research gaps would enable educators and health professionals to better support parents through the challenges of raising children in a digital world by providing a better understanding of how parents' perspectives are developed and how these relate to their decision-making regarding their children's use of technology.

Strengths and Limitations

Strengths of this systematic review included the developed search strategy applied in a wide range of databases as well as the cross-checking of study screening, quality assessment, and data extraction independently by 2 authors (CLR and IPHA). The development of a comprehensive, theory-based, 2-level coding framework for classifying the focus of the questionnaires and the items used was another strength. This framework, based on the child-technology interaction model [14], enabled a structured and systematic approach for assessing the diverse ways in which studies measured parental perspectives. Although we acknowledge that some codes could be classified under multiple dimensions of the child-technology interaction model, the application of this structured framework enhances the reproducibility of our findings and provides an early foundation for future research seeking to improve the measurement of perspectives on children's technology use.

Only reports published in English were considered for inclusion, and potentially relevant studies might have been missed due to unclear titles or abstracts and artificial intelligence–supported screening. Moreover, we aimed to report how perspectives on children's technology use may depend on the population group (eg, parents and health professionals) and the age of the child. However, these assessments were not feasible, as the only participants in the included studies were parents, and the age of the children was rarely specified.

Conclusions

This systematic review found that parents' perspectives on children's technology use have been assessed using questionnaires in several studies. However, the reported psychometric evaluation of the questionnaires was limited and incomplete, with most studies focusing on a single metric. Further, varied definitions of technologies make it difficult to establish to what extent the existing literature is examining variations in technologies relative to parents' perspectives. Study participants consisted of parents only, highlighting a clear evidence gap in understanding health professionals' perspectives on children's technology use. The reported parental perspectives were mixed. While positive views were found, considering the use of technology for enhancing children's learning and skill development, concerns were commonly raised about potential negative impacts on children's physical health and emotions and behaviors. As parents' perspectives may influence their children's use of technology and potentially associated development, there is a need for better-quality tools to measure adults' perspectives, understand how perspectives are developed, and how they influence practice. We encourage such work to focus on improving questionnaire design based on a clear theoretical understanding of technologies to prevent confusion in defining terms and item phrasing.

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Data Availability

Data sharing is not applicable to this paper as no new data were created or analyzed in this study.

Authors' Contributions

All authors have substantially contributed to the study. CLR, DH, JZ, and LS were involved with conception. All authors were involved in the design of the review. CLR and IPHA conducted the searches, study selection, and data extraction. CLR, DH, and JZ developed the coding framework. CLR drafted the manuscript and performed revisions. All authors provided substantial feedback and edited and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategy used for the following databases: PsycInfo, Web of Science (Core Collection), CINAHL, SPORTDiscus, Embase, MEDLINE, Scopus, and ProQuest.

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[DOCX File, 31 KB - pediatrics_v9i1e84712_app1.docx]

Multimedia Appendix 2
Results of the quality assessment of included studies.
[DOCX File, 47 KB - pediatrics_v9i1e84712_app2.docx]

Multimedia Appendix 3
Characteristics and psychometric properties of questionnaire used.
[DOCX File, 86 KB - pediatrics_v9i1e84712_app3.docx]

Multimedia Appendix 4
Reported questionnaire items used for measuring parents' perspectives on children's technology use.
[DOCX File, 84 KB - pediatrics_v9i1e84712_app4.docx]

Multimedia Appendix 5
Full summaries of study findings related to perspectives toward children's technology use based on questionnaire responses.
[DOCX File, 67 KB - pediatrics_v9i1e84712_app5.docx]

Multimedia Appendix 6
Distribution of reported perspectives within each of the 4 dimensions of the child-technology interaction model. See Table 2 for definition of each code within each of the 4 dimensions.
[PNG File, 43 KB - pediatrics_v9i1e84712_app6.png]

Checklist 1
PRISMA checklist.
[PDF File, 70 KB - pediatrics_v9i1e84712_app7.pdf]

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Abbreviations

CFA: confirmatory factor analysis
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
Q-SSP: Quality Assessment Checklist for Survey Studies in Psychology
RMSEA: root-mean-square error of approximation
SRMR: standardized root-mean-square residual

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Review

Effectiveness of Digital Storytelling and Immersive Technology Interventions in Reducing Preoperative Anxiety Among Children: Systematic Review and Meta-Analysis

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Abstract

Background: Preoperative anxiety affects an estimated 50% to 70% of children undergoing surgery and is associated with poorer perioperative cooperation, increased postoperative distress, and delayed recovery. Digital storytelling and immersive technologies, including virtual reality and augmented reality, have emerged as child-centered preparation tools to improve the preoperative experience.

Objective: This systematic review and meta-analysis aimed to synthesize and critically appraise the available evidence on the effects of these interventions in reducing preoperative anxiety among pediatric patients undergoing elective surgery.

Methods: A systematic search was conducted in PubMed, Scopus, Web of Science, and the Cochrane Library for studies published between January 2015 and June 2025. Randomized controlled trials and quasi-experimental studies evaluating digital storytelling (eg, narrative-based apps or videos) or immersive technologies (eg, virtual reality or augmented reality) were included. Preoperative anxiety was assessed using validated measures such as the Modified Yale Preoperative Anxiety Scale, State-Trait Anxiety Inventory, or Visual Analog Scale. Further, 2 reviewers independently screened studies and extracted data. Risk of bias was assessed using the Cochrane Risk of Bias tool version 2. A random-effects meta-analysis was performed in R using standardized mean differences.

Results: A total of 379 records were identified, and 13 studies met the inclusion criteria. Most studies reported lower preoperative anxiety in intervention groups compared with standard care or conventional preparation. Further, 9 studies provided sufficient comparable data for meta-analysis, showing a significant pooled reduction in anxiety favoring digital interventions (standardized mean difference=−0.67, 95% CI −0.93 to −0.41), with substantial heterogeneity (I^2=79.3%, P<.001). Overall risk of bias was high in most trials, primarily due to deviations from intended interventions and limitations in blinding.

Conclusions: This review suggests a trend toward reduced preoperative anxiety among pediatric patients receiving digital storytelling and immersive technology–based interventions. However, the certainty of evidence is limited by substantial heterogeneity, the small number of studies included in the meta-analysis, variability in outcome measures, and overall study quality. Therefore, the pooled estimate should be interpreted with caution. Further high-quality studies using standardized outcomes and robust methodology are needed, including evaluation of parental anxiety and longer-term postoperative effects.

Trial Registration: PROSPERO CRD420251111293; https://www.crd.york.ac.uk/PROSPERO/view/CRD420251111293

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KEYWORDS

preoperative anxiety; children; virtual reality; immersive technology; digital storytelling

Introduction

Preoperative anxiety is a common and often expected emotional response among children facing surgery, and it can arise at any point before the procedure [1]. It affects an estimated 50% to 70% of pediatric patients and represents a major concern in pediatric anesthesia and perioperative care [2]. High levels of anxiety can negatively influence cooperation with medical staff and increase perioperative distress. From a physiological perspective, heightened anxiety activates the stress response system, including increased sympathetic nervous system activity and hypothalamic-pituitary-adrenal axis activation, which may contribute to elevated heart rate, cortisol release, and heightened pain perception. These responses have been associated with greater postoperative pain and increased risk of emergence delirium [3,4].

From a psychological and behavioral perspective, anxiety may impair coping ability, increase anticipatory fear, and reduce a child's capacity to engage with medical procedures, which can lead to poorer perioperative cooperation and increased distress during anesthesia induction. In addition, negative perioperative experiences may reinforce maladaptive fear responses and contribute to postoperative behavioral changes, such as sleep disturbances, separation anxiety, or regression, which may persist beyond hospitalization [3,4]. These interconnected physiological and psychological pathways highlight the clinical importance of identifying effective and developmentally appropriate approaches to reduce anxiety before surgery.

Traditional strategies for reducing pediatric preoperative anxiety include pharmacological approaches (eg, benzodiazepine premedication) as well as nonpharmacological interventions such as preoperative education, hospital tours, behavioral preparation programs, child life specialist support, role-play, and distraction techniques [2,5]. Although these approaches can be beneficial, many require additional staffing and time, may not be consistently available across institutions, and can be challenging to implement in busy or resource-limited settings [6]. As a result, there is ongoing interest in scalable, engaging, and noninvasive preparation methods that can be delivered efficiently and tailored to children's developmental needs.

In recent years, digital storytelling and immersive technologies have emerged as promising alternatives for pediatric preoperative preparation. In this review, digital storytelling refers to narrative-based preparation delivered through mobile or tablet apps, interactive stories, animated educational content, or video-based formats that explain the surgical journey in a child-friendly manner [7]. In contrast, immersive technologies include platforms such as virtual reality (VR) and augmented reality (AR) that provide interactive and immersive simulated environments, often through head-mounted displays or AR-enabled devices. These interventions may reduce anxiety through several complementary mechanisms, including attentional distraction, increased engagement, improved procedural understanding, and enhanced coping through familiarization with the hospital environment [8].

Previous systematic reviews and meta-analyses have reported beneficial effects of VR-based interventions on anxiety and related perioperative outcomes in pediatric settings; however, these reviews often focus predominantly on VR and may not fully capture newer narrative-based digital storytelling tools or more recent immersive applications [9,10].

Despite increasing research interest, the available evidence remains heterogeneous in intervention type, delivery mode, timing of exposure, surgical populations, and anxiety measurement tools. In addition, the overall certainty of evidence is influenced by variability in study quality and reporting. Therefore, this systematic review and meta-analysis aimed to synthesize and critically appraise the available evidence on the effects of digital storytelling and immersive technology–based interventions (including VR, AR, and app-based storytelling tools) in reducing preoperative anxiety among pediatric patients undergoing elective surgery, compared with standard care or conventional preparation methods.

Methods

Study Design

This study was a systematic review and meta-analysis designed to synthesize and critically appraise the available evidence on the effects of digital storytelling and immersive technology–based interventions on preoperative anxiety in pediatric patients undergoing elective surgery. The review was structured according to the PICOS (Population, Intervention, Comparison, Outcomes, and Study) framework: the population comprised pediatric patients (≤18 years) undergoing elective surgical procedures; the interventions included digital storytelling and immersive technologies such as mobile or tablet-based apps, VR, AR, and related digital preparation tools; comparators consisted of standard care or conventional preoperative preparation methods (eg, routine verbal or written information); outcomes focused on quantitatively measured preoperative anxiety using validated instruments; and eligible study designs included randomized controlled trials (RCTs) and quasi-experimental comparative studies. The review was conducted in accordance with the *Cochrane Handbook for Systematic Reviews of Interventions* and reported following the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 guidelines [11,12]. The review protocol was prospectively registered in PROSPERO (CRD420251111293).

Search Strategy

A comprehensive electronic search was performed in 4 databases: PubMed, Scopus, Web of Science, and the Cochrane Library. Searches were developed using a combination of free-text keywords related to the population (child, pediatric, or pediatric), the outcome (preoperative anxiety, surgical anxiety, or procedure-related anxiety), and the intervention

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(digital storytelling, interactive story, animated book, VR, AR, mobile or tablet apps, and video-based education).

These concepts were combined using Boolean operators (AND/OR) and adapted to the syntax and indexing requirements of each database. The search was restricted to studies published between January 2015 and June 2025. The PROSPERO registration (CRD420251111293) reflects the initial planned search period up to January 2025; however, an updated search was conducted in June 2025 before final analysis to ensure inclusion of the most recent evidence. The search was limited to English-language publications where applicable. In addition, the reference lists of included studies and relevant reviews were manually screened to identify any additional eligible papers. The complete database-specific search strategies are provided in Multimedia Appendix 1.

Eligibility Criteria

Studies were eligible for inclusion if they met the following criteria:

- Population: pediatric participants undergoing elective surgical procedures. Although the review focus was children, studies were included if the participants were predominantly pediatric (≤18 years) or if pediatric data were extractable.
- Intervention: any digital or immersive preoperative preparation intervention delivered to the child, including (1) immersive technologies, such as VR, AR, or mixed reality (MR), and/or (2) digital storytelling interventions, such as narrative-based educational content delivered through mobile or tablet apps, interactive story formats, or video-based preparation tools. Studies in which the intervention combined digital and nondigital components (eg, verbal instruction plus a VR tool) were eligible only when the digital or immersive component was the primary active element intended to reduce anxiety.
- Comparator: standard care or conventional preparation methods, including routine verbal information, written materials, or usual preoperative practice.
- Outcomes: studies were required to report quantitative preoperative anxiety outcomes assessed using validated instruments such as the Modified Yale Preoperative Anxiety Scale (mYPAS), State-Trait Anxiety Inventory (STAI), Visual Analog Scale (VAS), or comparable validated measures.
- Study design: RCTs and quasi-experimental comparative studies.
- Publication characteristics: studies published in English with available full text.

Studies were excluded if they (1) included adult-only samples without extractable pediatric results; (2) did not report quantitative preoperative anxiety outcomes; or (3) used noncomparative publication formats, such as reviews, editorials, conference abstracts, protocols, or case reports.

Definition of Digital Storytelling and Immersive Technology Interventions

For this review, digital or immersive interventions were defined as preoperative preparation tools delivered through digital media or immersive platforms with the goal of reducing anxiety by improving engagement, familiarization, distraction, or coping before surgery.

Digital storytelling interventions were defined as narrative-based educational content delivered via digital devices (eg, smartphones, tablets, computers, or hospital screens). These interventions included story-driven or character-guided formats such as interactive stories, animated storybooks, app-based storytelling programs, or video-based educational storytelling designed to explain the surgical journey in a developmentally appropriate manner [13].

Immersive technology interventions were defined as interventions using immersive or interactive environments, including VR, AR, or MR, typically delivered through a head-mounted display or interactive AR-enabled devices. These interventions commonly provided simulated exposure to perioperative environments (eg, operating room tours) or interactive distraction content aimed at reducing anticipatory distress [7].

Some interventions combined digital components with conventional nondigital elements (eg, routine verbal explanations alongside a digital tool). In such cases, studies were considered eligible when the digital or immersive component represented the primary active element of the intervention, was delivered directly to the child preoperatively, and the study design allowed comparison with a control group receiving standard care or conventional preparation alone.

Study Selection and Screening

All search results were imported into Rayyan for initial screening and duplicate removal [14]. A total of 2 reviewers independently screened titles and abstracts for relevance. Full-text reviews were conducted for all studies that met the inclusion criteria or were deemed potentially eligible. Disagreements at any stage were resolved through discussion or by consulting a third reviewer to reach a consensus. Interrater agreement between the 2 reviewers during title and abstract screening was high (Cohen κ=0.82). Agreement at the full-text screening stage was also high (κ=0.86). Discrepancies were resolved through discussion or consultation with a third reviewer.

Quality Assessment

The risk of bias of included RCTs was assessed using the Cochrane Risk of Bias tool version 2 (RoB 2) [15]. RoB 2 evaluates potential bias across five domains: (D1) bias arising from the randomization process, (D2) bias due to deviations from intended interventions, (D3) bias due to missing outcome data, (D4) bias in measurement of the outcome, and (D5) bias in selection of the reported result. Each domain was rated as low risk of bias, some concerns, or high risk of bias, and an overall risk-of-bias judgment was assigned for each study based on the RoB 2 algorithm. Further, 2 reviewers independently conducted the assessments, and disagreements were resolved through discussion; when consensus could not be achieved, a third reviewer was consulted. This approach provided a structured and transparent evaluation of the internal validity of the included trials. Agreement between reviewers for risk-of-bias

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assessment was high (κ=0.84), with disagreements resolved through consensus.

Data Extraction and Management

A standardized data extraction form was developed and pilot-tested for consistency. Further, 4 reviewers independently extracted data on study characteristics (authors, year, and country), sample size, participant age and gender, type of surgery, intervention type and duration, control condition, anxiety measurement tools, outcome data (mean scores, SDs, and *P* values), and parental anxiety or treatment adherence if reported. Extracted data were cross-checked and managed using Microsoft Excel (Microsoft Corp). Any discrepancies were resolved through group discussion. Interrater agreement for data extraction was high (κ=0.88), indicating strong consistency between reviewers. The standardized data extraction form used in this review was developed and pilot-tested for consistency. The full extraction template, including variable definitions, is provided in Multimedia Appendix 2 to enhance transparency and reproducibility.

Statistical Analysis

All statistical analyses were conducted using R (R Foundation; version 4.3) with the *meta* and *metafor* packages. A random-effects meta-analysis model was used to account for expected clinical and methodological heterogeneity among the included studies. Studies were included in the meta-analysis only if they provided sufficient quantitative data to calculate standardized mean differences (SMDs; ie, means and SDs or equivalent statistics) at comparable preoperative time points, and used outcome measures considered sufficiently similar for pooling. Given the use of multiple validated anxiety measurement instruments across studies, effect sizes were standardized using SMDs with 95% CIs. While this approach allows pooling across different scales, it assumes that these instruments capture sufficiently comparable constructs of preoperative anxiety despite differences in measurement approach and underlying dimensions (Multimedia Appendix 3). Statistical heterogeneity was assessed using the I^2 statistic and the Cochran Q test. An I^2 value greater than 50% or a *P* value less than .10 from the Q test was considered indicative of substantial heterogeneity. Subgroup or sensitivity analyses were considered but ultimately not performed due to the small number of studies included in the meta-analysis (n=5). Conducting such analyses with a limited number of studies would result in low statistical power and a high risk of producing unstable or spurious findings. Therefore, these analyses were deemed methodologically inappropriate in this context. Publication bias assessment (eg, funnel plot or Egger test) was not performed because fewer than 10 studies were included in the pooled meta-analysis, limiting interpretability and statistical power [16]. All analyses were conducted with a significance level set at $P<.05$.

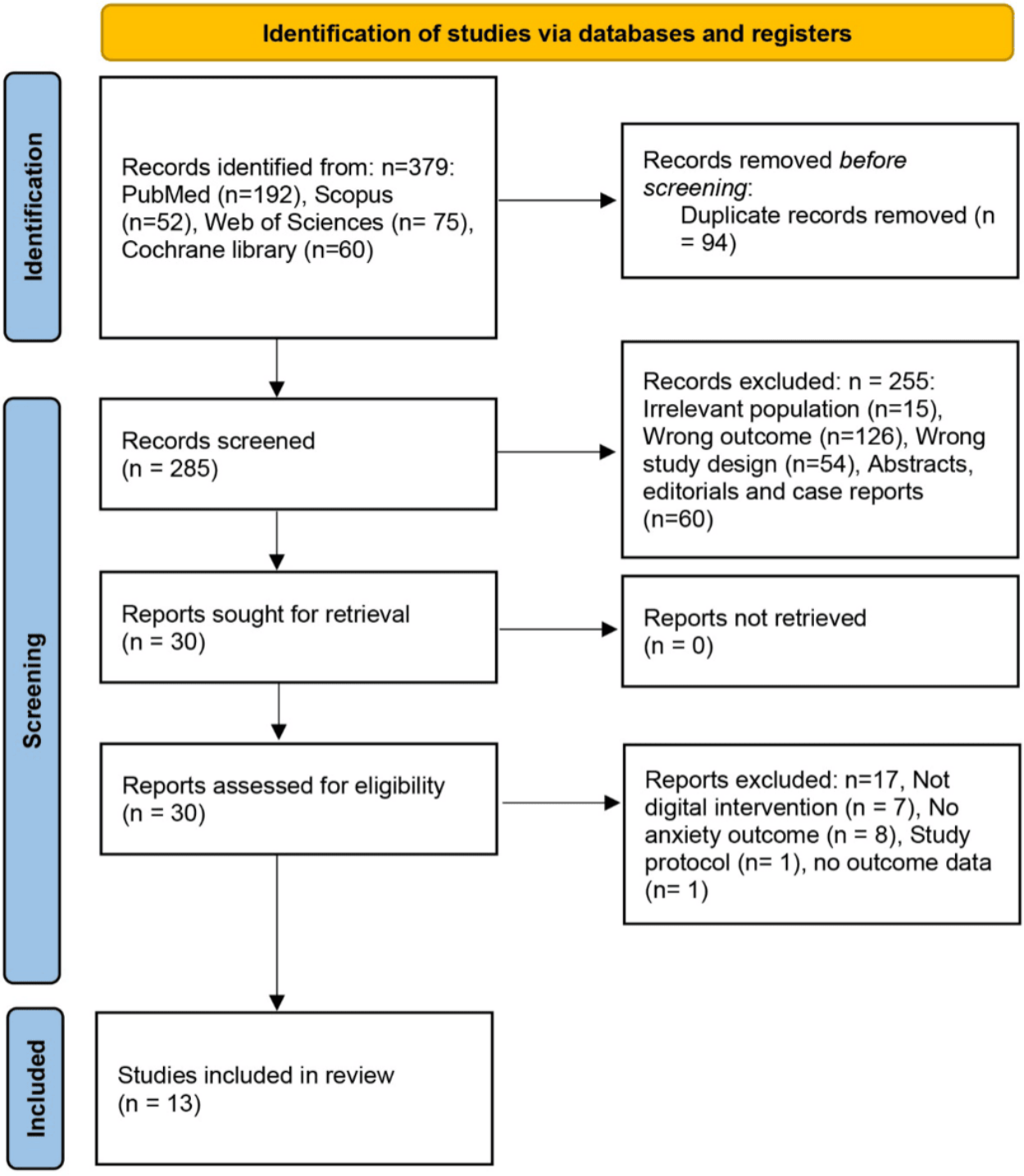
Results

Study Selection

A total of 379 records were initially identified through database searches: PubMed (n=192), Scopus (n=52), Web of Science (n=75), and the Cochrane Library (n=60; Figure 1). After removing 94 duplicates, 285 unique records were screened by title and abstract. During this stage, 255 records were excluded due to irrelevant population (n=15); wrong outcome (n=126); inappropriate study design (n=54); or publication type such as abstracts, editorials, or case reports (n=60). A total of 30 full-text papers were assessed for eligibility. Of these, 17 studies were excluded, including studies evaluating nondigital interventions (n=7), studies not reporting anxiety outcomes (n=8), and 2 additional publications that were not eligible for synthesis (a protocol and a secondary evidence synthesis). Ultimately, 13 studies met the inclusion criteria and were included in the final systematic review.

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Figure 1. PRISMA flow diagram of study selection for the systematic review and meta-analysis. PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses.



Characteristics of Included Studies

The 13 included studies were published between 2017 and 2025 and were conducted across multiple countries, including South Korea, Canada, Iran, the Netherlands, Turkey, China, Finland, and Spain (Table 1). Most studies were RCTs, with sample sizes ranging from 40 to 241 participants. The included studies primarily involved pediatric surgical populations, with some variability in reported age ranges, representing a potential source of clinical heterogeneity. The proportion of male participants varied across trials, including 1 study enrolling male-only participants (circumcision surgery). The types of surgery included general pediatric, ENT (ear, nose, and throat), ophthalmic, orthopedic, dental, abdominal, and circumcision procedures and were largely elective.

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Table 1. Characteristics of included studies and participant demographics. Gender percentages refer to male distribution within each group when available. Surgeries are elective unless otherwise specified.

Study	Country	Design	Sample size (IG[a]/CG[b])	Age range (y)	Male (IG/CG; %)[c]	Surgery type
Ryu et al, 2017 [17]	South Korea	RCT[d]	69 (34/35)	4-10 (6[e])	50/68.6	Elective inpatient
Chow et al, 2017 [18]	Canada	Pilot RCT	100 (20/20)	7-13[f]	50-55	Outpatient ENT[g] or herniorrhaphy
Park et al, 2019 [19]	South Korea	RCT	80 (40/40)	4-10[f]	68/50	Mixed elective
Ryu et al, 2019 [20]	South Korea	RCT	80 (41/39)	4-10 (6[e])	71/54	ENT, orthopedic, dental
Dehghan et al, 2019 [21]	Iran	Solomon 4-group RCT	40 (20/20)	6-12[f] (7.35)	77.5	Abdominal surgery
Eijlers et al, 2019 [22]	Netherlands	RCT	191 (94/97)	4-12 (8[e])	48/58	ENT, dental, general
Buyuk et al, 2021 [23]	Turkey	RCT	78 (40/38)	5-10[f]	100 (male)	Circumcision
Wu et al, 2022 [24]	China	RCT	99 (51/48)	4-12 (7[e])	86.3/87.5	ENT, hernia, penoplasty
Chamberlan d et al, 2024 [25]	Canada	RCT	101 (37/64)	5-17 (8-9[e])	70/55	Mixed elective pediatric surgeries
Lee et al, 2023 [26]	South Korea	RCT	102 (51/51)	4-8[f]	54.9/47.1	Ophthalmic, ENT, others
Kerimaa et al, 2023 [27]	Finland	RCT	70 (36/34)	2-6[f]	Not reported	Mixed day surgery
Carbó et al, 2024 [28]	Spain	RCT	241 (120/121)	3-12[f] (6.7/6.2)	83.3/71.1	General pediatric surgeries
Pan et al, 2025 [29]	China	RCT	104 (52/52)	4-10[f]	65	ENT surgeries

[a]IG: intervention group.

[b]CG: control group.

[c]Gender percentages refer to male distribution within each group to clarify baseline demographics.

[d]RCT: randomized controlled trial.

[e]Median.

[f]Mean.

[g]ENT: ear, nose, and throat.

Intervention Characteristics

Digital interventions varied in type and delivery mode across the included studies (Table 2). VR interventions were the most frequently evaluated modality and were typically delivered using head-mounted devices such as Samsung Gear VR, HTC Vive, Meta Quest 2, or NOLO VR systems. AR and MR approaches were less commonly studied and were delivered through AR-enabled devices, including platforms such as Microsoft HoloLens (Microsoft Corp). A smaller number of studies evaluated mobile or tablet-based apps, including digital storytelling interventions and video-based educational preparation tools.

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Table 2. Intervention characteristics and control conditions. Narrative content indicates whether the digital intervention included a story-based structure, character guidance, or procedural walkthrough. Delivery platforms range from immersive headsets to mobile or tablet apps. Duration and timing reflect when and for how long the intervention was used relative to the surgery. Interventions marked as "not reported" were either not stated or unclear in the original studies.

Study	Digital tool type	Delivery mode and platform	Narrative content	Control condition	Timing	Duration (min)
Ryu et al, 2017 [17]	VR[a] tour	Gear VR headset)Samsung)	Pororo cartoon guide	Verbal info	1 h preoperative	4
Chow et al, 2017 [18]	STM[b] tablet app	Android tablet	Story-led 3D cartoon	Usual care	Home and preoperative day	20
Park et al, 2019 [19]	VR + parental mirroring	Gear VR + Smart Mirroring (Samsung)	Pororo cartoon	VR (child-only)	1 h preoperative	4
Ryu et al, 2019 [20]	VR tour	Gear VR (Samsung)	Pororo cartoon guide	Verbal info	1 h preoperative	4
Dehghan et al, 2019 [21]	VR exposure	Headset + PC	OR simulation	Usual care	Immediate preoperative	5
Eijlers et al, 2019 [22]	VR exposure	HTC Vive (HTC corporation)	Perioperative journey	Routine care	Preoperative day	15
Buyuk et al, 2021 [23]	VR distraction	VR BOX 3.000 headset	No narrative	Standard care	Preoperative	4.5
Wu et al, 2022 [24]	VR simulation	NOLO VR	Mascot "Tantan" narrates	Nonnarrative animation + verbal	1 d preoperative	5
Chamberland et al, 2024 [25]	AR[c] + relaxation	Microsoft HoloLens 2	Story with characters	Standard care	Admission to OR[d]	≥20
Lee et al, 2023 [26]	3D VR education	Meta Quest 2	Characters explaining procedures	Tablet video	10 min preoperative	4
Kerimaa et al, 2023 [27]	Mobile app	BuddyCare (Buddy healthcare Ltd)	Story-based visuals/timeline	Routine education	Home and preoperative	Not reported
Carbó et al, 2024 [28]	VR education	Gear VR (Samsung)	Surgical journey walkthrough	Verbal/written info	7-10 d prior	≈5
Pan et al, 2025 [29]	Mobile app video	Smartphone QR code	Hospital staff explain the process	No app	1 d preoperative	11

[a]VR: virtual reality.

[b]STM: story-telling medicine.

[c]AR: augmented reality.

[d]OR: operating room.

Narrative elements, such as animated characters, guided procedural walkthroughs, and story-based visuals, were incorporated into many of the interventions, whereas a subset focused primarily on distraction without structured storytelling content. Control conditions generally consisted of standard preoperative care, including routine verbal and/or written information, usual education, or nonnarrative digital content. The timing and duration of interventions varied, ranging from immediate preoperative exposure to delivery up to 2 weeks before surgery, with most interventions lasting approximately 4 to 20 minutes.

Effectiveness of Digital Interventions

Anxiety outcomes were assessed using a range of validated instruments, including observer-rated measures (eg, mYPAS or Modified Yale Preoperative Anxiety Scale Short Form, or Yale Preoperative Anxiety Scale) and self-report tools (eg, STAI, VAS, or Children's Perioperative Multidimensional Anxiety Scale), across multiple perioperative time points. Table 3 provides a detailed summary of outcome measures, assessment timing, and between-group effects for each included study, along with reported findings on parental anxiety and intervention feasibility.

Across studies, most interventions were associated with lower levels of preoperative anxiety compared with control conditions, although the magnitude and statistical significance of these effects varied.

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Table 3. Impact of digital interventions on preoperative anxiety, parental stress, and treatment compliance. "Reduced anxiety" indicates lower anxiety scores in the intervention group compared with the control group. "No significant between-group difference" indicates statistical nonsignificance between intervention and control at reported time points. Time points (T0-T6) are reported as defined in the original studies.

Study	Anxiety measures	Assessment time points	Effect on child preoperative anxiety (between-group comparison)	Parental anxiety	Feasibility or adherence
Ryu et al, 2017 [17]	mYPAS[a]; PBRS[b]; ICC[c]	30 min post	Significant reduction in anxiety in VR[d] group (P<.001)	Not reported	Improved induction compliance (↑ ICC) and behavior (↓ PBRS)
Chow et al, 2017 [18]	CPMAS[e]	T1-T3	Significant reduction in anxiety in digital storytelling group (large effect size; Cohen d=0.96)	Not reported	90% completed the intervention
Park et al, 2019 [19]	mYPAS; NRS[f]	Baseline; induction	Significant reduction in anxiety in the mirrored VR group (P=.025)	Significant reduction in parental anxiety (NRS; P=.009)	Comparable adherence reported
Ryu et al, 2019 [20]	mYPAS	Baseline; preinduction	Significant reduction in anxiety in the VR group (P<.05)	Not reported	Not reported
Dehghan et al, 2019 [21]	YPAS[g]	Pre or post	Significant reduction in anxiety in the VR group (P<.05)	Not reported	Not reported
Eijlers et al, 2019 [22]	mYPAS; VAS[h]	T1-T5	No significant between-group difference	No significant between-group difference (STAI-S[i])	22% removed VR headset
Buyuk et al, 2021 [23]	CAM-S[j]	Pre or post	Significant reduction in anxiety in the VR group (P<.001)	Not reported	100% completed intervention
Wu et al, 2022 [24]	mYPAS-SF[k]	T1-T5	Significant reduction in anxiety in VR group at specific time points (eg, T3; P=9 × 10)	No significant between-group difference (STAI[l])	Improved induction compliance (↑ ICC; P=.003)
Chamberland et al, 2024 [25]	mYPAS-SF	Admission; induction	Significant reduction in anxiety in the AR[m] group compared with the control	Not reported	Dropouts reported (n=19 in AR group)
Lee et al, 2023 [26]	mYPAS	Baseline; preinduction	Significant reduction in anxiety in VR compared with tablet video (P=.02)	Not reported	Better induction compliance in VR (ICC; P=.007)
Kerimaa et al, 2023 [27]	VAS; STAI-S; FAS[n]	T1-T4	No significant between-group difference	No significant between-group difference	100% completed intervention
Carbó et al, 2024 [28]	mYPAS/m YPAS-SF	T0-T2	Significant reduction in anxiety in the VR education group (P<.001)	No significant between-group difference (STAI-S)	100% completed intervention
Pan et al, 2025 [29]	mYPAS-SF; VAS	T0-T4	Significant reduction in anxiety in the mobile-based intervention group (P=.012)	Significant reduction in parental anxiety (VAS; P=.013)	100% completed intervention

[a]mYPAS: Modified Yale Preoperative Anxiety Scale.

[b]PBRS: Procedure Behavior Rating Scale.

[c]ICC: Induction Compliance Checklist.

[d]VR: virtual reality.

[e]CPMAS: Children's Perioperative Multidimensional Anxiety Scale.

[f]NRS: Numeric Rating Scale.

[g]YPAS: Yale Preoperative Anxiety Scale.

[h]VAS: Visual Analog Scale.

[i]STAI-S: state subscale of State-Trait Anxiety Inventory.

[j]CAM-S: Children's Anxiety Meter Scale.

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[k]mYPAS-SF: Modified Yale Preoperative Anxiety Scale Short Form.

[l]STAI: State-Trait Anxiety Inventory.

[m]AR: augmented reality.

[n]FAS: Facial Affective Scale.

To provide a more systematic overview of findings, a structured narrative synthesis was conducted to assess the direction and consistency of intervention effects across all included studies (Table 4). Direction of effect was categorized as reduction in anxiety, no difference, or unclear, and statistical significance was determined based on between-group comparisons. As shown in Table 4, most studies (11 of 13) reported reductions in preoperative anxiety in the intervention groups compared with standard care or control conditions, with most demonstrating statistically significant between-group differences.

Table 4. Summary of direction and statistical significance of intervention effects across included studies.

Study	Intervention type	Anxiety outcome	Direction of effect	Statistical significance
Ryu et al, 2017 [17]	VR[a]	mYPAS[b]	↓ Anxiety	Significant
Chow et al, 2017 [18]	Digital storytelling	CPMAS[c]	↓ Anxiety	Significant
Park et al, 2019 [19]	VR + parental mirroring	mYPAS	↓ Anxiety	Significant
Ryu et al, 2019 [20]	VR	mYPAS	↓ Anxiety	Significant
Dehghan et al, 2019 [21]	VR	YPAS[d]	↓ Anxiety	Significant
Eijlers et al, 2019 [22]	VR	mYPAS, VAS[e]	No clear difference	Not significant
Buyuk et al, 2021 [23]	VR	CAM-S[f]	↓ Anxiety	Significant
Wu et al, 2022 [24]	VR	mYPAS-SF[g]	↓ Anxiety	Significant
Chamberland et al, 2024 [25]	AR[h]	mYPAS-SF	↓ Anxiety	Significant
Lee et al, 2023 [26]	VR vs tablet	mYPAS	↓ Anxiety	Significant
Kerimaa et al, 2023 [27]	Mobile app	VAS, STAI[i]	No clear difference	Not significant
Carbó et al, 2024 [28]	VR	mYPAS	↓ Anxiety	Significant
Pan et al, 2025 [29]	Mobile app	mYPAS-SF, VAS	↓ Anxiety	Significant

[a]VR: virtual reality.

[b]mYPAS: Modified Yale Preoperative Anxiety Scale.

[c]CPMAS: Children's Perioperative Multidimensional Anxiety Scale.

[d]YPAS: Yale Preoperative Anxiety Scale.

[e]VAS: Visual Analog Scale.

[f]CAM-S: Children's Anxiety Meter Scale.

[g]mYPAS-SF: Modified Yale Preoperative Anxiety Scale Short Form.

[h]AR: augmented reality.

[i]STAI: State-Trait Anxiety Inventory.

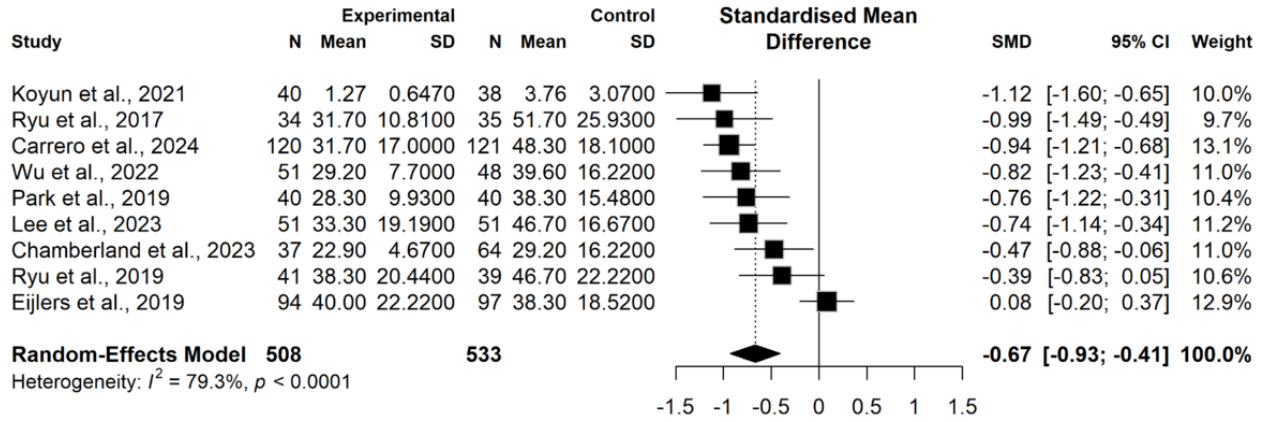
A total of 2 studies (Eijlers et al [22]; Kerimaa et al [27]) did not report statistically significant between-group differences, although both observed reductions in anxiety over time within groups. Overall, these findings indicate a generally consistent direction of effect favoring digital interventions, with variability in effect size and statistical significance likely reflecting differences in intervention type, timing of delivery, population characteristics, and outcome measurement tools. This structured synthesis complements the meta-analysis by highlighting patterns of consistency despite substantial heterogeneity.

Meta-Analysis Findings

Figure 2 [17,19,20,22-26,28] presents the results of the random-effects meta-analysis evaluating the effects of digital interventions on preoperative anxiety in pediatric patients undergoing elective surgery. Nine studies comprising 508 participants in the intervention groups and 533 participants in the control groups were included. Most studies demonstrated lower anxiety scores in children receiving digital interventions, with SMDs ranging from −1.12 to 0.08. The pooled analysis showed a statistically significant reduction in preoperative anxiety favoring digital interventions compared with standard care or conventional preparation methods (SMD=−0.67, 95% CI −0.93 to −0.41). However, substantial heterogeneity was observed across studies (I^2=79.3%, P<.001), indicating considerable variability in effect sizes. Given this heterogeneity and the diversity of intervention types, populations, and outcome measures, the pooled estimate should be interpreted with caution. Nevertheless, the overall direction of effect across studies generally favored digital interventions for reducing preoperative anxiety.

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Figure 2. Forest plot showing the effectiveness of digital storytelling and immersive technologies in reducing preoperative anxiety among children.

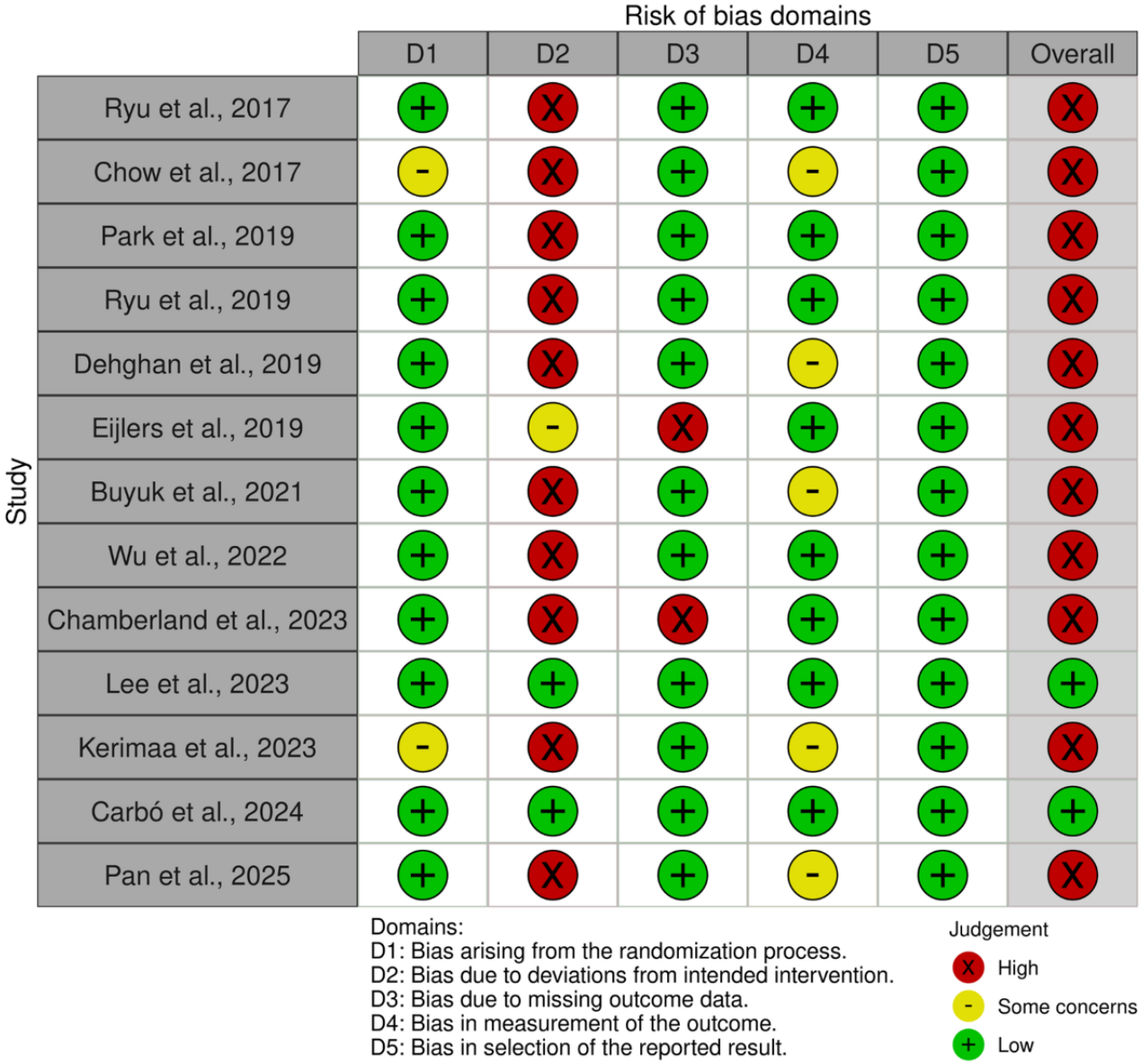


Risk of Bias Assessment

Risk of bias assessments using RoB 2 are summarized in Figure 3 [17-29]. For bias arising from the randomization process (D1), most studies were judged to be at low risk, while a minority raised some concerns due to limited reporting of allocation procedures. Bias due to deviations from intended interventions (D2) was the most frequent limitation, as blinding of participants and personnel was generally not feasible for interactive interventions (eg, VR or AR or app-based tools), potentially influencing engagement and subjective anxiety reporting.

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Figure 3. Risk of bias assessment of included studies.



Most studies were judged at low risk for missing outcome data (D3), although a small number had high risk or some concerns due to attrition or incomplete reporting. Bias in measurement of the outcome (D4) and selection of the reported result (D5) was generally low, with some concerns in studies with insufficient reporting detail. Overall, 2 studies were judged as low risk of bias (Carbó et al [28]; Lee et al [26]), 1 study had some concerns, and the remaining trials were judged as high risk of bias, largely driven by D2 (deviations from intended interventions).

Discussion

Principal Findings

This systematic review and meta-analysis synthesized the available evidence on the effectiveness of digital storytelling and immersive technology for reducing preoperative anxiety in children.

The findings suggest that digital storytelling and immersive technologies may reduce preoperative anxiety in children, although interpretation should remain cautious given heterogeneity and the overall risk of bias across included trials. These results align with a growing body of literature advocating for nonpharmacological, child-centered approaches to improve the perioperative experience.

The significant anxiety reduction observed in our analysis (SMD=–0.99) strongly supports the efficacy of digital interventions and can be understood through 2 primary psychological mechanisms: cognitive distraction and cognitive remodeling. These findings are consistent with a robust and growing body of evidence demonstrating the power of technology to positively shape the pediatric perioperative

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experience [30,31], the substantial heterogeneity observed (I^2=78.1%), and the small number of studies included in the meta-analysis limit the interpretability and clinical applicability of the pooled estimate.

This heterogeneity likely reflects multiple sources of variability across studies. First, interventions differed in modality and underlying mechanisms, including immersive technologies (eg, VR and AR) and narrative-based digital storytelling applications, which may influence anxiety through distinct pathways such as distraction, familiarization, or cognitive restructuring. Second, there was variation in the timing and duration of intervention delivery, ranging from immediate preoperative exposure to preparation delivered several days before surgery. Third, differences in clinical populations, including age ranges, types of surgical procedures, and perioperative contexts, may have influenced baseline anxiety levels and responsiveness to intervention. Finally, variability in outcome measurement, particularly the use of both observer-rated tools (eg, mYPAS) and self-report instruments (eg, STAI and VAS), may contribute to differences in effect size estimation, as these instruments capture different dimensions of anxiety.

Given these sources of heterogeneity and the limited number of studies available for quantitative synthesis, the pooled effect estimate should be interpreted as an approximate indication of overall effect direction rather than a precise or generalizable measure of intervention efficacy.

Only 5 studies provided sufficiently comparable outcome data for meta-analysis, which further limits the robustness of the pooled estimate. The remaining studies were synthesized narratively and generally demonstrated reductions in anxiety, although differences in reporting formats and assessment time points restricted quantitative integration. Accordingly, greater emphasis should be placed on the consistency and direction of findings across individual studies rather than the pooled estimate alone.

While the included studies did not directly assess underlying psychological or neurophysiological mechanisms, several theoretical frameworks may help explain the observed reductions in preoperative anxiety. One possible explanation, particularly for immersive technologies such as VR, is cognitive distraction. Grounded in the limited capacity model of attention, this principle suggests that the brain has finite resources to process simultaneous stimuli [10]. By immersing a child in a compelling, interactive, and sensorially rich virtual environment, these interventions may engage attentional resources, thereby reducing the capacity available to process anxiogenic cues from the clinical setting, such as unfamiliar equipment or procedural environments [32].

Evidence from prior research outside the included trials suggests that immersive environments may influence neural processing related to pain and emotional distress, including activity in regions such as the thalamus, insula, and anterior cingulate cortex [33]. In addition, the sense of “presence”—the subjective feeling of being immersed in a virtual environment—may further enhance attentional engagement and contribute to distraction effects [34]. Similarly, cognitive-behavioral frameworks support the role of gradual exposure and improved understanding in reducing anxiety responses. However, it is important to emphasize that these mechanisms were not directly measured in the included studies, which primarily assessed anxiety using behavioral or self-report instruments. Therefore, these explanations should be interpreted as theoretical rather than empirically established within this review. Additionally, different intervention types (eg, VR, AR, and narrative-based digital applications) are likely to operate through distinct mechanisms, and applying a single explanatory framework across all modalities may oversimplify their effects.

Our findings are consistent with existing systematic reviews and meta-analyses showing that immersive digital interventions, particularly VR, can reduce perioperative anxiety in pediatric populations. For example, Chen et al [30] conducted a systematic review and meta-analysis of randomized trials and reported that VR-based preoperative preparation reduced anxiety and improved induction compliance in children. Similarly, Eijlers et al [31] synthesized pediatric evidence across medical procedures and concluded that VR is an effective nonpharmacological intervention for reducing anxiety and pain in children. Other meta-analyses focused on surgical contexts have also reported beneficial effects of preoperative VR on anxiety, supporting the direction of effect observed in the present review [35]. In addition, more recent reviews have highlighted the growing interest in immersive perioperative tools, including VR and emerging AR platforms, although the evidence base remains heterogeneous and varies in methodological quality [8]. Taken together, our findings reinforce prior evidence supporting VR-based preparation, while extending the literature by incorporating newer formats such as digital storytelling and app-based interventions alongside immersive technologies.

Beyond distraction, several interventions, particularly those providing guided procedural walkthroughs or narrative-based preparation (eg, Wu et al [24]), may promote cognitive restructuring through procedural familiarization and skills rehearsal [24]. These tools function as a form of digital exposure therapy or guided preparation, allowing children to “rehearse” the surgical journey in a safe and engaging format [8]. By following a relatable animated character or interacting with a virtual model of the operating room, a child’s fear of the unknown is replaced with predictability and understanding [8]. This process aligns with principles of cognitive-behavioral therapy, where demystifying a stressful event helps to correct maladaptive thoughts and reduce anticipatory anxiety [36]. Furthermore, the interactive nature of these tools can instill a sense of agency and control in children, directly counteracting the feelings of powerlessness that often fuel preoperative anxiety.

This dual-action approach helps explain why these digital interventions often outperform traditional nonpharmacological methods [37]. While printed materials are static and verbal explanations can be difficult for young, distressed children to process, a digital narrative is dynamic and developmentally appropriate [8]. This is especially true for younger children, who are more receptive to narrative-based learning and “magical thinking,” making them ideal candidates for story-based interventions [38]. Ultimately, the interventions included in our

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review represent a sophisticated evolution of patient preparation, leveraging technology to create experiences that are not only distracting but also educational and empowering, leading to the substantial reductions in anxiety observed in our meta-analysis [39].

Limitations

Despite the promising findings, several limitations should be considered when interpreting this review. First, the overall certainty of evidence was limited by risk of bias, with most trials judged as high risk, particularly in the RoB 2 domain related to deviations from intended interventions, as blinding of participants and personnel was not feasible for interactive digital tools (eg, VR or AR and app-based preparation). This lack of blinding may have introduced performance bias, potentially inflating the observed intervention effects, especially for subjective anxiety outcomes [28].

Second, substantial clinical and methodological heterogeneity was present across studies, including differences in intervention type and duration, surgical settings, timing of delivery, and outcome assessment points. This heterogeneity represents a key source of uncertainty and limits the interpretability and generalizability of the pooled findings. In particular, variability in intervention modality (eg, VR, AR, and digital storytelling), differences in delivery timing (immediate vs days before surgery), and diversity in patient populations (age ranges and surgical types) may have contributed to the observed inconsistency in effect sizes.

An additional limitation relates to the heterogeneity of outcome measures. The included studies used a range of anxiety instruments, including observer-rated tools (eg, mYPAS) and self-report measures (eg, STAI or VAS), which capture different dimensions of anxiety (behavioral vs subjective). Although the use of SMDs enables statistical pooling across scales, it does not fully address conceptual differences between instruments. These differences may result in nonequivalent outcome constructs being combined, thereby contributing to statistical heterogeneity and uncertainty in the pooled estimate. Therefore, the pooled estimate should be interpreted with caution, as it may combine outcomes that are not entirely equivalent.

Third, only a subset of studies provided sufficient and comparable outcome data for meta-analysis, and most eligible studies were synthesized narratively, which may reduce the precision of pooled estimates. The small number of studies included in the meta-analysis (n=5) also limited the feasibility of conducting subgroup or sensitivity analyses, restricting further exploration of potential sources of heterogeneity. Publication bias could not be reliably assessed because fewer than 10 studies were included in the quantitative synthesis.

Finally, some trials included broader pediatric age ranges than initially planned, and relatively few studies assessed secondary outcomes such as parental anxiety, adherence, postoperative behavioral changes, or longer-term recovery, limiting conclusions regarding the wider impact of these interventions on families and perioperative outcomes. Taken together, these limitations indicate that the findings should be interpreted as indicative rather than definitive, and highlight the need for more standardized, high-quality studies to strengthen the evidence base.

Implications for Practice and Research

The results of this review suggest that immersive and storytelling-based technologies represent a feasible, engaging, and effective adjunct to conventional preoperative preparation. Their scalability and adaptability across cultural and clinical settings make them attractive options in pediatric care. To strengthen the evidence base, future trials should focus on improving methodological rigor, particularly with respect to blinding and standardized reporting.

Implementation feasibility may differ across contexts. In resource-rich perioperative units, VR or AR headsets may offer strong engagement but require equipment, staff support, and infection-control processes. In lower-resource settings or high-throughput outpatient clinics, tablet-based storytelling apps or brief mobile interventions may represent more practical and scalable alternatives. Further research should also investigate cost-effectiveness, age-specific preferences, and the differential value of narrative vs nonnarrative content. Importantly, studies should extend beyond immediate preoperative anxiety to examine outcomes such as postoperative behavior, recovery, and parental well-being, which are critical to holistic perioperative care.

Conclusions

This systematic review and meta-analysis synthesized and critically appraised the available evidence on the effects of digital storytelling and immersive technology–based interventions on preoperative anxiety in pediatric patients undergoing elective surgery. Overall, the included studies suggest a trend toward reduced preoperative anxiety in children receiving digital interventions compared with standard care. However, the certainty of this evidence is limited. The pooled meta-analytic estimate should be interpreted with considerable caution due to substantial heterogeneity, the small number of studies included in the quantitative synthesis, and the overall risk of bias across trials. In addition, variability in intervention types (eg, VR, AR, and narrative-based applications), outcome measures, and study designs limits the ability to draw definitive or generalizable conclusions. While these interventions appear to be feasible and engaging approaches to preoperative preparation, current evidence does not allow firm conclusions regarding their comparative effectiveness or optimal implementation. Future high-quality studies with standardized outcome measures, clearly defined intervention protocols, and robust methodological design are needed. Further research should also examine parental anxiety, cost-effectiveness, and longer-term postoperative outcomes to better inform clinical practice.

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Data Availability

The datasets used and analyzed during this study are available from the corresponding author on reasonable request.

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Authors' Contributions

FAA worked on the data screening and extraction, conceptualization, data analysis, manuscript writing, and project administration (Project Leader). SIA, GTA, RMM, TAA, and RMA handled data screening and extraction, and manuscript writing. MA was the senior author and mentor who reviewed and supervised.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategies.
[DOCX File , 15 KB - pediatrics_v9i1e92880_app1.docx]

Multimedia Appendix 2
Data extraction table.
[DOCX File , 17 KB - pediatrics_v9i1e92880_app2.docx]

Multimedia Appendix 3
Tables analyzing data on studies.
[DOCX File , 18 KB - pediatrics_v9i1e92880_app3.docx]

Multimedia Appendix 4
PRISMA 2020 checklist.
[PDF File (Adobe PDF File), 211 KB - pediatrics_v9i1e92880_app4.pdf]

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Abbreviations

AR: augmented reality
ENT: ear, nose, and throat
MR: mixed reality
mYPAS: Modified Yale Preoperative Anxiety Scale
PICOS: Population, Intervention, Comparison, Outcomes, and Study
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT: randomized controlled trial
RoB 2: Cochrane Risk of Bias tool version 2
SMD: standardized mean difference
STAI: State-Trait Anxiety Inventory
VAS: Visual Analog Scale
VR: virtual reality

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