JMIR Pediatrics and Parenting

Impact Factor (2023): 2.1
Volume 9 (2026)   ISSN 2561-6722   Editor in Chief: Sherif Badawy, MS, MD, MBA

Contents

Original Papers

Review Paper

Research Letters

Reviews

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

Paavani Reddy[1,2*], MD; Margaret Locke[3*], MD; Sherif Badawy[4,5*], MD, MS, MBA

[1]Department of Psychiatry, Massachusetts General Hospital, Boston, MA, United States
[2]Department of Psychiatry, McLean Hospital, Belmont, MA, United States
[3]Department of Hematology and Oncology, Donald & Barbara Zucker School of Medicine at Hofstra/Northwell, Hempstead, NY, United States
[4]Division of Hematology, Oncology, and Stem Cell Transplant, Lurie Children's Hospital, 225 E Chicago Ave Box #30, Chicago, IL, United States
[5]Department of Pediatrics, Northwestern University Feinberg School of Medicine, Chicago, IL, United States
[*]all authors contributed equally

Corresponding Author:
Sherif Badawy, MD, MS, MBA
Division of Hematology, Oncology, and Stem Cell Transplant, Lurie Children's Hospital, 225 E Chicago Ave Box #30, Chicago, IL, United States

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.

(JMIR Pediatr Parent 2026;9:e69584) doi:10.2196/69584

KEYWORDS

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

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 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).

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 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%).

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.

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 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.

Acknowledgments

The authors thank Leonardo Barrera at Ann and Robert H. Lurie Children’s Hospital of Chicago for his support in coordinating study logistics. Generative artificial intelligence was not used in any portion of the writing of this manuscript.

Funding

This project was supported by grant K23HL150232 (principal investigator: SB) from the National Heart, Lung, and Blood Institute of the National Institutes of Health. The content is solely the responsibility of the authors and does not necessarily represent the views of the National Institutes of Health.

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.

References

1. Cao A, Galanello R. Beta-thalassemia. Genet Med 2010 Feb;12(2):61-76. [doi: 10.1097/GIM.0b013e3181cd68ed] [Medline: 20098328]
2. Reddy PS, Locke M, Badawy SM. A systematic review of adherence to iron chelation therapy among children and adolescents with thalassemia. Ann Med 2022 Dec;54(1):326-342. [doi: 10.1080/07853890.2022.2028894] [Medline: 35103514]
3. Locke M, Reddy PS, Badawy SM. Adherence to iron chelation therapy among adults with thalassemia: a systematic review. Hemoglobin 2022 Jul;46(4):201-213. [doi: 10.1080/03630269.2022.2072320] [Medline: 35930250]
4. Rofail D, Abetz L, Viala M, Gait C, Baladi JF, Payne K. Satisfaction and adherence in patients with iron overload receiving iron chelation therapy as assessed by a newly developed patient instrument. Value Health 2009;12(1):109-117. [doi: 10.1111/j.1524-4733.2008.00390.x] [Medline: 18637142]
5. Porter J, Bowden DK, Economou M, et al. Health-related quality of life, treatment satisfaction, adherence and persistence in β-thalassemia and myelodysplastic syndrome patients with iron overload receiving deferasirox: results from the EPIC clinical trial. Anemia 2012;2012:297641. [doi: 10.1155/2012/297641] [Medline: 22924125]
6. Peipert JD, Badawy SM, Baik SH, et al. Development of the NIH patient-reported outcomes measurement information system (PROMIS) medication adherence scale (PMAS). Patient Prefer Adherence 2020;14:971-983. [doi: 10.2147/PPA.S249079] [Medline: 32606615]
7. Borrelli B, Ritterband LM. Special issue on eHealth and mHealth: challenges and future directions for assessment, treatment, and dissemination. Health Psychol 2015 Dec;34S:1205-1208. [doi: 10.1037/hea0000323] [Medline: 26651461]
8. Radovic A, Badawy SM. Technology use for adolescent health and wellness. Pediatrics 2020 May;145(Suppl 2):S186-S194. [doi: 10.1542/peds.2019-2056G] [Medline: 32358210]
9. Mobile fact sheet. Pew Research Center. 2021. URL: https://www.pewresearch.org/internet/fact-sheet/mobile/ [accessed 2025-05-25]

10. Teens, social media & technology. Pew Research Center. 2022. URL: https://tinyurl.com/2f99f5m7 [accessed 2025-05-25]
11. Sanders CK, Scanlon E. The digital divide is a human rights issue: advancing social inclusion through social work advocacy. J Hum Rights Soc Work 2021;6(2):130-143. [doi: 10.1007/s41134-020-00147-9] [Medline: 33758780]
12. Naslund JA, Grande SW, Aschbrenner KA, Elwyn G. Naturally occurring peer support through social media: the experiences of individuals with severe mental illness using YouTube. PLoS ONE 2014;9(10):e110171. [doi: 10.1371/journal.pone.0110171] [Medline: 25333470]
13. Bal MI, Sattoe JN, Roelofs P, Bal R, van Staa A, Miedema HS. Exploring effectiveness and effective components of self-management interventions for young people with chronic physical conditions: a systematic review. Patient Educ Couns 2016 Aug;99(8):1293-1309. [doi: 10.1016/j.pec.2016.02.012] [Medline: 26954345]
14. Badawy SM, Kuhns LM. Texting and mobile phone app interventions for improving adherence to preventive behavior in adolescents: a systematic review. JMIR Mhealth Uhealth 2017 Apr 19;5(4):e50. [doi: 10.2196/mhealth.6837] [Medline: 28428157]
15. Badawy SM, Barrera L, Sinno MG, Kaviany S, O’Dwyer LC, Kuhns LM. Text messaging and mobile phone apps as interventions to improve adherence in adolescents with chronic health conditions: a systematic review. JMIR Mhealth Uhealth 2017 May 15;5(5):e66. [doi: 10.2196/mhealth.7798] [Medline: 28506955]
16. Badawy SM, Thompson AA, Liem RI. Technology access and smartphone app preferences for medication adherence in adolescents and young adults with sickle cell disease. Pediatr Blood Cancer 2016 May;63(5):848-852. [doi: 10.1002/pbc.25905] [Medline: 26844685]
17. Leonard S, Anderson LM, Jonassaint J, Jonassaint C, Shah N. Utilizing a novel mobile health “selfie” application to improve compliance to iron chelation in pediatric patients receiving chronic transfusions. J Pediatr Hematol Oncol 2017 Apr;39(3):223-229. [doi: 10.1097/MPH.0000000000000743] [Medline: 28099398]
18. Wartella E, Rideout V, Montague H, Beaudoin-Ryan L, Lauricella A. Teens, health and technology: a national survey. MaC 2016 Jun 16;4(3):13-23. [doi: 10.17645/mac.v4i3.515]
19. Perski O, Blandford A, West R, Michie S. Conceptualising engagement with digital behaviour change interventions: a systematic review using principles from critical interpretive synthesis. Transl Behav Med 2017 Jun;7(2):254-267. [doi: 10.1007/s13142-016-0453-1] [Medline: 27966189]
20. Blandford A, Gibbs J, Newhouse N, Perski O, Singh A, Murray E. Seven lessons for interdisciplinary research on interactive digital health interventions. Digit Health 2018;4:2055207618770325. [doi: 10.1177/2055207618770325] [Medline: 29942629]
21. Schnall R, Rojas M, Bakken S, et al. A user-centered model for designing consumer mobile health (mHealth) applications (apps). J Biomed Inform 2016 Apr;60:243-251. [doi: 10.1016/j.jbi.2016.02.002] [Medline: 26903153]
22. Badawy SM, Cronin RM, Hankins J, et al. Patient-centered eHealth interventions for children, adolescents, and adults with sickle cell disease: systematic review. J Med Internet Res 2018 Jul 19;20(7):e10940. [doi: 10.2196/10940] [Medline: 30026178]
23. Heneghan MB, Hussain T, Barrera L, et al. Access to technology and preferences for an mHealth intervention to promote medication adherence in pediatric acute lymphoblastic leukemia: approach leveraging behavior change techniques. J Med Internet Res 2021 Feb 18;23(2):e24893. [doi: 10.2196/24893] [Medline: 33599621]
24. Tarricone R, Cucciniello M, Armeni P, et al. Mobile health divide between clinicians and patients in cancer care: results from a cross-sectional international survey. JMIR Mhealth Uhealth 2019 Sep 6;7(9):e13584. [doi: 10.2196/13584] [Medline: 31493318]
25. Webb TL, Joseph J, Yardley L, Michie S. Using the internet to promote health behavior change: a systematic review and meta-analysis of the impact of theoretical basis, use of behavior change techniques, and mode of delivery on efficacy. J Med Internet Res 2010 Feb 17;12(1):e4. [doi: 10.2196/jmir.1376] [Medline: 20164043]
26. Badawy SM, Thompson AA, Kuhns LM. Medication adherence and technology-based interventions for adolescents with chronic health conditions: a few key considerations. JMIR Mhealth Uhealth 2017 Dec 22;5(12):e202. [doi: 10.2196/mhealth.8310] [Medline: 29273573]
27. Hanghøj S, Boisen KA. Self-reported barriers to medication adherence among chronically ill adolescents: a systematic review. J Adolesc Health 2014 Feb;54(2):121-138. [doi: 10.1016/j.jadohealth.2013.08.009] [Medline: 24182940]
28. Hilliard ME, Hahn A, Ridge AK, Eakin MN, Riekert KA. User preferences and design recommendations for an mHealth app to promote cystic fibrosis self-management. JMIR Mhealth Uhealth 2014 Oct 24;2(4):e44. [doi: 10.2196/mhealth.3599] [Medline: 25344616]
29. Cafazzo JA, Casselman M, Hamming N, Katzman DK, Palmert MR. Design of an mHealth app for the self-management of adolescent type 1 diabetes: a pilot study. J Med Internet Res 2012 May 8;14(3):e70. [doi: 10.2196/jmir.2058] [Medline: 22564332]
30. Frøisland DH, Arsand E, Skårderud F. Improving diabetes care for young people with type 1 diabetes through visual learning on mobile phones: mixed-methods study. J Med Internet Res 2012 Aug 6;14(4):e111. [doi: 10.2196/jmir.2155] [Medline: 22868871]

Abbreviations

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

Edited by A Mavragani; submitted 03.Dec.2024; peer-reviewed by N Levitz, P Romadhon; revised version received 26.Oct.2025; accepted 27.Oct.2025; published 24.Mar.2026.

Please cite as:
Reddy P, Locke M, Badawy S
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
JMIR Pediatr Parent 2026;9:e69584
URL: https://pediatrics.jmir.org/2026/1/e69584
doi:10.2196/69584

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

Ana Cristina Lindsay[1], MPH, DDS, DrPH; Denise Lima Nogueira[2], RN, MPH, PhD; Steven A Cohen[3], BA, MPH, DrPH; Mary L Greaney[3], AB, MPH, PhD

[1]Department of Urban Public Health, Robert and Donna Manning College of Nursing and Health Sciences, University of Massachusetts Boston, 240 Morrissey Blvd, Boston, MA, United States

[2]School of Nursing, Faculty Luciano Feijão, Sobral, Brazil

[3]University of Rhode Island, Kingstown, RI, United States

Corresponding Author:
Ana Cristina Lindsay, MPH, DDS, DrPH
Department of Urban Public Health, Robert and Donna Manning College of Nursing and Health Sciences, University of Massachusetts Boston, 240 Morrissey Blvd, Boston, MA, United States

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.

(JMIR Pediatr Parent 2026;9:e78835) doi:10.2196/78835

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

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 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 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%).

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)

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.

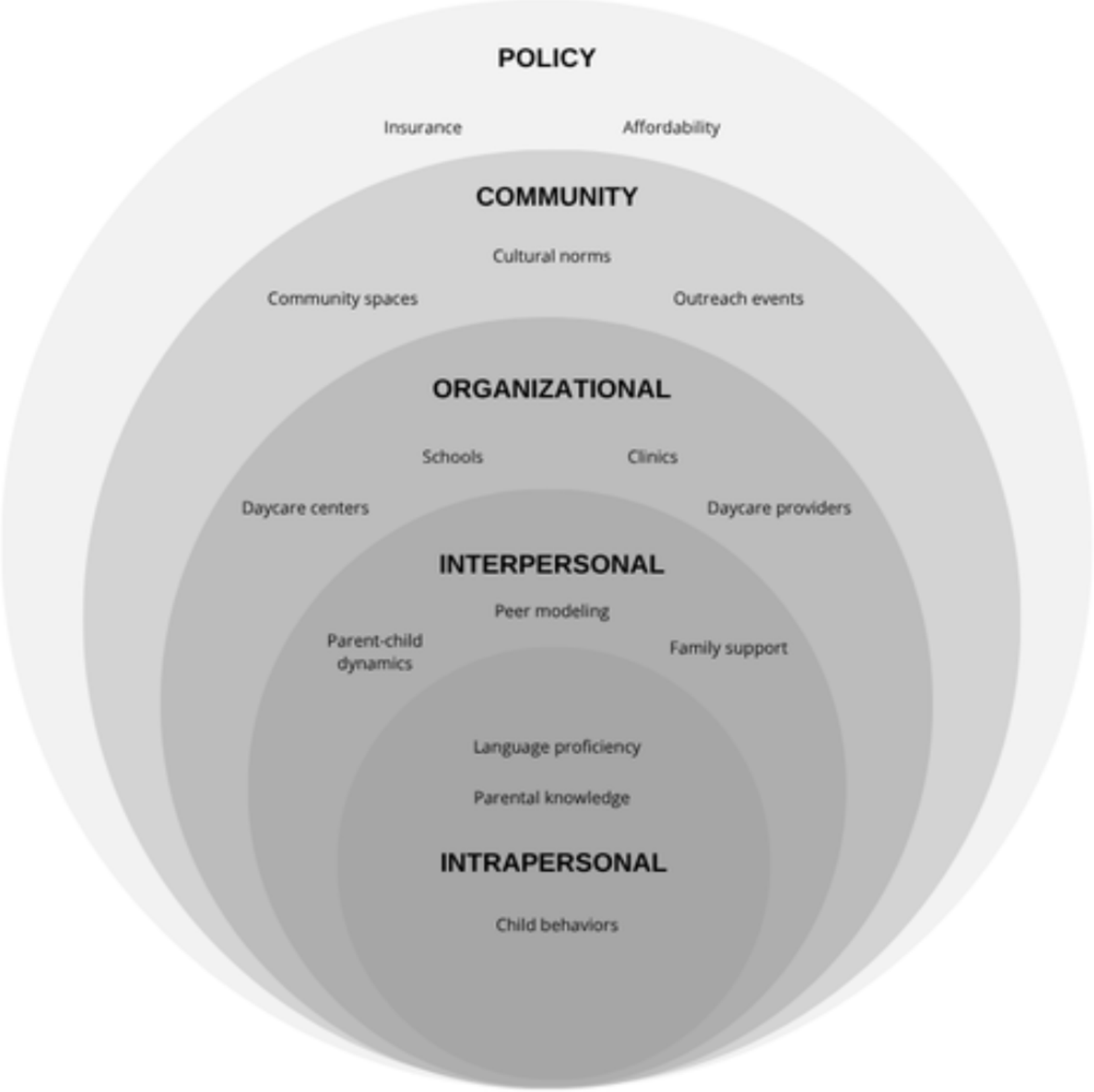
Educational attainment varied among participants, with 79.2% (n=38) having completed high school or more. About half reported an annual household income between US $45,000 and US $65,000 (n=25, 52.1%). Most parents (n=34, 70.8%) had one child aged 2 to 5 years, while 29.2% (n=14) had 2 children in that 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.

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 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 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).

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.

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.

Acknowledgments

We sincerely thank the mothers and fathers who participated in this study for their valuable insights. We also appreciate the support from community members and organizations serving Brazilian immigrants in Massachusetts, which was essential to the success of this research.

Funding

This research was supported by the National Institute of Dental and Craniofacial Research under grant number 1R21DE032853-01 (ACL as the principal investigator). The views expressed in this paper are those of the authors and do not necessarily reflect those of the National Institute of Dental and Craniofacial Research.

Authors' Contributions

Conceptualization: ACL, DLN, MLG
Data curation: ACL, DLN
Formal analysis: DLN, ACL, SAC
Funding acquisition: ACL
Investigation: ACL, DLN
Methodology: ACL, MLG, DLN
Project administration: ACL
Resources: ACL, MLG
Validation: ACL, DLN, MLG
Writing – original draft preparation: ACL, DLN, MLG
Writing – review and editing: ACL, DLN, MLG, SAC
All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

None declared.

References

1. Peres MA, Macpherson LMD, Weyant RJ, et al. Oral diseases: a global public health challenge. Lancet 2019 Jul 20;394(10194):249-260. [doi: 10.1016/S0140-6736(19)31146-8] [Medline: 31327369]
2. Hooley M, Skouteris H, Boganin C, Satur J, Kilpatrick N. Parental influence and the development of dental caries in children aged 0-6 years: a systematic review of the literature. J Dent 2012 Nov;40(11):873-885. [doi: 10.1016/j.jdent.2012.07.013] [Medline: 22842202]
3. Pitts NB, Mayne C. Making cavities history: a global policy consensus for achieving a dental cavity–free future. JDR Clin Trans Res 2021 Jul;6(3):264-267. [doi: 10.1177/23800844211020298] [Medline: 34027737]
4. Oral health surveillance report: dental caries, tooth retention, and edentulism, United States, 2017–March 2020. : Centers for Disease Control and Prevention; 2024 URL: https://www.cdc.gov/oral-health/media/pdfs/2024/10/CS351478-D_OralHealthSurvReprt-28Pgs-91824_Print_FINAL.pdf [accessed 2026-03-03]
5. de Castro e Lima Á, Dutra M. Brazilians in the greater Boston region: building community for more than a half century. The Boston Foundation. 2024 URL: https://www.tbf.org/-/media/tbf/reports-and-covers/2024/brazilians-in-the-greater-boston-region-english.pdf [accessed 2026-03-03]
6. Nogueira DL, Miranda Fontenele MG, Bento A, Cohen SA, Greaney ML, Lindsay AC. Exploring Brazilian immigrant mothers' beliefs and practices regarding their preschool children's oral health: a qualitative study conducted in the United States. Int J Environ Res Public Health 2024 Nov 27;21(12):1574. [doi: 10.3390/ijerph21121574] [Medline: 39767416]
7. Blizzard B, Batalova J. Brazilian immigrants in the United States. Migration Policy Institute. 2019. URL: https://www.migrationpolicy.org/article/brazilian-immigrants-united-states-2017 [accessed 2025-05-21]
8. Tiwari T, Wilson AR, Mulvahill M, Rai N, Albino J. Maternal factors associated with early childhood caries in urban Latino children. JDR Clin Trans Res 2018 Jan;3(1):83-90. [doi: 10.1177/2380084417718175]
9. Finlayson TL, Beltran NY, Becerra K. Psychosocial factors and oral health practices of preschool-aged children: a qualitative study with Hispanic mothers. Ethn Health 2019 Jan;24(1):94-112. [doi: 10.1080/13557858.2017.1315366] [Medline: 28398070]
10. Cortés DE, Réategui-Sharpe L, Spiro Iii A, García RI. Factors affecting children’s oral health: perceptions among Latino parents. J Public Health Dent 2012;72(1):82-89. [doi: 10.1111/j.1752-7325.2011.00287.x] [Medline: 22316378]
11. Walker KK, Martínez-Mier EA, Soto-Rojas AE, et al. Midwestern Latino caregivers’ knowledge, attitudes and sense making of the oral health etiology, prevention and barriers that inhibit their children’s oral health: a CBPR approach. BMC Oral Health 2017 Mar 2;17(1):61. [doi: 10.1186/s12903-017-0354-9] [Medline: 28253872]

12. Lopez A, Hoeft KS, Guerra C, Barker JC, Chung LH, Burke NJ. Spanish-speaking Mexican-American parents' experiences while navigating the dental care system for their children. J Public Health Dent 2022 Jan;82(1):99-104. [doi: 10.1111/jphd.12495] [Medline: 34981539]
13. Ayala GX, Elder JP. Qualitative methods to ensure acceptability of behavioral and social interventions to the target population. J Public Health Dent 2011;71(1):S69-S79. [doi: 10.1111/j.1752-7325.2011.00241.x] [Medline: 21656958]
14. Kumanyika S, Grier S. Targeting interventions for ethnic minority and low-income populations. Future Child 2006;16(1):187-207. [doi: 10.1353/foc.2006.0005] [Medline: 16532664]
15. Naidu RS, Nunn JH. Oral health knowledge, attitudes and behaviour of parents and caregivers of preschool children: implications for oral health promotion. Oral Health Prev Dent 2020 Jul 4;18(2):245-252. [doi: 10.3290/j.ohpd.a43357] [Medline: 32618448]
16. Vermaire JH, van Exel N. Parental attitudes towards oral health and caries-risk in their children. Int J Dent Hyg 2018 May;16(2):241-248. [doi: 10.1111/idh.12296] [Medline: 28613022]
17. Gazzaz AZ, Carpiano RM, Aleksejuniene J. Parenting stress as a mediator in the oral health of children and adolescents: a stress process model. Comm Dent Oral Epid 2020 Aug;48(4):288-295. [doi: 10.1111/cdoe.12531]
18. Nayee S, Klass C, Findlay G, Gallagher JE. Parenting and oral health in an inner-city environment: a qualitative pilot study. BMC Oral Health 2018 Oct 20;18(1):168. [doi: 10.1186/s12903-018-0584-5] [Medline: 30342497]
19. Banihashem Rad SA, Esteves-Oliveira M, Maklennan A, Douglas GVA, Castiglia P, Campus G. Oral health inequalities in immigrant populations worldwide: a scoping review of dental caries and periodontal disease prevalence. BMC Public Health 2024 Jul 23;24(1):1968. [doi: 10.1186/s12889-024-19354-4] [Medline: 39044172]
20. Luo H, Wu B, Wu Y, Moss ME. Dental caries and preventive dental visits among children in the US: the impact of race/ethnicity and immigration. AJPM Focus 2024 Aug;3(4):100230. [doi: 10.1016/j.focus.2024.100230] [Medline: 38766463]
21. Crespo E. The importance of oral health in immigrant and refugee children. Children (Basel) 2019 Sep 9;6(9):102. [doi: 10.3390/children6090102] [Medline: 31505903]
22. Dahlan R, Bohlouli B, Salami B, Saltaji H, Amin M. Parental acculturation and oral health of children among immigrants. J Public Health Dent 2022 Sep;82(4):426-436. [doi: 10.1111/jphd.12481] [Medline: 34672365]
23. Lindsay AC, Wallington SF, Greaney ML, et al. Sociocultural and environmental influences on Brazilian immigrant mothers' beliefs and practices related to child feeding and weight status. Matern Child Health J 2017 May;21(5):1085-1094. [doi: 10.1007/s10995-016-2207-6] [Medline: 28032238]
24. Lindsay AC, Wallington SF, Greaney ML, Hasselman MH, Tavares Machado MM, Mezzavilla RS. Brazilian immigrant mothers' beliefs and practices related to infant feeding: a qualitative study. J Hum Lact 2017 Aug;33(3):595-605. [doi: 10.1177/0890334416676267] [Medline: 27881729]
25. Lindsay AC, de Oliveira MG, Wallington SF, et al. Access and utilization of healthcare services in Massachusetts, United States: a qualitative study of the perspectives and experiences of Brazilian-born immigrant women. BMC Health Serv Res 2016 Sep 2;16(1):467. [doi: 10.1186/s12913-016-1723-9] [Medline: 27590849]
26. McLeroy KR, Bibeau D, Steckler A, Glanz K. An ecological perspective on health promotion programs. Health Educ Q 1988;15(4):351-377. [doi: 10.1177/109019818801500401] [Medline: 3068205]
27. Reda M, Sen A, Mustafa M. Prevention of caries and obesity in children with immigrant background in Norway—a study protocol for a cluster randomized controlled trial. BMC Oral Health 2023 Sep 1;23(1):620. [doi: 10.1186/s12903-023-03329-9] [Medline: 37658341]
28. Reda M, Sen A, Åstrøm AN, Mustafa M. Effects of an intervention on immigrant parents' knowledge and attitudes toward their children's oral health: a cluster randomized trial in Norway. Eur J Oral Sci 2025 Feb;133(1):e13037. [doi: 10.1111/eos.13037] [Medline: 39821537]
29. Lin YC, Lin YC, Chen JH, Lin PL, Chen T, Huang HL. Long-term effects of a lay health advisor intervention on immigrant children's dental caries and maternal preventive behaviour: a randomized controlled trial. Community Dent Oral Epidemiol 2022 Aug;50(4):280-291. [doi: 10.1111/cdoe.12670] [Medline: 34169539]
30. Tiwari T, Albino J. Acculturation and pediatric minority oral health interventions. Dent Clin North Am 2017 Jul;61(3):549-563. [doi: 10.1016/j.cden.2017.02.006] [Medline: 28577636]
31. Nápoles-Springer AM, Stewart AL. Overview of qualitative methods in research with diverse populations. Making research reflect the population. Med Care 2006 Nov;44(11 Suppl 3):S5-S9. [doi: 10.1097/01.mlr.0000245252.14302.f4] [Medline: 17060835]
32. Creswell JW, Poth CN. Qualitative Inquiry and Research Design: Choosing Among Five Approaches: SAGE Publications; 2018. URL: https://collegepublishing.sagepub.com/products/qualitative-inquiry-and-research-design-4-246896 [accessed 2026-03-03]
33. Lindsay AC, Wallington SF, Rabello LM, et al. Faith, family, and social networks: effective strategies for recruiting Brazilian immigrants in maternal and child health research. J Racial and Ethnic Health Disparities 2021 Feb;8(1):47-59. [doi: 10.1007/s40615-020-00753-3]

34. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007 Dec;19(6):349-357. [doi: 10.1093/intqhc/mzm042] [Medline: 17872937]
35. McCracken G. The Long Interview: Sage Publications; 1988. [doi: 10.4135/9781412986229]
36. Chang CP, Barker JC, Hoeft KS, Guerra C, Chung LH, Burke NJ. Importance of content and format of oral health instruction to low-income Mexican immigrant parents: a qualitative study. Pediatr Dent 2018 Jan 1;40(1):30-36. [Medline: 29482680]
37. Floríndez LI, Floríndez DC, Floríndez FM, et al. Oral care experiences of Latino parents/caregivers with children with Autism and with typically developing children. Int J Environ Res Public Health 2019 Aug 14;16(16):2905. [doi: 10.3390/ijerph16162905] [Medline: 31416123]
38. Tiwari T, Rai NK, Wilson AR, Gansky SA, Albino J. What can we learn from parents of caries-free and caries-active Hispanic children? JDR Clin Transl Res 2021 Jan;6(1):47-58. [doi: 10.1177/2380084420904043]
39. Hoeft KS, Rios SM, Pantoja Guzman E, Barker JC. Using community participation to assess acceptability of “Contra Caries”, a theory-based, promotora-led oral health education program for rural Latino parents: a mixed methods study. BMC Oral Health 2015 Sep 3;15:103. [doi: 10.1186/s12903-015-0089-4] [Medline: 26335081]
40. Hoeft KS, Masterson EE, Barker JC. Mexican American mothers’ initiation and understanding of home oral hygiene for young children. Pediatr Dent 2009;31(5):395-404. [Medline: 19947134]
41. Rivera Y, Boyd LD, Libby L. Hispanic seasonal farmworker caregivers' beliefs and perceptions of early childhood caries. J Dent Hyg 2020 Oct;94(5):14-21. [Medline: 33008945]
42. Marin G, Sabogal F, Marin BV, Otero-Sabogal R, Perez-Stable EJ. Development of a short acculturation scale for Hispanics. Hisp J Behav Sci 1987 Jun;9(2):183-205. [doi: 10.1177/07399863870092005]
43. Ellison J, Jandorf L, Duhamel K. Assessment of the Short Acculturation Scale for Hispanics (SASH) among low-income, immigrant Hispanics. J Cancer Educ 2011 Sep;26(3):478-483. [doi: 10.1007/s13187-011-0233-z] [Medline: 21688089]
44. Bardin L. Análise de Conteúdo [Book in Portuguese]: Edições 70; 2016.
45. Miles M, Huberman A. Qualitative Data Analysis: An Expanded Sourcebook: Sage Publications; 1994. URL: https://openlibrary.org/books/OL21978508M/Qualitative_data_analysis [accessed 2026-03-03]
46. Rädiker S, Kuckartz U. Focused Analysis of Qualitative Interviews with MAXQDA: Step by Step: MAXQDA Press; 2020. [doi: 10.36192/978-3-948768072]
47. Statistical analysis software 9.4. SAS Institute Inc. 2013. URL: https://www.scirp.org/reference/referencespapers?referenceid=2911957 [accessed 2026-03-03]
48. Nicol P, Al-Hanbali A, King N, Slack-Smith L, Cherian S. Informing a culturally appropriate approach to oral health and dental care for pre-school refugee children: a community participatory study. BMC Oral Health 2014 Jun 13;14:69. [doi: 10.1186/1472-6831-14-69] [Medline: 24923308]
49. Nguyen DP, McQuistan MR, Qian F, Hernández M, Macek MD, Chi DL. The interactive effects of oral health literacy and acculturation on dental care use among Hispanic adults. J Public Health Dent 2022 Jun;82(3):295-302. [doi: 10.1111/jphd.12529] [Medline: 35644999]
50. Hull PC, Reece MC, Patton M, et al. A community-based oral health self-care intervention for Hispanic families. Int J Public Health 2014 Feb;59(1):61-66. [doi: 10.1007/s00038-013-0470-5] [Medline: 23612890]
51. Gibbs L, Waters E, de Silva A, et al. An exploratory trial implementing a community-based child oral health promotion intervention for Australian families from refugee and migrant backgrounds: a protocol paper for Teeth Tales. BMJ Open 2014 Mar 12;4(3):e004260. [doi: 10.1136/bmjopen-2013-004260] [Medline: 24622949]
52. Borrelli B, Henshaw M, Endrighi R, et al. An interactive parent-targeted text messaging intervention to improve oral health in children attending urban pediatric clinics: feasibility randomized controlled trial. JMIR Mhealth Uhealth 2019 Nov 11;7(11):e14247. [doi: 10.2196/14247] [Medline: 31710306]
53. Chen R, Irving M, Christian B, et al. SmilesUp text message intervention for early childhood dental caries prevention: a protocol for a randomised controlled trial. PLoS ONE 2024;19(9):e0310561. [doi: 10.1371/journal.pone.0310561] [Medline: 39348422]
54. de Jong-Lenters M, L’Hoir M, Polak E, Duijster D. Promoting parenting strategies to improve tooth brushing in children: design of a non-randomised cluster-controlled trial. BMC Oral Health 2019 Sep 6;19(1):210. [doi: 10.1186/s12903-019-0902-6] [Medline: 31492121]
55. Lotto M, Strieder AP, Ayala Aguirre PE, et al. Parental-oriented educational mobile messages to aid in the control of early childhood caries in low socioeconomic children: a randomized controlled trial. J Dent 2020 Oct;101:103456. [doi: 10.1016/j.jdent.2020.103456] [Medline: 32827598]
56. Joufi AI, Claiborne DM, Shuman D. Oral health education and promotion activities by early head start programs in the United States: a systematic review. J Dent Hyg 2021 Oct;95(5):14-21. [Medline: 34654711]
57. Bryant LL, Quissell DO, Braun PA, et al. A community-based oral health intervention in Navajo Nation Head Start: participation factors and contextual challenges. J Community Health 2016 Apr;41(2):340-353. [doi: 10.1007/s10900-015-0102-5] [Medline: 26467679]
58. Dudovitz R, Teutsch C, Holt K, Herman A. Improving parent oral health literacy in Head Start programs. J Public Health Dent 2020 Jun;80(2):150-158. [doi: 10.1111/jphd.12361] [Medline: 32083725]

59. Ramos-Gomez F, Parkinson S, Garcia de Jesus V, Rios JA, Kinsler JJ. Pediatric oral health online education for rural and migrant head start programs in the United States. Int J Environ Res Public Health 2024 Apr 25;21(5):544. [doi: 10.3390/ijerph21050544] [Medline: 38791758]
60. Pawloski C, Hilgert J, Senturia K, Davis S, Koday M, Cunha-Cruz J. Medical–dental integration in a rural community health center: a qualitative program evaluation. Health Promot Pract 2022 May;23(3):416-424. [doi: 10.1177/15248399211002832] [Medline: 33853397]
61. Cruz S, Kerr D, Patiño Nguyen D, Carlyle A, Chi DL. Qualitative evaluation of the pre-implementation phase of a rural dental clinic co-located within a health center in the Pacific Northwest of the United States. Community Dent Oral Epidemiol 2023 Apr;51(2):256-264. [doi: 10.1111/cdoe.12734] [Medline: 35261055]
62. Feldens CA, Fortuna MJ, Kramer PF, Ardenghi TM, Vítolo MR, Chaffee BW. Family Health Strategy associated with increased dental visitation among preschool children in Brazil. Int J Paediatr Dent 2018 Nov;28(6):624-632. [doi: 10.1111/ipd.12421] [Medline: 30175414]
63. Baldani MH, Fadel CB, Possamai T, Queiroz MGS. Inclusion of oral health services in the Family Health Program in the State of Paraná, Brazil. Cad Saúde Pública 2005 Aug;21(4):1026-1035. [doi: 10.1590/S0102-311X2005000400005]
64. de Souza TMS, Roncalli AG. Saúde bucal no Programa Saúde da Família: uma avaliação do modelo assistencial [Article in Portuguese]. Cad Saúde Pública 2007 Nov;23(11):2727-2739. [doi: 10.1590/S0102-311X2007001100020]
65. Do LG, Song YH, Du M, Spencer AJ, Ha DH. Socioecological determinants of child oral health—a scoping review. Community Dent Oral Epidemiol 2023 Oct;51(5):1024-1036. [doi: 10.1111/cdoe.12819] [Medline: 36440603]
66. Fisher-Owens SA, Gansky SA, Platt LJ, et al. Influences on children's oral health: a conceptual model. Pediatrics 2007 Sep;120(3):e510-e520. [doi: 10.1542/peds.2006-3084] [Medline: 17766495]
67. Galiatsatos P, Hale WD. Promoting health and wellness in congregations through lay health educators: a case study of two churches. J Relig Health 2016 Feb;55(1):288-295. [doi: 10.1007/s10943-015-0069-7] [Medline: 26014461]
68. Vashishtha V, Kote S, Basavaraj P, Singla A, Pandita V, Malhi RK. Reach the unreached—a systematic review on mobile dental units. J Clin Diagn Res 2014 Aug;8(8):ZE05-ZE08. [doi: 10.7860/JCDR/2014/8688.4717] [Medline: 25302288]
69. Gupta S, Hakim M, Patel D, et al. Reaching vulnerable populations through portable and mobile dentistry—current and future opportunities. Dent J (Basel) 2019 Aug 1;7(3):75. [doi: 10.3390/dj7030075] [Medline: 31374831]
70. Balasubramanian M, Ghanbarzadegan A, Sohn W, et al. Primary school mobile dental program in New South Wales, Australia: protocol for the evaluation of a state government oral health initiative. BMC Public Health 2023 Feb 20;23(1):363. [doi: 10.1186/s12889-023-15241-6] [Medline: 36803579]
71. Nation A, Pukallus M, Stormon N, Foley M, Lalloo R. Health professionals delivering oral health interventions in early childhood: a scoping review of Australian and New Zealand literature. Health Promot J Austr 2023 Apr;34(2):303-315. [doi: 10.1002/hpja.678] [Medline: 36444715]
72. Okunseri CE, Rota K, Okunseri E, et al. Dental service utilization and immigrant family structure. J Public Health Dent 2021 Sep;81(3):198-205. [doi: 10.1111/jphd.12432] [Medline: 33258107]

Abbreviations

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

Edited by S Badawy; submitted 10.Jun.2025; peer-reviewed by L Ou, O Igunma; revised version received 17.Oct.2025; accepted 04.Nov.2025; published 07.Apr.2026.

Please cite as:
Lindsay AC, Nogueira DL, Cohen SA, Greaney ML
Brazilian Immigrant Parents' Perspectives on Oral Health in Early Childhood and Suggested Strategies for Education, Access, and Care: Qualitative Study
JMIR Pediatr Parent 2026;9:e78835
URL: https://pediatrics.jmir.org/2026/1/e78835
doi:10.2196/78835

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

Darcy A Thompson[1,2], MPH, MD; Laura K Kaizer[3], MPH; Sarah J Schmiege[3], PhD; Natasha J Cabrera[4], PhD; Lauren Clark[5], PhD, RN; Haley Ringwood[6,7], MD; Estefania Miramontes Valdes[2], MD; Andrea Jimenez-Zambrano[1,2], PhD; Carol Gorman[2], MBA; Marko Babiak[2], BA; Jeanne M Tschann[8], PhD

[1]Department of Pediatrics, School of Medicine, University of Colorado Anschutz Medical Campus, 12631 East 17th Avenue, Aurora, CO, United States

[2]Adult & Child Center for Outcomes Research and Delivery Science, School of Medicine, University of Colorado Anschutz Medical Campus, Aurora, CO, United States

[3]Department of Biostatistics and Informatics, Colorado School of Public Health, University of Colorado Anschutz Medical Campus, Aurora, CO, United States

[4]College of Education, University of Maryland, College Park, College Park, MD, United States

[5]School of Nursing, University of California, Los Angeles, Los Angeles, CA, United States

[6]Denver Health and Hospital Authority, Denver, CO, United States

[7]Department of Family Medicine, School of Medicine, University of Colorado Anschutz Medical Campus, Aurora, CO, United States

[8]Department of Psychiatry and Behavioral Sciences, University of California, San Francisco, San Francisco, CA, United States

Corresponding Author:
Darcy A Thompson, MPH, MD
Department of Pediatrics, School of Medicine, University of Colorado Anschutz Medical Campus, 12631 East 17th Avenue, Aurora, CO, United States

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.

(JMIR Pediatr Parent 2026;9:e76873) doi:10.2196/76873

KEYWORDS

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

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

[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

(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 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).

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

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 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 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 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.

Acknowledgments

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Funding

Research reported in this publication was supported by the National Institute of Nursing Research of the National Institutes of Health (NIH) under award R01NR017605 (principal investigator DAT) and by NIH/National Center for Advancing Translational Sciences Colorado Clinical and Translational Science Awards grant UL1 TR002535.

Conflicts of Interest

None declared.

References

1. Hill D, Ameenuddin N, Reid Chassiakos YL. Media and young minds. Pediatrics 2016 Nov;138(5):e20162591. [doi: 10.1542/peds.2016-2591] [Medline: 27940793]
2. Tremblay MS, Leblanc AG, Carson V, et al. Canadian sedentary behaviour guidelines for the early years (aged 0-4 years). Appl Physiol Nutr Metab 2012 Apr;37(2):370-391. [doi: 10.1139/h2012-019] [Medline: 22448609]
3. Guidelines on physical activity, sedentary behaviour, and sleep for children under 5 years of age. : World Health Organization; 2019 URL: https://iris.who.int/server/api/core/bitstreams/60a1cbaa-2bef-4251-9557-e52ce22112b3/content
4. Schmidt ME, Haines J, O'Brien A, et al. Systematic review of effective strategies for reducing screen time among young children. Obesity (Silver Spring) 2012 Jul;20(7):1338-1354. [doi: 10.1038/oby.2011.348] [Medline: 22222926]
5. Jones A, Armstrong B, Weaver RG, Parker H, von Klinggraeff L, Beets MW. Identifying effective intervention strategies to reduce children's screen time: a systematic review and meta-analysis. Int J Behav Nutr Phys Act 2021 Sep 16;18(1):126. [doi: 10.1186/s12966-021-01189-6] [Medline: 34530867]
6. Marsh S, Foley LS, Wilks DC, Maddison R. Family-based interventions for reducing sedentary time in youth: a systematic review of randomized controlled trials. Obes Rev 2014 Feb;15(2):117-133. [doi: 10.1111/obr.12105] [Medline: 24102891]
7. Paudel S, Jancey J, Subedi N, Leavy J. Correlates of mobile screen media use among children aged 0-8: a systematic review. BMJ Open 2017 Oct 24;7(10):e014585. [doi: 10.1136/bmjopen-2016-014585] [Medline: 29070636]
8. Downing KL, Hnatiuk J, Hesketh KD. Prevalence of sedentary behavior in children under 2years: a systematic review. Prev Med 2015 Sep;78:105-114. [doi: 10.1016/j.ypmed.2015.07.019] [Medline: 26231111]

9. Jones RA, Hinkley T, Okely AD, Salmon J. Tracking physical activity and sedentary behavior in childhood: a systematic review. Am J Prev Med 2013 Jun;44(6):651-658. [doi: 10.1016/j.amepre.2013.03.001] [Medline: 23683983]
10. Barr R, Kirkorian H, Coyne S, Radesky J. Early Childhood and Digital Media: Cambridge University Press; 2024. URL: https://www.cambridge.org/core/product/identifier/9781108885751/type/element [accessed 2026-01-21] [doi: 10.1017/9781108885751]
11. Xu H, Wen LM, Hardy LL, Rissel C. A 5-year longitudinal analysis of modifiable predictors for outdoor play and screen-time of 2- to 5-year-olds. Int J Behav Nutr Phys Act 2016 Aug 26;13(1):96. [doi: 10.1186/s12966-016-0422-6] [Medline: 27561357]
12. Duch H, Fisher EM, Ensari I, Harrington A. Screen time use in children under 3 years old: a systematic review of correlates. Int J Behav Nutr Phys Act 2013 Aug 23;10:102. [doi: 10.1186/1479-5868-10-102] [Medline: 23967799]
13. Holmgren HG, Stockdale L, Gale M, Coyne SM. Parent and child problematic media use: the role of maternal postpartum depression and dysfunctional parent-child interactions in young children. Comput Human Behav 2022 Aug;133:107293. [doi: 10.1016/j.chb.2022.107293]
14. Domoff SE, Borgen AL, Radesky JS. Interactional theory of childhood problematic media use. Hum Behav Emerg Technol 2020 Oct;2(4):343-353. [doi: 10.1002/hbe2.217] [Medline: 36381426]
15. Barr R, Kirkorian H, Radesky J, et al. Beyond screen time: a synergistic approach to a more comprehensive assessment of family media exposure during early childhood. Front Psychol 2020;11:1283. [doi: 10.3389/fpsyg.2020.01283] [Medline: 32754078]
16. Thompson DA, Tschann JM. Update on screen-related parenting practices in early childhood. Acad Pediatr 2020;20(8):1066-1068. [doi: 10.1016/j.acap.2020.07.007] [Medline: 32653689]
17. Minuchin JP. Looking toward the horizon: present and future in the study of family systems. In: McHale JP, Grolnick WS, editors. Retrospect and Prospect in the Psychological Study of Families: Routledge; 2002:259-287 URL: https://www.taylorfrancis.com/chapters/edit/10.4324/9781410604637-17/looking-toward-horizon-present-future-study-family-systems?context=ubx&refId=2eb6ccac-9f81-4d1c-bf13-8e209b646f71 [accessed 2026-01-21]
18. Xu H, Wen LM, Rissel C. Associations of parental influences with physical activity and screen time among young children: a systematic review. J Obes 2015;2015:546925. [doi: 10.1155/2015/546925] [Medline: 25874123]
19. Benita N, Gordon-Hacker A, Gueron-Sela N. Sleep through toddlerhood: the distinct roles of overall media use and use of media to regulate child distress. J Dev Behav Pediatr 2020 Dec;41(9):690-697. [doi: 10.1097/DBP.0000000000000836] [Medline: 32618818]
20. Coyne SM, Rogers A, Shawcroft J, et al. Meltdowns and media: moment-to-moment fluctuations in young children's media use transitions and the role of children's mood states. Comput Human Behav 2022 Nov;136:107360. [doi: 10.1016/j.chb.2022.107360]
21. Elias N, Sulkin I. Screen-assisted parenting: the relationship between toddlers' screen time and parents' use of media as a parenting tool. J Fam Issues 2019 Dec;40(18):2801-2822. [doi: 10.1177/0192513X19864983]
22. Fitzpatrick C, Cristini E, Bernard JY, Garon-Carrier G. Meeting preschool screen time recommendations: which parental strategies matter? Front Psychol 2023;14:1287396. [doi: 10.3389/fpsyg.2023.1287396] [Medline: 38022940]
23. Thompson DA, Schmiege SJ, Johnson SL, et al. Screen-related parenting practices in low-income Mexican American families. Acad Pediatr 2018;18(7):820-827. [doi: 10.1016/j.acap.2018.05.002] [Medline: 29777781]
24. Tang L, Darlington G, Ma DWL, Haines J, Guelph Family Health Study. Mothers' and fathers' media parenting practices associated with young children's screen-time: a cross-sectional study. BMC Obes 2018;5(1):37. [doi: 10.1186/s40608-018-0214-4] [Medline: 30524742]
25. Lauricella AR, Wartella E, Rideout VJ. Young children's screen time: the complex role of parent and child factors. J Appl Dev Psychol 2015 Jan;36:11-17. [doi: 10.1016/j.appdev.2014.12.001]
26. Barber SE, Kelly B, Collings PJ, Nagy L, Bywater T, Wright J. Prevalence, trajectories, and determinants of television viewing time in an ethnically diverse sample of young children from the UK. Int J Behav Nutr Phys Act 2017 Jul 6;14(1):88. [doi: 10.1186/s12966-017-0541-8] [Medline: 28683801]
27. De Decker E, Hesketh K, De Craemer M, et al. Parental influences on preschoolers' TV viewing time: mediation analyses on Australian and Belgian data. J Phys Act Health 2015 Sep;12(9):1272-1279. [doi: 10.1123/jpah.2014-0190] [Medline: 25525967]
28. Bleakley A, Jordan AB, Hennessy M. The relationship between parents' and children's television viewing. Pediatrics 2013 Aug;132(2):e364-e371. [doi: 10.1542/peds.2012-3415] [Medline: 23858418]
29. Arts J, Gubbels JS, Verhoeff AP, Chinapaw MJM, Lettink A, Altenburg TM. A systematic review of proxy-report questionnaires assessing physical activity, sedentary behavior and/or sleep in young children (aged 0-5 years). Int J Behav Nutr Phys Act 2022 Feb 14;19(1):18. [doi: 10.1186/s12966-022-01251-x] [Medline: 35164783]
30. Vandewater EA, Lee SJ. Measuring children's media use in the digital age: issues and challenges. Am Behav Sci 2009 Apr 1;52(8):1152-1176. [doi: 10.1177/0002764209331539] [Medline: 19763246]
31. Perez O, Garza T, Hindera O, et al. Validated assessment tools for screen media use: a systematic review. PLoS ONE 2023;18(4):e0283714. [doi: 10.1371/journal.pone.0283714] [Medline: 37053175]

32. Danet M, Miller AL, Weeks HM, Kaciroti N, Radesky JS. Children aged 3-4 years were more likely to be given mobile devices for calming purposes if they had weaker overall executive functioning. Acta Paediatr 2022 Jul;111(7):1383-1389. [doi: 10.1111/apa.16314] [Medline: 35238076]
33. Lee EY, Hesketh KD, Rhodes RE, Rinaldi CM, Spence JC, Carson V. Role of parental and environmental characteristics in toddlers' physical activity and screen time: Bayesian analysis of structural equation models. Int J Behav Nutr Phys Act 2018 Feb 9;15(1):17. [doi: 10.1186/s12966-018-0649-5] [Medline: 29426324]
34. McArthur BA, Volkova V, Tomopoulos S, Madigan S. Global prevalence of meeting screen time guidelines among children 5 years and younger: a systematic review and meta-analysis. JAMA Pediatr 2022 Apr 1;176(4):373-383. [doi: 10.1001/jamapediatrics.2021.6386] [Medline: 35157028]
35. Thompson DA, Jimenez-Zambrano AM, Ringwood H, Tschann JM, Clark L. Parenting a toddler in the era of pervasive screens: interviews with low-income Mexican American parents. Int J Environ Res Public Health 2023 Apr 11;20(8):5461. [doi: 10.3390/ijerph20085461] [Medline: 37107743]
36. Li C, Cheng G, Sha T, Cheng W, Yan Y. The relationships between screen use and health indicators among infants, toddlers, and preschoolers: a meta-analysis and systematic review. Int J Environ Res Public Health 2020 Oct 7;17(19):7324. [doi: 10.3390/ijerph17197324] [Medline: 33036443]
37. Tahir MJ, Willett W, Forman MR. The association of television viewing in childhood with overweight and obesity throughout the life course. Am J Epidemiol 2019 Feb 1;188(2):282-293. [doi: 10.1093/aje/kwy236] [Medline: 30321270]
38. Dennison BA, Erb TA, Jenkins PL. Television viewing and television in bedroom associated with overweight risk among low-income preschool children. Pediatrics 2002 Jun;109(6):1028-1035. [doi: 10.1542/peds.109.6.1028] [Medline: 12042539]
39. Wen LM, Baur LA, Rissel C, Xu H, Simpson JM. Correlates of body mass index and overweight and obesity of children aged 2 years: findings from the healthy beginnings trial. Obesity (Silver Spring) 2014 Jul;22(7):1723-1730. [doi: 10.1002/oby.20700] [Medline: 24415528]
40. Kourlaba G, Kondaki K, Liarigkovinos T, Manios Y. Factors associated with television viewing time in toddlers and preschoolers in Greece: the GENESIS study. J Public Health (Oxf) 2009 Jun;31(2):222-230. [doi: 10.1093/pubmed/fdp011] [Medline: 19224946]
41. Hu J, Ding N, Yang L, Ma Y, Gao M, Wen D. Association between television viewing and early childhood overweight and obesity: a pair-matched case-control study in China. BMC Pediatr 2019 Jun 8;19(1):184. [doi: 10.1186/s12887-019-1557-9] [Medline: 31176368]
42. Asplund KM, Kair LR, Arain YH, Cervantes M, Oreskovic NM, Zuckerman KE. Early childhood screen time and parental attitudes toward child television viewing in a low-income Latino population attending the special supplemental nutrition program for women, infants, and children. Child Obes 2015 Oct;11(5):590-599. [doi: 10.1089/chi.2015.0001] [Medline: 26390321]
43. Olafsdottir S, Berg C, Eiben G, et al. Young children's screen activities, sweet drink consumption and anthropometry: results from a prospective European study. Eur J Clin Nutr 2014 Feb;68(2):223-228. [doi: 10.1038/ejcn.2013.234] [Medline: 24253759]
44. Fuller-Tyszkiewicz M, Skouteris H, Hardy LL, Halse C. The associations between TV viewing, food intake, and BMI. a prospective analysis of data from the Longitudinal Study of Australian Children. Appetite 2012 Dec;59(3):945-948. [doi: 10.1016/j.appet.2012.09.009] [Medline: 23000277]
45. Pagani LS, Fitzpatrick C, Barnett TA, Dubow E. Prospective associations between early childhood television exposure and academic, psychosocial, and physical well-being by middle childhood. Arch Pediatr Adolesc Med 2010 May;164(5):425-431. [doi: 10.1001/archpediatrics.2010.50] [Medline: 20439793]
46. Poitras VJ, Gray CE, Janssen X, et al. Systematic review of the relationships between sedentary behaviour and health indicators in the early years (0-4 years). BMC Public Health 2017 Nov 20;17(Suppl 5):868. [doi: 10.1186/s12889-017-4849-8] [Medline: 29219092]
47. Bae EJ, Nam SH. How mothers' problematic smartphone use affects adolescents' problematic smartphone use: mediating roles of time mothers spend with adolescents and adolescents' self-esteem. Psychol Res Behav Manag 2023;16:885-892. [doi: 10.2147/PRBM.S401515] [Medline: 36968806]
48. Ogden CL, Carroll MD, Lawman HG, et al. Trends in obesity prevalence among children and adolescents in the United States, 1988-1994 through 2013-2014. JAMA 2016 Jun 7;315(21):2292-2299. [doi: 10.1001/jama.2016.6361] [Medline: 27272581]
49. Ogden CL, Carroll MD, Kit BK, Flegal KM. Prevalence of childhood and adult obesity in the United States, 2011-2012. JAMA 2014 Feb 26;311(8):806-814. [doi: 10.1001/jama.2014.732] [Medline: 24570244]
50. Guerrero AD, Mao C, Fuller B, Bridges M, Franke T, Kuo AA. Racial and ethnic disparities in early childhood obesity: growth trajectories in body mass index. J Racial Ethn Health Disparities 2016 Mar;3(1):129-137. [doi: 10.1007/s40615-015-0122-y] [Medline: 26896112]
51. Rogers R, Eagle TF, Sheetz A, et al. The relationship between childhood obesity, low socioeconomic status, and race/ethnicity: lessons from Massachusetts. Child Obes 2015 Dec;11(6):691-695. [doi: 10.1089/chi.2015.0029] [Medline: 26562758]

52. Davis KE, Li X, Adams-Huet B, Sandon L. Infant feeding practices and dietary consumption of US infants and toddlers: National Health and Nutrition Examination Survey (NHANES) 2003-2012. Public Health Nutr 2018 Mar;21(4):711-720. [doi: 10.1017/S1368980017003184] [Medline: 29166968]
53. Rideout V, Lauricella A, Wartella E. Children, media, and race media use among White, Black, Hispanic, and Asian American children. : Center on Media and Human Development, School of Communication, Northwestern University; 2011 URL: http://static1.1.sqspcdn.com/static/f/1083077/14689973/1318952548830/Children+Media+and+Race.FINAL.pdf [accessed 2026-01-21]
54. Zero to eight: children's media use in America 2013. : Common Sense Media; 2013 URL: https://www.commonsensemedia.org/research/zero-to-eight-childrens-media-use-in-america-2013 [accessed 2020-11-29]
55. Thompson DA, Matson PA, Ellen JM. Television viewing in low-income Latino children: variation by ethnic subgroup and English proficiency. Child Obes 2013 Feb;9(1):22-28. [doi: 10.1089/chi.2012.0113] [Medline: 23301653]
56. Thompson DA, Sibinga EMS, Jennings JM, Bair-Merritt MH, Christakis DA. Television viewing by young Hispanic children: evidence of heterogeneity. Arch Pediatr Adolesc Med 2010 Feb;164(2):174-179. [doi: 10.1001/archpediatrics.2009.257] [Medline: 20124147]
57. Motel S, Patten E. The 10 largest Hispanic origin groups: characteristics, rankings, top counties. : Pew Hispanic Center; 2012 Jun 27 URL: http://www.pewhispanic.org/2012/06/27/the-10-largest-hispanic-origin-groups-characteristics-rankings-top-counties [accessed 2026-01-21]
58. Gonzalez-Barrera A, Lopez MH. A demographic portrait of Mexican-origin Hispanics in the United States. : Pew Hispanic Center; 2013 URL: https://www.pewresearch.org/wp-content/uploads/sites/5/2013/05/2013-04_Demographic-Portrait-of-Mexicans-in-the-US.pdf [accessed 2026-01-21]
59. Murphey D, Guzman L, Torres A. America's Hispanic children: gaining ground, looking forward. : Child Trends Hispanic Institute; 2014 Sep 24 URL: https://cms.childtrends.org/wp-content/uploads/2014/09/2014-38AmericaHispanicChildren.pdf [accessed 2026-01-21]
60. Chen Y, Guzman L. Most U.S. Hispanic children can trace their heritage to Mexico, but many other Hispanic children's family roots extend across Latin America. National Research Center on Hispanic Children & Families. 2021 Oct 6. URL: https://doi.org/10.59377/218v6151w [accessed 2026-02-10]
61. Anderson DR, Field DE, Collins PA, Lorch EP, Nathan JG. Estimates of young children's time with television: a methodological comparison of parent reports with time-lapse video home observation. Child Dev 1985 Oct;56(5):1345-1357. [doi: 10.1111/j.1467-8624.1985.tb00202.x] [Medline: 4053746]
62. Thompson DA, Kaizer LK, Schmiege SJ, et al. Screen-related parenting practices in Mexican American families with toddlers: development of culturally- and contextually-relevant scales. Children (Basel) 2025 Jul 2;12(7):874. [doi: 10.3390/children12070874] [Medline: 40723067]
63. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research Electronic Data Capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform 2009 Apr;42(2):377-381. [doi: 10.1016/j.jbi.2008.08.010] [Medline: 18929686]
64. Marín G, Marín BVO, editors. Research with Hispanic Populations: Applied Social Research Series: Sage Publications, Inc; 1991. URL: https://methods.sagepub.com/book/edvol/research-with-hispanic-populations/toc#_ [accessed 2026-01-21] [doi: 10.4135/9781412985734]
65. Thompson DA, Fineman MS, Miramontes Valdes E, Tschann JM, Meltzer LJ. Forward and back is not enough: applying best practices for translation of pediatric sleep questionnaires. Front Sleep 2024;2:1329405. [doi: 10.3389/frsle.2023.1329405] [Medline: 38585369]
66. Willis GB. Cognitive Interviewing: Sage Publications; 2005:335 URL: https://methods.sagepub.com/book/mono/cognitive-interviewing/toc [accessed 2026-01-21] [doi: 10.4135/9781412983655]
67. Thompson DA, Kaizer LK, Schmiege SJ, et al. Measuring attraction to screen devices in early childhood: development of the Affinity-TV and Affinity-Mobile scales. Front Pediatr 2025;13:1496225. [doi: 10.3389/fped.2025.1496225] [Medline: 40109280]
68. Mendoza JA, McLeod J, Chen TA, Nicklas TA, Baranowski T. Convergent validity of preschool children's television viewing measures among low-income Latino families: a cross-sectional study. Child Obes 2013 Feb;9(1):29-34. [doi: 10.1089/chi.2012.0116] [Medline: 23270534]
69. Maqbool A, Olsen IE, Stallings VA. Clinical assessment of nutritional status. In: Duggan C, Watkins JB, Walker WA, editors. Nutrition in Pediatrics: Basic Science, Clinical Applications: BC Decker Inc; 2008:5-13 URL: https://openlibrary.org/books/OL19149525M/Nutrition_in_pediatrics?utm_source=chatgpt.com [accessed 2026-01-21]
70. Blossner M, Siyam A, Borghi E, de Onis M, Onyango A, Yang H. The WHO child growth standards: WHO anthro (version 3.2.2, 2011) for personal computers. : World Health Organization; 2010 URL: https://cdn.who.int/media/docs/default-source/child-growth/child-growth-standards/software/anthro-pc-manual-v322.pdf [accessed 2026-01-21]
71. Roy SM, Spivack JG, Faith MS, et al. Infant BMI or weight-for-length and obesity risk in early childhood. Pediatrics 2016 May;137(5):e20153492. [doi: 10.1542/peds.2015-3492] [Medline: 27244803]

72. Campbell K, Hesketh K, Crawford D, Salmon J, Ball K, McCallum Z. The Infant Feeding Activity and Nutrition Trial (INFANT) an early intervention to prevent childhood obesity: cluster-randomised controlled trial. BMC Public Health 2008 Mar 31;8(1):103. [doi: 10.1186/1471-2458-8-103] [Medline: 18373877]
73. Silverwood RJ, De Stavola BL, Cole TJ, Leon DA. BMI peak in infancy as a predictor for later BMI in the Uppsala Family Study. Int J Obes (Lond) 2009 Aug;33(8):929-937. [doi: 10.1038/ijo.2009.108] [Medline: 19564879]
74. Hof MHP, Vrijkotte TGM, de Hoog MLA, van Eijsden M, Zwinderman AH. Association between infancy BMI peak and body composition and blood pressure at age 5-6 years. PLoS ONE 2013;8(12):e80517. [doi: 10.1371/journal.pone.0080517] [Medline: 24324605]
75. Smego A, Woo JG, Klein J, et al. High body mass index in infancy may predict severe obesity in early childhood. J Pediatr 2017 Apr;183:87-93. [doi: 10.1016/j.jpeds.2016.11.020] [Medline: 27916426]
76. Thompson DA, Tschann JM, Jimenez-Zambrano AM, et al. Screen-related discord and dismay in low-income Mexican American families with toddlers: a qualitative study. J Pediatr Nurs 2023;68:60-67. [doi: 10.1016/j.pedn.2022.09.009] [Medline: 36396565]
77. Marin G, Gamba RJ. A new measurement of acculturation for Hispanics: the Bidimensional Acculturation Scale for Hispanics (BAS). Hisp J Behav Sci 1996 Aug;18(3):297-316. [doi: 10.1177/07399863960183002]
78. Matarma T, Koski P, Löyttyniemi E, Lagström H. The factors associated with toddlers' screen time change in the STEPS Study: a two-year follow-up. Prev Med 2016 Mar;84:27-33. [doi: 10.1016/j.ypmed.2015.12.014] [Medline: 26740349]
79. Bernard JY, Padmapriya N, Chen B, et al. Predictors of screen viewing time in young Singaporean children: the GUSTO cohort. Int J Behav Nutr Phys Act 2017 Sep 5;14(1):112. [doi: 10.1186/s12966-017-0562-3] [Medline: 28870219]
80. Vaala SE, Hornik RC. Predicting US infants' and toddlers' TV/video viewing rates: mothers' cognitions and structural life circumstances. J Child Media 2014 Apr 1;8(2):163-182. [doi: 10.1080/17482798.2013.824494] [Medline: 25489335]
81. Wertlieb D, American Academy of Pediatrics Task Force on the Family. Converging trends in family research and pediatrics: recent findings for the American Academy of Pediatrics Task Force on the family. Pediatrics 2003 Jun;111(6 Pt 2):1572-1587. [Medline: 12777596]
82. O'Connor TM, Hingle M, Chuang RJ, et al. Conceptual understanding of screen media parenting: report of a working group. Child Obes 2013 Aug;9 Suppl(Suppl 1):S110-S118. [doi: 10.1089/chi.2013.0025] [Medline: 23944919]
83. Thompson DA, Johnson SL, Vandewater EA, et al. Parenting and preschooler TV viewing in low-income Mexican Americans: development of the Parenting Practices Regarding TV Viewing (PPRTV) scale. J Dev Behav Pediatr 2016;37(6):465-474. [doi: 10.1097/DBP.0000000000000309] [Medline: 27355878]
84. Ochoa W, Reich SM. Parents' beliefs about the benefits and detriments of mobile screen technologies for their young children's learning: a focus on diverse Latine mothers and fathers. Front Psychol 2020;11:570712. [doi: 10.3389/fpsyg.2020.570712] [Medline: 33162913]
85. Beck AL, Huang JC, Lendzion L, Fernandez A, Martinez S. Impact of the coronavirus disease 2019 pandemic on parents' perception of health behaviors in children with overweight and obesity. Acad Pediatr 2021;21(8):1434-1440. [doi: 10.1016/j.acap.2021.05.015] [Medline: 34023488]
86. Madigan S, Eirich R, Pador P, McArthur BA, Neville RD. Assessment of changes in child and adolescent screen time during the COVID-19 pandemic: a systematic review and meta-analysis. JAMA Pediatr 2022 Dec 1;176(12):1188-1198. [doi: 10.1001/jamapediatrics.2022.4116] [Medline: 36342702]
87. Glassman J, Humphreys KL, Jauregui A, Milstein A, Sanders L. Evidence for changes in screen use in the United States during early childhood related to COVID-19 pandemic parent stressors: repeated cross-sectional study. JMIR Pediatr Parent 2024 May 22;7:e43315. [doi: 10.2196/43315] [Medline: 38446995]
88. Vadathya AK, Musaad S, Beltran A, et al. An objective system for quantitative assessment of television viewing among children (Family Level Assessment of Screen Use in the Home-Television): system development study. JMIR Pediatr Parent 2022 Mar 24;5(1):e33569. [doi: 10.2196/33569] [Medline: 35323113]

Abbreviations

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

Edited by J Hagström; submitted 04.May.2025; peer-reviewed by CE Kehoe, CV Jaarsveld; revised version received 14.Nov.2025; accepted 15.Dec.2025; published 19.Feb.2026.

Please cite as:
Thompson DA, Kaizer LK, Schmiege SJ, Cabrera NJ, Clark L, Ringwood H, Miramontes Valdes E, Jimenez-Zambrano A, Gorman C, Babiak M, Tschann JM
Maternal Screen-Related Behaviors, Toddler Screen Use, and Toddler BMI in Mexican American Families: Cross-Sectional Study
JMIR Pediatr Parent 2026;9:e76873
URL: https://pediatrics.jmir.org/2026/1/e76873
doi:10.2196/76873

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

Amanda Machell, PhD; Katherine Downing, PhD; Simone J J M Verswijveren, MMSc, PhD; Kylie D Hesketh, PhD

Institute for Physical Activity and Nutrition (IPAN), Deakin University, 1 Gheringhap Street, Geelong, Australia

Corresponding Author:
Amanda Machell, PhD
Institute for Physical Activity and Nutrition (IPAN), Deakin University, 1 Gheringhap Street, Geelong, Australia

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.

(JMIR Pediatr Parent 2026;9:e85215) doi:10.2196/85215

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 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, 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

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

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

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.

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.

Acknowledgments

The authors would like to acknowledge Keenan Baker for providing assistance with coding the video camera footage for screen use contexts. The authors would also like to acknowledge the research assistants who initially coded the video camera footage for screen use.

Funding

KDH is supported by a Heart Foundation Future Leader Fellowship (105929). AM and SJJMV are both supported by Deakin University Postdoctoral Research Fellowships.

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]

References

1. Radesky JS, Christakis DA. Increased screen time: implications for early childhood development and behavior. Pediatr Clin North Am 2016 Oct;63(5):827-839. [doi: 10.1016/j.pcl.2016.06.006] [Medline: 27565361]
2. Mann S, Calvin A, Lenhart A, Robb MB. The common sense census: media use by kids zero to eight. : Common Sense Media; 2025 URL: https://www.commonsensemedia.org/sites/default/files/research/report/2025-common-sense-census-web-2.pdf [accessed 2026-02-15]

3. Okely AD, Ghersi D, Hesketh KD, et al. A collaborative approach to adopting/adapting guidelines - the Australian 24-hour movement guidelines for the early years (birth to 5 years): an integration of physical activity, sedentary behavior, and sleep. BMC Public Health 2017 Nov 20;17(Suppl 5):869. [doi: 10.1186/s12889-017-4867-6] [Medline: 29219094]
4. Tremblay MS, Chaput JP, Adamo KB, et al. Canadian 24-hour movement guidelines for the early years (0-4 years): an integration of physical activity, sedentary behaviour, and sleep. BMC Public Health 2017 Nov 20;17(Suppl 5):874. [doi: 10.1186/s12889-017-4859-6] [Medline: 29219102]
5. Guidelines on physical activity, sedentary behaviour and sleep for children under 5 years of age. World Health Organization. 2018. URL: https://www.who.int/publications/i/item/9789241550536 [accessed 2026-02-24]
6. Sanders T, Noetel M, Parker P, et al. An umbrella review of the benefits and risks associated with youths' interactions with electronic screens. Nat Hum Behav 2024 Jan;8(1):82-99. [doi: 10.1038/s41562-023-01712-8] [Medline: 37957284]
7. Mallawaarachchi S, Burley J, Mavilidi M, et al. Early childhood screen use contexts and cognitive and psychosocial outcomes: a systematic review and meta-analysis. JAMA Pediatr 2024 Oct 1;178(10):1017-1026. [doi: 10.1001/jamapediatrics.2024.2620] [Medline: 39102255]
8. Canadian Paediatric Society, Digital Health Task Force, Ottawa, Ontario. Screen time and young children: promoting health and development in a digital world. Paediatr Child Health 2017 Nov;22(8):461-477. [doi: 10.1093/pch/pxx123] [Medline: 29601064]
9. The health impacts of screen time: a guide for clinicians and parents. : Royal College of Paediatrics and Child Health; 2019 URL: https://opis-cdn.tinkoffjournal.ru/mercury/kids-psychiatry-doc1.xp3sfr..pdf [accessed 2026-02-15]
10. Council on Communications and Media. Media and young minds. Pediatrics 2016 Nov;138(5):e20162591. [doi: 10.1542/peds.2016-2591] [Medline: 27940793]
11. Madigan S, McArthur BA, Anhorn C, Eirich R, Christakis DA. Associations between screen use and child language skills: a systematic review and meta-analysis. JAMA Pediatr 2020 Jul 1;174(7):665-675. [doi: 10.1001/jamapediatrics.2020.0327] [Medline: 32202633]
12. Stiglic N, Viner RM. Effects of screentime on the health and well-being of children and adolescents: a systematic review of reviews. BMJ Open 2019 Jan 3;9(1):e023191. [doi: 10.1136/bmjopen-2018-023191] [Medline: 30606703]
13. Lubans DR, Hesketh K, Cliff DP, et al. A systematic review of the validity and reliability of sedentary behaviour measures used with children and adolescents. Obes Rev 2011 Oct;12(10):781-799. [doi: 10.1111/j.1467-789X.2011.00896.x] [Medline: 21676153]
14. Mallawaarachchi SR, Anglim J, Horwood S. Types and contexts of child mobile screen use and associations with early childhood behavior. Early Child Res Q 2025;70:274-286. [doi: 10.1016/j.ecresq.2024.10.010]
15. Brosnan B, Meredith-Jones KA, Haszard JJ, et al. From dusk to dawn: examining how adolescents engage with digital media using objective measures of screen time in a repeated measures study. Int J Behav Nutr Phys Act 2025 Jan 7;22(1):4. [doi: 10.1186/s12966-024-01698-0] [Medline: 39773653]
16. Lowe BM, Smith M, Jaine R, Stanley J, Gage R, Signal L. Watching the watchers: assessing the nature and extent of children's screen time using wearable cameras. N Z Med J 2023 Jul 7;136(1578):12-31. [doi: 10.26635/6965.6023] [Medline: 37414074]
17. Thomas G, Bennie JA, De Cocker K, Dwi Andriyani F, Booker B, Biddle SJH. Using wearable cameras to categorize the type and context of screen-based behaviors among adolescents: observational study. JMIR Pediatr Parent 2022 Mar 21;5(1):e28208. [doi: 10.2196/28208] [Medline: 35311672]
18. Rideout V, Peebles A, Mann S, Robb MB. The common sense census: media use by tweens and teens, 2021. : Common Sense; 2022 URL: https://www.commonsensemedia.org/sites/default/files/research/report/8-18-census-integrated-report-final-web_0.pdf [accessed 2026-02-15]
19. Socio-economic indexes for areas (SEIFA), Australia. Australian Bureau of Statistics. 2021. URL: https://www.abs.gov.au/statistics/people/people-and-communities/socio-economic-indexes-areas-seifa-australia/latest-release [accessed 2025-08-20]
20. Ratings and reviews parents trust. Common Sense Media. URL: https://www.commonsensemedia.org/ [accessed 2025-04-03]
21. Taggart J, Eisen S, Lillard AS. The current landscape of US children's television: violent, prosocial, educational, and fantastical content. J Child Media 2019 Jul 3;13(3):276-294. [doi: 10.1080/17482798.2019.1605916]
22. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics 1977 Mar;33(1):159-174. [doi: 10.2307/2529310] [Medline: 843571]
23. Bentley GF, Turner KM, Jago R. Mothers' views of their preschool child's screen-viewing behaviour: a qualitative study. BMC Public Health 2016 Aug 4;16:718. [doi: 10.1186/s12889-016-3440-z] [Medline: 27492488]
24. Alroqi H, Serratrice L, Cameron-Faulkner T. The association between screen media quantity, content, and context and language development. J Child Lang 2023 Sep;50(5):1155-1183. [doi: 10.1017/S0305000922000265] [Medline: 35758141]
25. Rai J, Predy M, Wiebe SA, Rinaldi C, Zheng Y, Carson V. Patterns of preschool children's screen time, parent-child interactions, and cognitive development in early childhood: a pilot study. Pilot Feasibility Stud 2023 Mar 14;9(1):39. [doi: 10.1186/s40814-023-01266-6] [Medline: 36918980]
26. Mares ML, Pan Z. Effects of Sesame Street: a meta-analysis of children's learning in 15 countries. J Appl Dev Psychol 2013;34(3):140-151. [doi: 10.1016/j.appdev.2013.01.001]

27. Rice ML, Huston AC, Truglio R, Wright JC. Words from “Sesame Street”: learning vocabulary while viewing. Dev Psychol 1990;26(3):421-428. [doi: 10.1037/0012-1649.26.3.421]
28. Anderson DR, Huston AC, Schmitt KL, Linebarger DL, Wright JC. Early childhood television viewing and adolescent behavior: the recontact study. Monogr Soc Res Child Dev 2001;66(1):I-VIII. [doi: 10.1111/1540-5834.00120] [Medline: 11326591]
29. Christakis DA, Garrison MM, Herrenkohl T, et al. Modifying media content for preschool children: a randomized controlled trial. Pediatrics 2013 Mar;131(3):431-438. [doi: 10.1542/peds.2012-1493] [Medline: 23420911]
30. Strouse GA, Troseth GL, O’Doherty KD, Saylor MM. Co-viewing supports toddlers’ word learning from contingent and noncontingent video. J Exp Child Psychol 2018 Feb;166:310-326. [doi: 10.1016/j.jecp.2017.09.005] [Medline: 28992611]
31. Taylor G, Sala G, Kolak J, Gerhardstein P, Lingwood J. Does adult-child co-use during digital media use improve children’s learning aged 0–6 years? A systematic review with meta-analysis. Educ Res Rev 2024 Aug;44:100614. [doi: 10.1016/j.edurev.2024.100614]

Edited by S Badawy; submitted 03.Oct.2025; peer-reviewed by G Thomas, SR Wickham; accepted 24.Dec.2025; published 26.Feb.2026.

Please cite as:
Machell A, Downing K, Verswijveren SJJM, Hesketh KD
Using Wearable Video Cameras to Assess Screen Use Contexts in Preschool-Aged Children: Pilot Observational Study
JMIR Pediatr Parent 2026;9:e85215
URL: https://pediatrics.jmir.org/2026/1/e85215
doi:10.2196/85215

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

Dongmei Liu[1*], BEng; Yujie Wen[2*], MPH; Meijing An[1], MPH, PhD; Nan Wu[3], BMed; Xiaojing Ren[3], BMed; Xiyao Liu[1], MPH; Jie Huang[4], PhD; Qianling Zhou[1], BEng, MSc, PhD

[1]Department of Maternal and Child Health, School of Public Health, Peking University, No. 38 Xueyuan Road, Haidian District, Beijing, China
[2]Jinan Maternity and Child Care Hospital Affiliated to Shandong First Medical University, Jinan, Shandong Province, China
[3]Loudi Town Hospital of Luancheng District, Shijiazhuang, Hebei Province, China
[4]School of Public Health and Emergency Management, Southern University of Science and Technology, Shenzhen, Guangdong Province, China
[*]these authors contributed equally

Corresponding Author:
Qianling Zhou, BEng, MSc, PhD
Department of Maternal and Child Health, School of Public Health, Peking University, No. 38 Xueyuan Road, Haidian District, Beijing, China

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.

(JMIR Pediatr Parent 2026;9:e78028) doi:10.2196/78028

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 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, 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 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).

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.

[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).

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 (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.

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.

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 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.

Acknowledgments

We acknowledge the Peking University Research Initiation Fund for their support. We also gratefully acknowledge Olivier Friard and Marco Gamba for allowing free use of Behavioral Observation Research Interactive Software.

Funding

This study was funded by the Peking University Research Initiation Fund (grant number: BMU2018YJ005).

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]

References

1. Britto PR, Lye SJ, Proulx K, et al. Nurturing care: promoting early childhood development. Lancet 2017 Jan 7;389(10064):91-102. [doi: 10.1016/S0140-6736(16)31390-3] [Medline: 27717615]
2. Nurturing care for early childhood development: a framework for helping children survive and thrive to transform health and human potential: executive summary. : World Health Organization; 2018 URL: https://iris.who.int/server/api/core/bitstreams/4d4a2e78-c587-408f-81e3-7ab2614d66f6/content [accessed 2026-02-04]
3. Black MM, Aboud FE. Responsive feeding is embedded in a theoretical framework of responsive parenting. J Nutr 2011 Mar;141(3):490-494. [doi: 10.3945/jn.110.129973] [Medline: 21270366]
4. Dewey K. Guiding Principles for Complementary Feeding of the Breastfed Child: Pan American Health Organization; 2003. URL: https://iris.paho.org/handle/10665.2/752 [accessed 2026-02-04]
5. Wen Y, An M, Wu N, et al. Association between caregivers' responsive feeding practices and eating behaviors of children aged 6-35 months. Appetite 2025 Sep 1;213:108141. [doi: 10.1016/j.appet.2025.108141] [Medline: 40388989]
6. An M, Liu X, Wu N, Zhou Q. Association between caregivers' responsive feeding practices and the intake of fruit and vegetable among children aged 6-36 months: the mediating role of children's enjoyment of food. Appetite 2026 Feb 1;217:108325. [doi: 10.1016/j.appet.2025.108325] [Medline: 41016710]
7. Moding KJ, Fries LR. Feeding practices demonstrated by parents of toddlers: an observational analysis of breakfast, lunch, dinner, and snacks. Appetite 2020 Dec 1;155:104825. [doi: 10.1016/j.appet.2020.104825] [Medline: 32777244]
8. Rodgers RF, Paxton SJ, McLean SA, et al. Maternal negative affect is associated with emotional feeding practices and emotional eating in young children. Appetite 2014 Sep;80:242-247. [doi: 10.1016/j.appet.2014.05.022] [Medline: 24859640]
9. Guo S, Wang Y, Fries LR, et al. Infant and preschooler feeding behaviors in Chinese families: a systematic review. Appetite 2022 Jan 1;168:105768. [doi: 10.1016/j.appet.2021.105768] [Medline: 34688731]
10. Hurley KM, Cross MB, Hughes SO. A systematic review of responsive feeding and child obesity in high-income countries. J Nutr 2011 Mar;141(3):495-501. [doi: 10.3945/jn.110.130047] [Medline: 21270360]
11. Heller RL, Mobley AR. Instruments assessing parental responsive feeding in children ages birth to 5 years: a systematic review. Appetite 2019 Jul 1;138:23-51. [doi: 10.1016/j.appet.2019.03.006] [Medline: 30853452]
12. Pesch MH, Lumeng JC. Methodological considerations for observational coding of eating and feeding behaviors in children and their families. Int J Behav Nutr Phys Act 2017 Dec 15;14(1):170. [doi: 10.1186/s12966-017-0619-3] [Medline: 29246234]
13. Abebe Z, Haki GD, Baye K. Child feeding style is associated with food intake and linear growth in rural Ethiopia. Appetite 2017 Sep 1;116:132-138. [doi: 10.1016/j.appet.2017.04.033] [Medline: 28461197]
14. Sacco LM, Bentley ME, Carby-Shields K, Borja JB, Goldman BD. Assessment of infant feeding styles among low-income African-American mothers: comparing reported and observed behaviors. Appetite 2007 Jul;49(1):131-140. [doi: 10.1016/j.appet.2007.01.004] [Medline: 17336423]
15. Bergmeier HJ, Skouteris H, Haycraft E, Haines J, Hooley M. Reported and observed controlling feeding practices predict child eating behavior after 12 months. J Nutr 2015 Jun;145(6):1311-1316. [doi: 10.3945/jn.114.206268] [Medline: 25878204]

16. Xie LH. Development and evaluation of Parents' Feeding Practice Scale for Infant and Young Child [Master's thesis in Chinese]. : Capital Institute of Pediatrics; 2017 URL: https://cdmd.cnki.com.cn/Article/CDMD-87120-1018811923.htm [accessed 2026-02-04]
17. Thompson AL, Mendez MA, Borja JB, Adair LS, Zimmer CR, Bentley ME. Development and validation of the Infant Feeding Style Questionnaire. Appetite 2009 Oct;53(2):210-221. [doi: 10.1016/j.appet.2009.06.010] [Medline: 19576254]
18. Ma JQ, Zhou LL, Hu YQ, Liu SS, Sheng XY. Association between feeding practices and weight status in young children. BMC Pediatr 2015 Aug 26;15(1):97. [doi: 10.1186/s12887-015-0418-4] [Medline: 26306490]
19. McNally J, Hugh-Jones S, Caton S, Vereijken C, Weenen H, Hetherington MM. The eyes have it: infant gaze as an indicator of hunger and satiation. Appetite 2019 Feb 1;133:353-361. [doi: 10.1016/j.appet.2018.11.026] [Medline: 30502439]
20. Palfreyman Z, Haycraft E, Meyer C. Parental modelling of eating behaviours: observational validation of the Parental Modelling of Eating Behaviours scale (PARM). Appetite 2015 Mar;86:31-37. [doi: 10.1016/j.appet.2014.08.008] [Medline: 25111293]
21. Haycraft EL, Blissett JM. Maternal and paternal controlling feeding practices: reliability and relationships with BMI. Obesity (Silver Spring) 2008 Jul;16(7):1552-1558. [doi: 10.1038/oby.2008.238] [Medline: 18421263]
22. Friard O, Gamba M. BORIS: a free, versatile open‐source event‐logging software for video/audio coding and live observations. Methods Ecol Evol 2016 Nov;7(11):1325-1330. [doi: 10.1111/2041-210X.12584]
23. Powell F, Farrow C, Meyer C, Haycraft E. The importance of mealtime structure for reducing child food fussiness. Matern Child Nutr 2017 Apr;13(2):27062194. [doi: 10.1111/mcn.12296] [Medline: 27062194]
24. Hodges EA, Johnson SL, Hughes SO, Hopkinson JM, Butte NF, Fisher JO. Development of the responsiveness to child feeding cues scale. Appetite 2013 Jun;65:210-219. [doi: 10.1016/j.appet.2013.02.010] [Medline: 23419965]
25. Guo SY, Xie SX, Xiong YL, Zhang JD. Study on the correlation between dietary behaviors of children aged two years old and gender and maternal feeding styles [Article in Chinese]. Maternal and Child Health Care of China 2017;32(1):85-88 [FREE Full text]
26. Lo K, Cheung C, Lee A, Keung V, Tam W. Associated demographic factors of instrumental and emotional feeding in parents of Hong Kong children. J Acad Nutr Diet 2016 Dec;116(12):1925-1931. [doi: 10.1016/j.jand.2016.06.006] [Medline: 27469278]
27. Klerks M, Roman S, Bernal MJ, Haro-Vicente JF, Sanchez-Siles LM. Complementary feeding practices and parental pressure to eat among Spanish infants and toddlers: a cross-sectional study. Int J Environ Res Public Health 2021 Feb 18;18(4):1982. [doi: 10.3390/ijerph18041982] [Medline: 33670769]
28. Thompson AL, Adair LS, Bentley ME. Pressuring and restrictive feeding styles influence infant feeding and size among a low-income African-American sample. Obesity (Silver Spring) 2013 Mar;21(3):562-571. [doi: 10.1002/oby.20091] [Medline: 23592664]
29. Marr C, Breeze P, Caton SJ. A comparison between parent and grandparent dietary provision, feeding styles and feeding practices when caring for preschool-aged children. Appetite 2022 Jan 1;168:105777. [doi: 10.1016/j.appet.2021.105777] [Medline: 34715243]
30. Farrow C. A comparison between the feeding practices of parents and grandparents. Eat Behav 2014 Aug;15(3):339-342. [doi: 10.1016/j.eatbeh.2014.04.006] [Medline: 25064278]
31. Jiang J, Rosenqvist U, Wang H, Greiner T, Lian G, Sarkadi A. Influence of grandparents on eating behaviors of young children in Chinese three-generation families. Appetite 2007 May;48(3):377-383. [doi: 10.1016/j.appet.2006.10.004] [Medline: 17166624]
32. Wungrath J, Chanwikrai Y, Khumai N, Sutan P. Perception towards food choice among low-income factory worker parents of pre-school children in Northern Thailand: a qualitative study. Malaysian J Public Health Med 2022;22(3):98-106. [doi: 10.37268/mjphm/vol.22/no.3/art.1682]
33. Black MM. Toddler development and autonomy: baby-led weaning, neophobia, and responsive parenting. Nestle Nutr Inst Workshop Ser 2020;95:1-11. [doi: 10.1159/000511518] [Medline: 33161408]
34. Ruggiero CF, McHale SM, Paul IM, Savage JS. Learned experience and resource dilution: conceptualizing sibling influences on parents' feeding practices. Int J Environ Res Public Health 2021 May 27;18(11):5739. [doi: 10.3390/ijerph18115739] [Medline: 34071852]
35. Ongprasert K, Chawachat J, Wungrath J, Kiratipaisarl W. Prevalence and determinants of inappropriate complementary feeding practices among children aged 6-23 months in Chiang Mai, Northern Thailand: a cross-sectional study. BMC Public Health 2025 Jun 2;25(1):2043. [doi: 10.1186/s12889-025-23293-z] [Medline: 40457324]
36. China Population Census Yearbook 2020 [Article in Chinese]: National Bureau of Statistics of China; 2020. URL: https://www.stats.gov.cn/sj/pcsj/rkpc/7rp/indexch.htm [accessed 2026-02-03]
37. 2022年河北省居民健康素养水平稳步提升 (Health literacy of residents in Hebei Province improves steadily in 2022) [Article in Chinese]. Health Commission of Hebei Province. 2023. URL: https://wsjkw.hebei.gov.cn/sjdt/394661.jhtml [accessed 2026-02-03]
38. 2022 年中国居民健康素养监测情况 (The national surveillance of health literacy among Chinese residents in 2022) [Article in Chinese]. National Health Commission of the People's Republic of China. 2023. URL: https://www.gov.cn/lianbo/bumen/202308/P020230822019124684406.pdf [accessed 2026-02-03]

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

Edited by S Badawy; submitted 27.May.2025; peer-reviewed by E Hentschel, J Wungrath; revised version received 29.Dec.2025; accepted 25.Jan.2026; published 26.Feb.2026.

Please cite as:
Liu D, Wen Y, An M, Wu N, Ren X, Liu X, Huang J, Zhou Q
Responsive Feeding Practices Among Caregivers of Children Aged 6-35 Months in China: Descriptive Study Involving Survey and Video Observation Methods
JMIR Pediatr Parent 2026;9:e78028
URL: https://pediatrics.jmir.org/2026/1/e78028
doi:10.2196/78028

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

Ying Lau[1], BSc, BN (Hons), MN, PhD, RN, RM; Yueyang Yi[2], BEng (Hons), MSc; Zebulon To[3], BA, MA, MSocSc; Sai Ho Wong[4], BSN (Hons), RN; Thomas Yuen Tung Lam[1], BNurs, MSc, PhD, RN

[1]Nethersole School of Nursing, The Chinese University of Hong Kong, 6-8/F, Esther Lee Building, Shatin, New Territories, Hong Kong, China (Hong Kong)

[2]Stanley Ho Big Data Decision Analytics Research Center, The Chinese University of Hong Kong, Hong Kong, China (Hong Kong)

[3]Institute of Digestive Disease, The Chinese University of Hong Kong, Hong Kong, China (Hong Kong)

[4]Alexandra Hospital, Singapore, Singapore

Corresponding Author:
Thomas Yuen Tung Lam, BNurs, MSc, PhD, RN
Nethersole School of Nursing, The Chinese University of Hong Kong, 6-8/F, Esther Lee Building, Shatin, New Territories, Hong Kong, China (Hong Kong)

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.

(JMIR Pediatr Parent 2026;9:e80637) doi:10.2196/80637

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.

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].

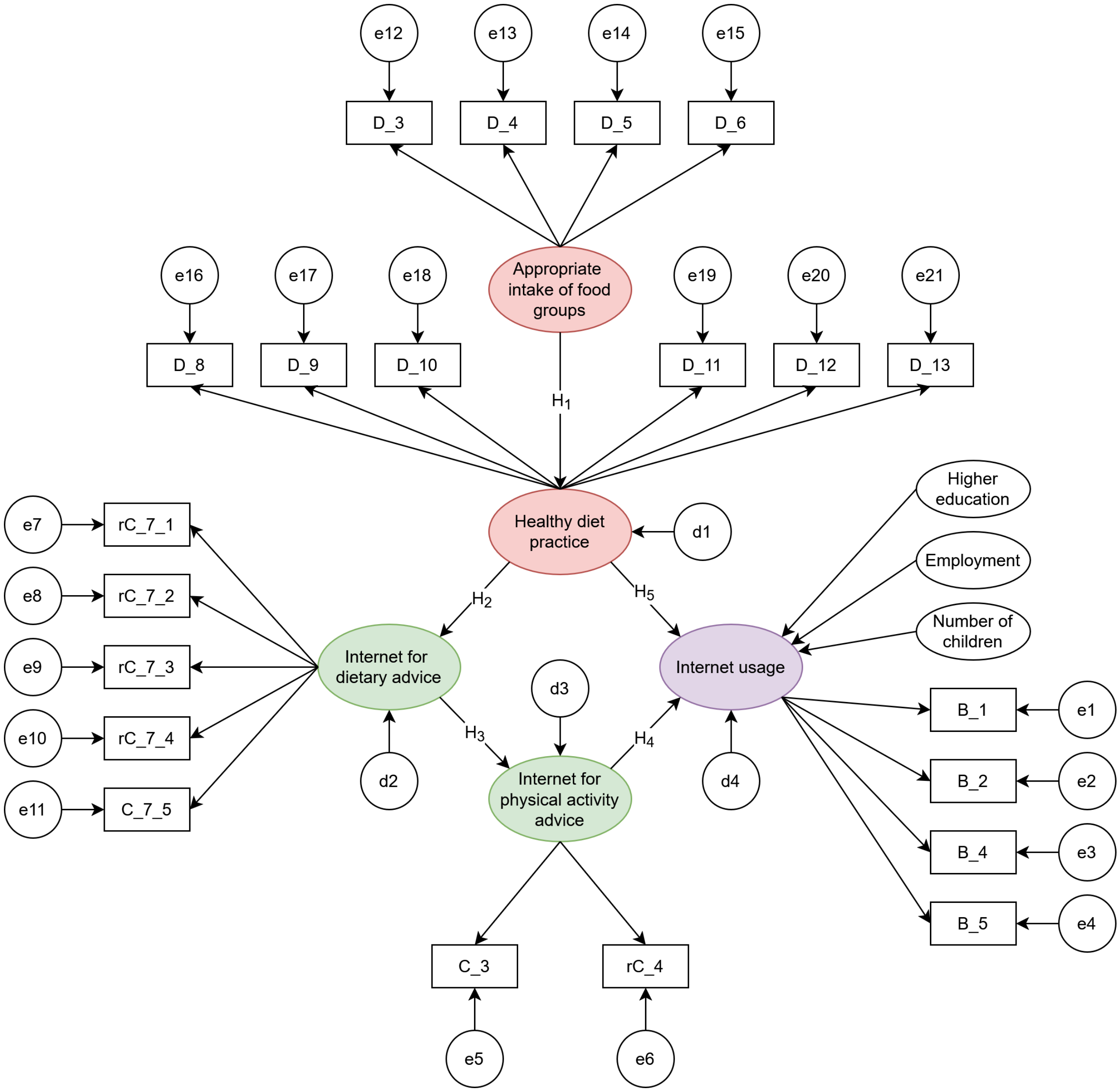
According to the SCT, self-control is the ability to regulate current thoughts, feelings, and behavior to secure future benefits [15], which is very important for health and well-being and involves the repeated act of overriding a dominant response [16]. This trait can manifest in behaviors such as adopting 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.

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 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 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.

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]

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]

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.

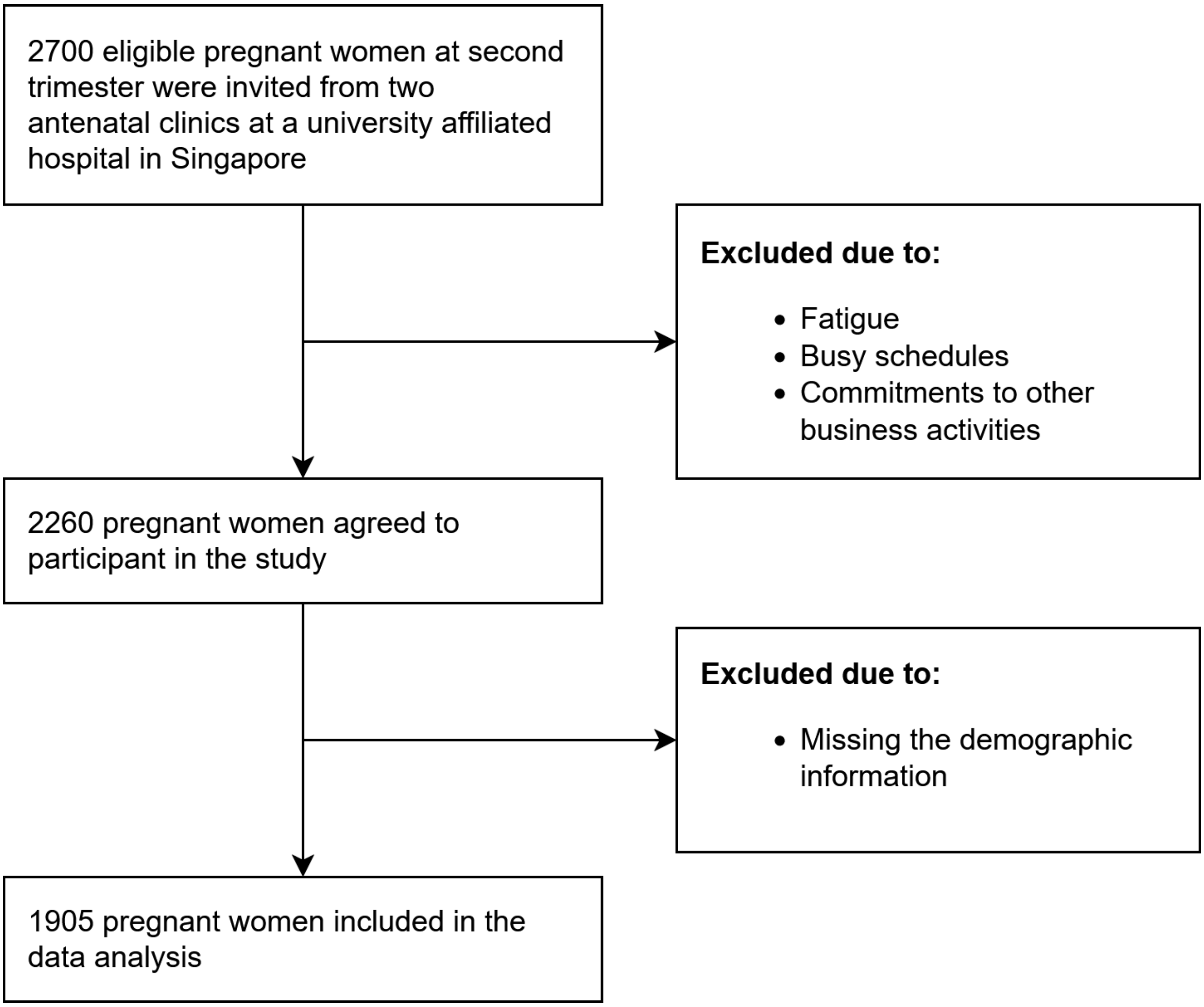
[h] *P*<.05.

[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

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.

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)

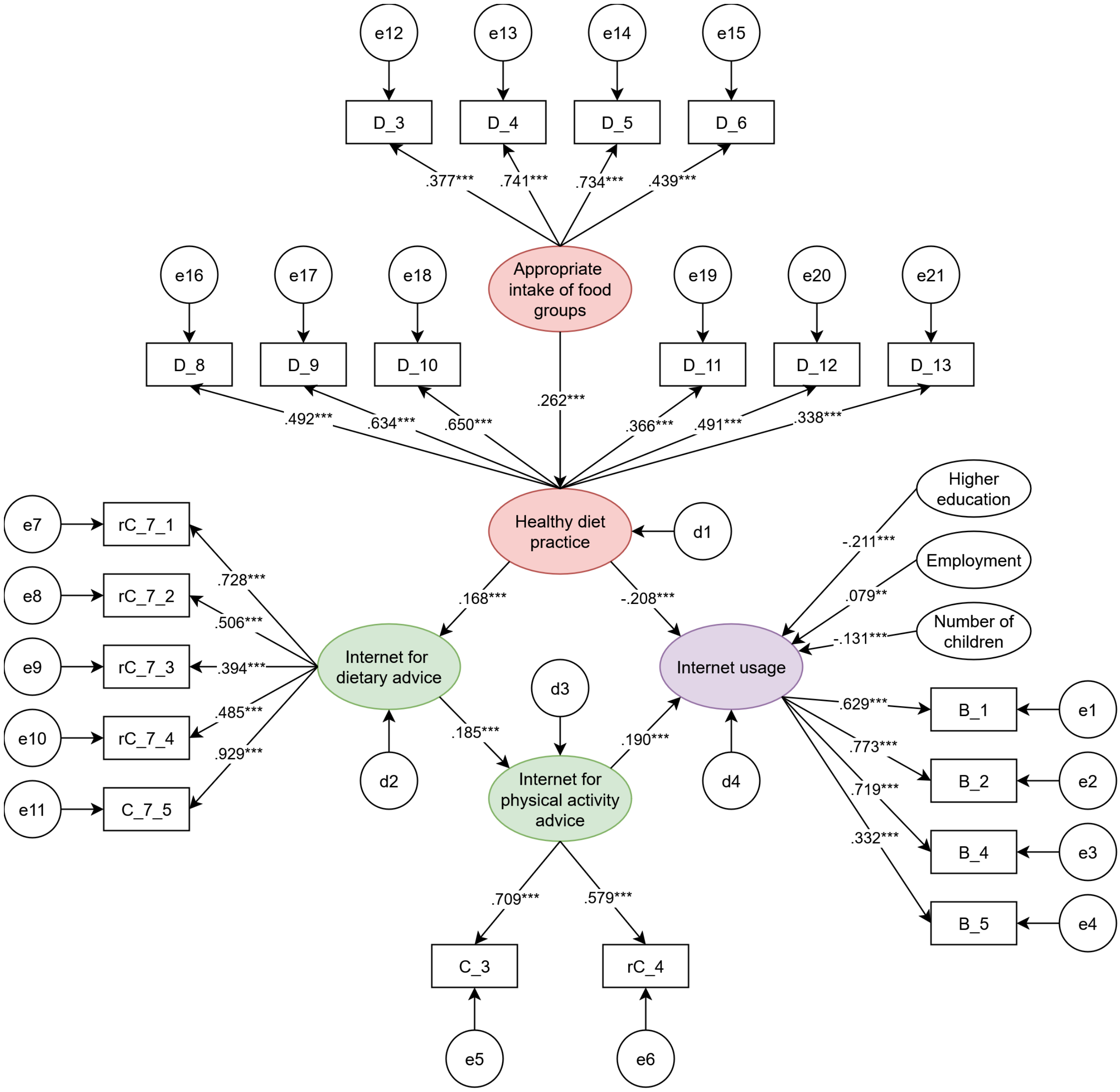
[a] IFI: incremental fit index.

[b] TLI: Tucker-Lewis index.

[c] CFI: comparative fit index.

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

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.

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]										

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]										

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.

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

[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.

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.

Acknowledgments

The authors would like to acknowledge pregnant women in Singapore who participated in our study.

Funding

The study was funded by Humanities & Social Sciences Seed Fund Grant, National University of Singapore, Singapore (grant number HSS Seed Funding-1/2016, WBS number: R545-000-076-646).

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]

References

1. Morales-Suarez-Varela M, Rocha-Velasco OA. Impact of ultra-processed food consumption during pregnancy on maternal and child health outcomes: a comprehensive narrative review of the past five years. Clin Nutr ESPEN 2025 Feb;65:288-304. [doi: 10.1016/j.clnesp.2024.12.006] [Medline: 39662587]
2. Xie W, Zhang L, Cheng J, Wang Y, Kang H, Gao Y. Physical activity during pregnancy and the risk of gestational diabetes mellitus: a systematic review and dose-response meta-analysis. BMC Public Health 2024 Feb 23;24(1):594. [doi: 10.1186/s12889-024-18131-7] [Medline: 38395913]

3. Yamamoto JM, Murphy HR. Technology and pregnancy. Diabetes Technol Ther 2024 Mar;26(S1):S108-S116. [doi: 10.1089/dia.2024.2507] [Medline: 38441447]
4. Digital 2025: Singapore. DataReportal – Global Digital Insights. 2025. URL: https://datareportal.com/reports/digital-2025-singapore [accessed 2025-12-24]
5. Conrad M. Health information-seeking internet behaviours among pregnant women: a narrative literature review. J Reprod Infant Psychol 2024 Mar;42(2):194-208. [doi: 10.1080/02646838.2022.2088711] [Medline: 35703164]
6. Uzan LM, Brust M, Molenaar JM, Leistra E, Boor K, Kiefte-de Jong JC. A cross-sectional analysis of factors associated with the teachable moment concept and health behaviors during pregnancy. BMC Pregnancy Childbirth 2024 Feb 20;24(1):147. [doi: 10.1186/s12884-024-06348-8] [Medline: 38378517]
7. Gjestvang C, Haakstad LAH. Navigating pregnancy: information sources and lifestyle behavior choices-a narrative review. J Pregnancy 2024;2024(1):4040825. [doi: 10.1155/2024/4040825] [Medline: 39346810]
8. Aghasi M, Matinfar A, Golzarand M, Salari-Moghaddam A, Ebrahimpour-Koujan S. Internet use in relation to overweight and obesity: a systematic review and meta-analysis of cross-sectional studies. ADV Nutr 2020 Mar 1;11(2):349-356. [doi: 10.1093/advances/nmz073] [Medline: 31386144]
9. Rezaee R, Ravangard R, Amani F, Dehghani Tafti A, Shokrpour N, Bahrami MA. Healthy lifestyle during pregnancy: uncovering the role of online health information seeking experience. PLoS ONE 2022;17(8):e0271989. [doi: 10.1371/journal.pone.0271989] [Medline: 35913949]
10. Al-Dahshan A, Kehyayan V, Al-Kubaisi N, Selim N. Utilization of the internet for physical activity and diet information and its influence on pregnant women's lifestyle habits in Qatar. Front Public Health 2023;11:1272109. [doi: 10.3389/fpubh.2023.1272109] [Medline: 37829092]
11. Maddux JE, Rogers RW. Protection motivation and self-efficacy: a revised theory of fear appeals and attitude change. J Exp Soc Psychol 1983 Sep;19(5):469-479. [doi: 10.1016/0022-1031(83)90023-9]
12. Vohs KD, Baumeister RF. Handbook of Self-Regulation: Research, Theory, and Applications, 3rd edition: The Guilford Press; 2018. [doi: 10.5860/CHOICE.42-3719]
13. Rogers RW. A protection motivation theory of fear appeals and attitude change1. J Psychol 1975 Sep;91(1):93-114. [doi: 10.1080/00223980.1975.9915803] [Medline: 28136248]
14. Bagherzadeh R, Gharibi T, Safavi B, Mohammadi SZ, Karami F, Keshavarz S. Pregnancy; an opportunity to return to a healthy lifestyle: a qualitative study. BMC Pregnancy Childbirth 2021 Nov 5;21(1):751. [doi: 10.1186/s12884-021-04213-6] [Medline: 34740317]
15. Ridder D, Adriaanse M, Fujita K. Self-control in health and well-being: concepts, theories, and central issues. In: Routledge International Handbook of Self-Control in Health and Well-Being: Routledge; 2017:1-7. [doi: 10.4324/9781315648576-1]
16. Beames JR, Schofield TP, Denson TF. A meta-analysis of improving self-control with practice. In: Routledge International Handbook of Self-Control in Health and Well-Being Routledge 2017:405-417. [doi: 10.4324/9781315648576-32]
17. Kartchner LC, Dunn A, Taylor KH, et al. Lifestyle modifications prior to pregnancy and their impact on maternal and perinatal outcomes: a review. J Clin Med 2025 Sep 18;14(18):6582. [doi: 10.3390/jcm14186582] [Medline: 41010783]
18. Sample size calculator. Raosoft. URL: http://www.raosoft.com/samplesize.html [accessed 2017-04-25]
19. Su LL, Chong YS, Chan YH, et al. Antenatal education and postnatal support strategies for improving rates of exclusive breast feeding: randomised controlled trial. BMJ 2007 Sep 22;335(7620):596. [doi: 10.1136/bmj.39279.656343.55] [Medline: 17670909]
20. Chen KK, Wee SL, Pang BWJ, et al. Relationship between BMI with percentage body fat and obesity in Singaporean adults - the Yishun study. BMC Public Health 2021 Jun 1;21(1):1030. [doi: 10.1186/s12889-021-11070-7] [Medline: 34074272]
21. Segal-Isaacson CJ, Wylie-Rosett J, Gans KM. Validation of a short dietary assessment questionnaire: the Rapid Eating and Activity Assessment for Participants short version (REAP-S). Diabetes Educ 2004;30(5):774-781. [doi: 10.1177/014572170403000512] [Medline: 15510530]
22. Segal-Isaacson CJ, Tobin JN, Weiss SM, et al. Improving dietary habits in disadvantaged women with HIV/AIDS: the SMART/EST women's project. AIDS Behav 2006 Nov;10(6):659-670. [doi: 10.1007/s10461-006-9115-5] [Medline: 16770694]
23. Gans KM, Risica PM, Wylie-Rosett J, et al. Development and evaluation of the nutrition component of the rapid eating and activity assessment for patients (REAP): a new tool for primary care providers. J Nutr Educ Behav 2006;38(5):286-292. [doi: 10.1016/j.jneb.2005.12.002] [Medline: 16966049]
24. Huberty J, Dinkel D, Beets MW, Coleman J. Describing the use of the internet for health, physical activity, and nutrition information in pregnant women. Matern Child Health J 2013 Oct;17(8):1363-1372. [doi: 10.1007/s10995-012-1160-2] [Medline: 23090284]
25. Lagan BM, Sinclair M, Kernohan WG. A Web-based survey of midwives' perceptions of women using the Internet in pregnancy: a global phenomenon. Midwifery 2011 Apr;27(2):273-281. [doi: 10.1016/j.midw.2009.07.002] [Medline: 19700228]
26. Monetti DM, Whatley MA. A factor analytic study of the Internet Usage Scale (IUS). J Res Educ 2011(2):14-23 [FREE Full text]
27. The R project for statistical computing. The R Foundation. 2023. URL: https://www.R-project.org/ [accessed 2025-07-11]

28. SAS 9.4 Software overview for the customer. SAS Support. 2024. URL: https://support.sas.com/software/94/ [accessed 2025-07-11]
29. Bagozzi RP, Yi Y. Specification, evaluation, and interpretation of structural equation models. J of the Acad Mark Sci 2012 Jan;40(1):8-34. [doi: 10.1007/s11747-011-0278-x]
30. Satorra A, Bentler PM. Corrections to test statistics and standard errors in covariance structure analysis. In: von Eye A, Clogg CC, editors. Latent Variables Analysis: Applications for Developmental Research: Sage Publications, Inc; 1994:399-419 URL: https://psycnet.apa.org/record/1996-97111-016 [accessed 2025-07-11]
31. Schafer JL. Analysis of Incomplete Multivariate Data: Chapman and Hall; 1997.
32. Rubin DB. Multiple Imputation for Nonresponse in Surveys: John Wiley & Sons; 1987. [doi: 10.1002/9780470316696]
33. Kline RB. Principles and Practice of Structural Equation Modeling, 4th edition: Guilford Press; 2016. URL: https://research.ebsco.com/linkprocessor/plink?id=f888389b-df0e-3740-9f72-9e7cb1f2bac0 [accessed 2025-07-11]
34. van Prooijen JW, van der Kloot WA. Confirmatory analysis of exploratively obtained factor structures. Educ Psychol Meas 2001 Oct;61(5):777-792. [doi: 10.1177/00131640121971518]
35. West SG, Taylor AB, Wu W. Model fit and model selection in structural equation modeling. In: Hoyle RH Handbook of Structural Equation Modeling: The Guilford Press; 2012:209-231.
36. Hu LT, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. Struct Equ Modeling 1999 Jan;6(1):1-55. [doi: 10.1080/10705519909540118]
37. Deng X, Doll WJ, Hendrickson AR, Scazzero JA. A multi-group analysis of structural invariance: an illustration using the technology acceptance model. Information & Management 2005 Jul;42(5):745-759. [doi: 10.1016/j.im.2004.08.001]
38. Mihiret GT, Meselu BT, Wondmu KS, Getaneh T, Moges NA. Health-promoting lifestyle behaviors and their associated factors among pregnant women in Debre Markos, northwest Ethiopia: a cross-sectional study. Front Glob Womens Health 2024;5:1468725. [doi: 10.3389/fgwh.2024.1468725] [Medline: 39830937]
39. Daigle Millan K, Poccia S, Fung TT. Information seeking behaviors, attitudes, and beliefs about pregnancy-related nutrition and supplementation: a qualitative study among US women. Nutr Health 2022 Dec;28(4):563-569. [doi: 10.1177/02601060211038842] [Medline: 34931929]
40. Kolovos S, Jimenez-Moreno AC, Pinedo-Villanueva R, Cassidy S, Zavala GA. Association of sleep, screen time and physical activity with overweight and obesity in Mexico. Eat Weight Disord 2021 Feb;26(1):169-179. [doi: 10.1007/s40519-019-00841-2] [Medline: 31893356]
41. Syed H, Slayman T, DuChene Thoma K. ACOG committee opinion no. 804: physical activity and exercise during pregnancy and the postpartum period. Obstet Gynecol 2021 Feb 1;137(2):375-376. [doi: 10.1097/AOG.0000000000004266] [Medline: 33481513]
42. Amalia L, Lisna AF, Putri ST, Sumartini S, Mega N. The contribution of pregnant women characteristics to pregnancy exercise perception. 2020 Presented at: 4th International Conference on Sport Science, Health, and Physical Education (ICSSHPE 2019); Oct 8-9, 2019. [doi: 10.2991/ahsr.k.200214.045]
43. Syed Nor SF, Idris IB, Md Isa Z. Physical inactivity in early pregnancy and the determinants in an urban city setting of Kuala Lumpur, Malaysia. BMC Public Health 2022 Jan 13;22(1):93. [doi: 10.1186/s12889-022-12513-5] [Medline: 35027033]
44. Alur A, Phipps JE, Simmons LA. Socioecological factors influencing the risk of developing hypertensive disorders of pregnancy in India: a rapid review. BMC Pregnancy Childbirth 2024 Oct 12;24(1):669. [doi: 10.1186/s12884-024-06879-0] [Medline: 39395960]
45. Md Yunus NF, Abdul Manaf R, Kadir Shahar H, Ismail S, Jathin R. Barriers and preferences to antenatal exercise among pregnant women in Kuala Selangor. Malays J Med Health Sci 2024;20(4):72-78. [doi: 10.47836/mjmhs20.4.10]
46. Janakiraman B, Ramachandran A, Ravichandran H, et al. Physical activity level among pregnant women attending maternal healthcare services in rural Karnataka; findings of a cross-sectional study. F1000Res 2024;13:1223. [doi: 10.12688/f1000research.151485.1]
47. Progress report on women’s development. Ministry of Social and Family Development. 2024. URL: https://www.msf.gov.sg/docs/default-source/research-data/progressonsingaporewomensdevelopmentreport2024.pdf?sfvrsn=806a1902_2 [accessed 2026-03-10]
48. Kim J, Heazell AEP, Whittaker M, Stacey T, Watson K. Impact of health literacy on pregnancy outcomes in socioeconomically disadvantaged and ethnic minority populations: a scoping review. Int J Gynaecol Obstet 2025 Jan;168(1):69-81. [doi: 10.1002/ijgo.15852] [Medline: 39175268]
49. Rebelle CCP, Jette SL, Mills JM, Tinius RA. Examining beliefs, behaviors, and provider counseling on physical activity during pregnancy: a cross-sectional study in the Southern United States. JOPPPAH 2024 Apr 10;38(1):17-34. [doi: 10.62858/apphZ6Ir1Amf]
50. Hsiung Y, Lee CF, Chi LK, Huang JP. “Moving for My Baby!” Motivators and perceived barriers to facilitate readiness for physical activity during pregnancy among obese and overweight women of urban areas in northern Taiwan. Int J Environ Res Public Health 2021 May 15;18(10):5275. [doi: 10.3390/ijerph18105275] [Medline: 34063538]

51. Olloqui-Mundet MJ, Cavia MDM, Alonso-Torre SR, Carrillo C. Dietary habits and nutritional knowledge of pregnant women: the importance of nutrition education. Foods 2024 Oct 8;13(19):3189. [doi: 10.3390/foods13193189] [Medline: 39410224]
52. Kington RS, Arnesen S, Chou WYS, Curry SJ, Lazer D, Villarruel AM. Identifying credible sources of health information in social media: principles and attributes. NAM Perspect 2021;2021. [doi: 10.31478/202107a] [Medline: 34611600]
53. Ketchum K, Jevitt CM. Evidence-based eating patterns and behavior changes to limit excessive gestational weight gain: a scoping review. Int J Environ Res Public Health 2023 Dec 21;21(1):15. [doi: 10.3390/ijerph21010015] [Medline: 38276803]
54. Simonson AP, Davis KK, Barone Gibbs B, Venditti EM, Jakicic JM. Comparison of mindful and slow eating strategies on acute energy intake. Obes Sci Pract 2020 Dec;6(6):668-676. [doi: 10.1002/osp4.441] [Medline: 33354345]
55. Huang J, Kumar S, Hu C. Does culture matter? A comparative study on the motivations for online identity reconstruction between China and Malaysia. SAGE Open 2020 Apr;10(2):2158244020929311. [doi: 10.1177/2158244020929311]
56. Jamalova M. Cultural values and digital gap: overview of behavioral patterns. PLoS ONE 2024;19(10):e0311390. [doi: 10.1371/journal.pone.0311390] [Medline: 39352898]
57. Bromell D. Challenges in regulating online content. In: Bromell D, editor. Regulating Free Speech in a Digital Age: Hate, Harm and the Limits of Censorship: Springer International Publishing; 2022:29-53. [doi: 10.1007/978-3-030-95550-2_2]

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

---

Edited by A Nguyen; submitted 14.Jul.2025; peer-reviewed by H Mahmoodi, J Volkman; revised version received 25.Dec.2025; accepted 08.Jan.2026; published 30.Mar.2026.

Please cite as:
Lau Y, Yi Y, To Z, Wong SH, Lam TYT
Healthy Lifestyle Practices, Online Health Information–Seeking Behaviors, and Internet Usage Among Pregnant Women: Multigroup Structural Equation Modeling Approach
JMIR Pediatr Parent 2026;9:e80637
URL: https://pediatrics.jmir.org/2026/1/e80637
doi:10.2196/80637

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

Jessie L Juusola[1], PhD; Shefali Kumar[1], MPH; Meghana S Iragavarapu[1], MPH; Luke Mueller[2], MS; Neil Batlivala[2,3], BS; Michael K Ong[4], MD, PhD; Andrey Ostrovsky[5], MD; Nathan Favini[2,6], MD, MS

[1]Anchor Outcomes LLC, 1933 California Street, San Francisco, CA, United States
[2]Pair Team, 1459 18th Street, #206, San Francisco, CA, United States
[3]School of Computer Science, Carnegie Mellon University, Pittsburgh, PA, United States
[4]Departments of Medicine & Health Policy and Management, University of California, Los Angeles, Los Angeles, CA, United States
[5]Social Innovation Ventures, Lewes, DE, United States
[6]School of Public Health, University of California, Berkeley, Berkeley, CA, United States

Corresponding Author:
Nathan Favini, MD, MS
Pair Team, 1459 18th Street, #206, San Francisco, CA, United States

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.

(JMIR Pediatr Parent 2026;9:e88204) doi:10.2196/88204

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, 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 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 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.

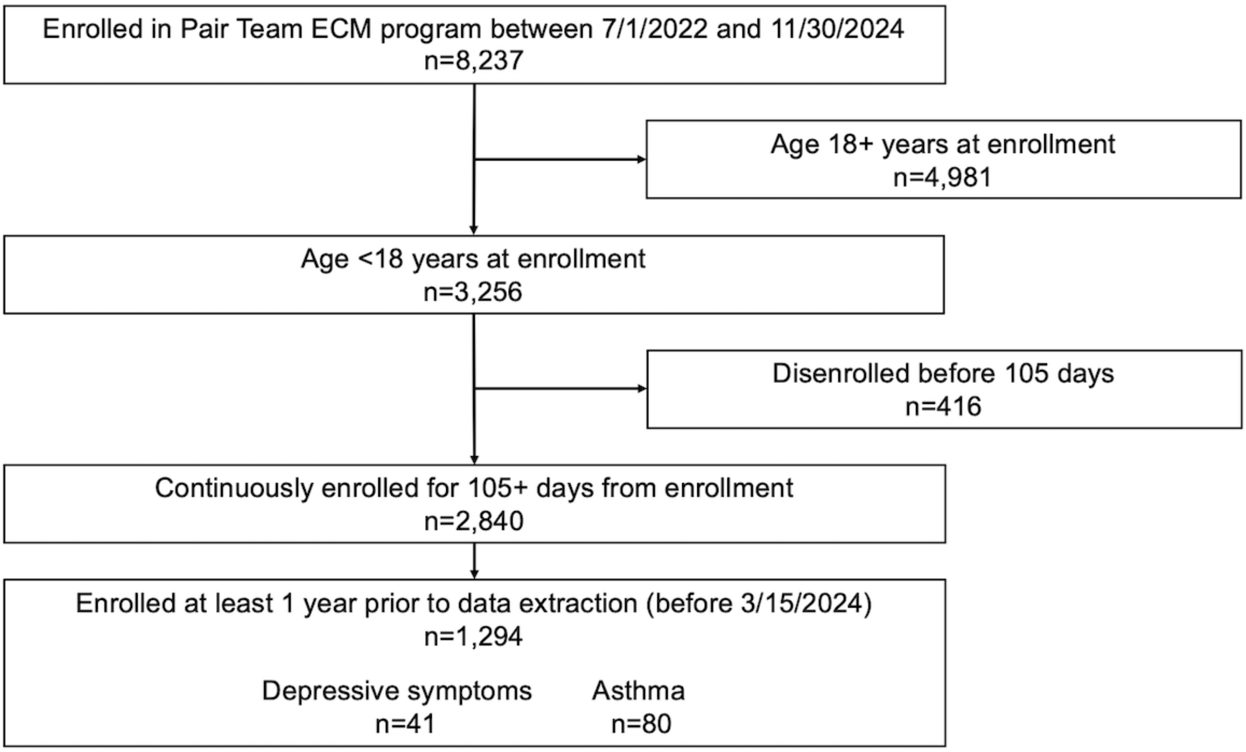


Table . Description of study cohort.

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

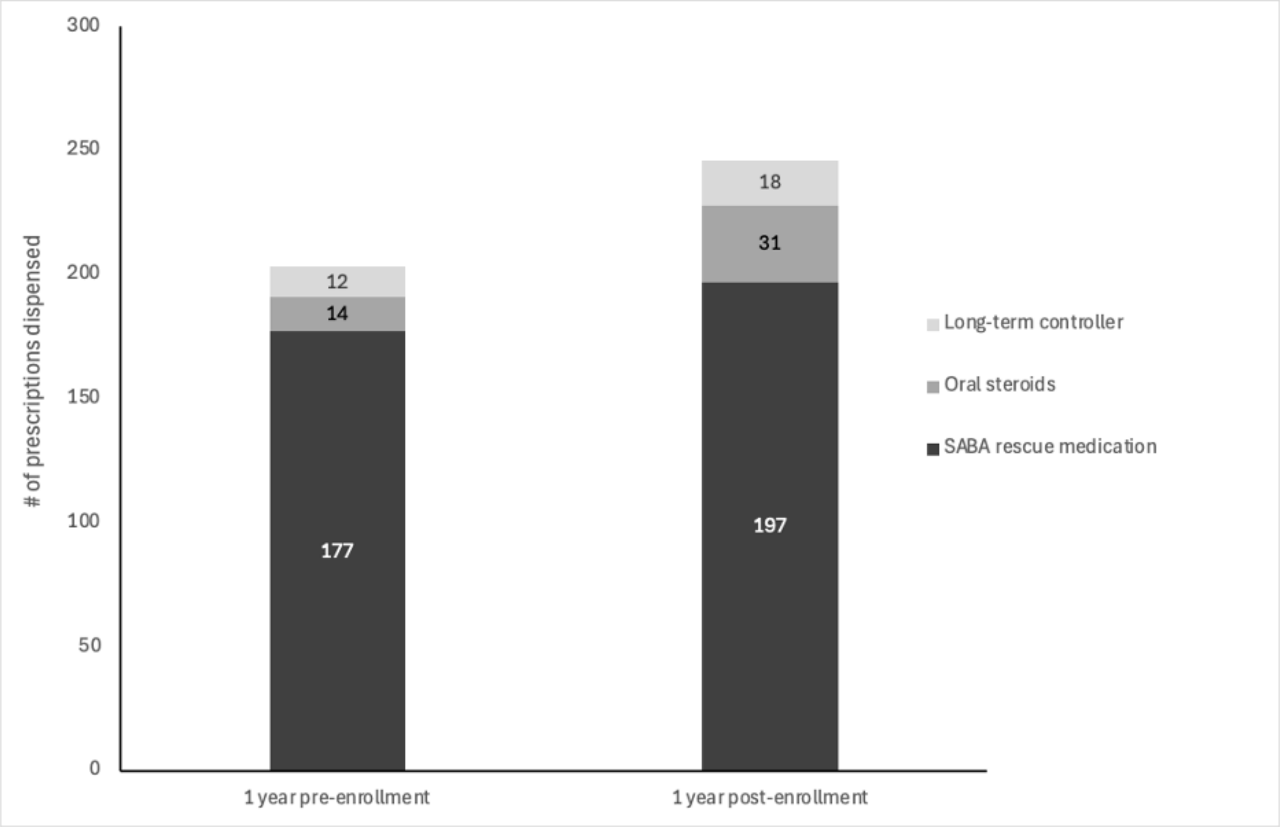
As noted above, retention after 3 months of enrollment was 87.2% (2840/3256). Among the 2726 pediatric patients who enrolled in the program at least 6 months prior to data extraction, retention at 6 months was 71.3% (1943/2726). Among the 1491 who enrolled at least 12 months prior to data extraction, 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 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).

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 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.

Acknowledgments

We thank Cassie Choi, RN, Pair Team Co-Founder, and Connie Kim, MS, for their development of and contributions to Pair Team’s intervention.

Funding

This work was supported by the California Health Care Foundation (grant number G-34129). The funder did not have any role in study design, data collection or analysis, in writing of the report, or the decision to submit the article for publication.

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.

References

1. Berry JG, Hall M, Cohen E, O’Neill M, Feudtner C. Ways to identify children with medical complexity and the importance of why. J Pediatr 2015 Aug;167(2):229-237. [doi: 10.1016/j.jpeds.2015.04.068] [Medline: 26028285]
2. Jones EB, Lucienne TM. The Integrated Care for Kids Model: addressing fragmented care for pediatric medicaid enrollees in seven communities. J Health Care Poor Underserved 2023;34(1):503-509. [doi: 10.1353/hpu.2023.0034] [Medline: 37464510]
3. Peltz A, Samuels-Kalow ME, Rodean J, et al. Characteristics of children enrolled in medicaid with high-frequency emergency department use. Pediatrics 2017 Sep;140(3):e20170962. [doi: 10.1542/peds.2017-0962] [Medline: 28765381]
4. Cheung PT, Wiler JL, Lowe RA, Ginde AA. National study of barriers to timely primary care and emergency department utilization among Medicaid beneficiaries. Ann Emerg Med 2012 Jul;60(1):4-10. [doi: 10.1016/j.annemergmed.2012.01.035] [Medline: 22418570]
5. Smith A, Serban N, Fitzpatrick A. Asthma prevalence among medicaid-enrolled children. J Allergy Clin Immunol Pract 2019 Apr;7(4):1207-1213. [doi: 10.1016/j.jaip.2018.10.008] [Medline: 30339856]

6. CALAIM Enhanced care management policy guide. California Department of Health care services. 2024 Aug. URL: https://www.dhcs.ca.gov/CalAIM/ECM/Documents/ECM-Policy-Guide.pdf [accessed 2025-06-25]
7. Enhanced care management (ECM) implementation timeline & updated populations of focus. California Department of Health Care Services. 2022 Dec. URL: https://www.dhcs.ca.gov/Documents/MCQMD/ECM-Implementation-Timeline-Updated-POFs.pdf [accessed 2025-06-25]
8. Implementers' perspectives on the present and future of enhanced care management (ECM) for children and youth. Lucile Packard Foundation for Children's Health. 2025 Apr. URL: https://lpfch.org/resource/implementers-on-enhanced-care-management-for-children-and-youth/ [accessed 2025-06-25]
9. ECM and community supports quarterly implementation report. : HCS; 2025 Mar URL: https://storymaps.arcgis.com/collections/a07f998dfefa497fbd7613981e4f6117 [accessed 2025-06-25]
10. Pair Team — Connecting underserved communities to high quality care. URL: https://www.pairteam.com/ [accessed 2025-06-19]
11. Mueller L, Batlivala N, Palisoc J, et al. A novel intervention for Medicaid beneficiaries with complex needs. J Gen Intern Med 2025 Sep 25. [doi: 10.1007/s11606-025-09839-2] [Medline: 40999264]
12. Wisk LE, Sharma N. Prevalence and trends in pediatric-onset chronic conditions in the United States, 1999–2018. Acad Pediatr 2025 May;25(4):102810. [doi: 10.1016/j.acap.2025.102810]
13. Zanobetti A, Ryan PH, Coull B, et al. Childhood asthma incidence, early and persistent wheeze, and neighborhood socioeconomic factors in the ECHO/CREW Consortium. JAMA Pediatr 2022 Aug 1;176(8):759-767. [doi: 10.1001/jamapediatrics.2022.1446] [Medline: 35604671]
14. Byck GR, Bolland J, Dick D, Ashbeck AW, Mustanski BS. Prevalence of mental health disorders among low-income African American adolescents. Soc Psychiatry Psychiatr Epidemiol 2013 Oct;48(10):1555-1567. [doi: 10.1007/s00127-013-0657-3]
15. Merchant R, Szefler SJ, Bender BG, et al. Impact of a digital health intervention on asthma resource utilization. World Allergy Organ J 2018;11(1):28. [doi: 10.1186/s40413-018-0209-0] [Medline: 30524644]
16. Seol HY, Wi CI, Ryu E, King KS, Divekar RD, Juhn YJ. A diagnostic codes-based algorithm improves accuracy for identification of childhood asthma in archival data sets. J Asthma 2021 Aug;58(8):1077-1086. [doi: 10.1080/02770903.2020.1759624] [Medline: 32315558]
17. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med 2001 Sep;16(9):606-613. [doi: 10.1046/j.1525-1497.2001.016009606.x] [Medline: 11556941]
18. Thorndike AL, Yetman HE, Thorndike AN, Jeffrys M, Rowe M. Unmet health needs and barriers to health care among people experiencing homelessness in San Francisco's Mission District: a qualitative study. BMC Public Health 2022 May 30;22(1):1071. [doi: 10.1186/s12889-022-13499-w] [Medline: 35637496]
19. McCormick KA, Chatham A, Klodnick VV, Schoenfeld EA, Cohen DA. Mental health service experiences among transition-age youth: interpersonal continuums that influence engagement in care. Child Adolesc Soc Work J 2023 Aug;40(4):525-536. [doi: 10.1007/s10560-022-00890-0]
20. Shipp CL, Gergen PJ, Gern JE, Matsui EC, Guilbert TW. Asthma management in children. J Allergy Clin Immunol Pract 2023 Jan;11(1):9-18. [doi: 10.1016/j.jaip.2022.10.031] [Medline: 36334702]
21. Ojo RO, Okobi OE, Ezeamii PC, et al. Epidemiology of current asthma in children under 18: a two-decade overview using National Center for Health Statistics (NCHS) data. Cureus 2023 Nov;15(11):e49229. [doi: 10.7759/cureus.49229] [Medline: 38143602]
22. Goff SL, Shieh MS, Lindenauer PK, Ash AS, Krishnan JA, Geissler KH. Differences in health care utilization for asthma by children with Medicaid versus private insurance. Popul Health Manag 2024 Apr;27(2):105-113. [doi: 10.1089/pop.2023.0244] [Medline: 38574325]
23. Kim H, McConnell KJ, Sun BC. Comparing emergency department use among medicaid and commercial patients using all-payer all-claims data. Popul Health Manag 2017 Aug;20(4):271-277. [doi: 10.1089/pop.2016.0075] [Medline: 28075692]
24. Wattles BA, Vidwan NK, Feygin Y, Jawad KS, Creel LM, Smith MJ. Antibiotic prescribing to Kentucky Medicaid children, 2012-2017: prescribing is higher in rural areas. J Rural Health 2022 Mar;38(2):427-432. [doi: 10.1111/jrh.12584] [Medline: 33978987]
25. Lehrer BJ, Mutamba G, Thure KA, et al. Optimal pediatric outpatient antibiotic prescribing. JAMA Netw Open 2024 Oct 1;7(10):e2437409. [doi: 10.1001/jamanetworkopen.2024.37409] [Medline: 39361280]
26. Cummings JR, Kalk T, Trello S, Walker ER, Graetz I. Therapists' perspectives on access to telemental health among Medicaid-enrolled youth. Am J Manag Care 2023 Nov 1;29(11):e339-e347. [doi: 10.37765/ajmc.2023.89430] [Medline: 37948654]
27. Harvey AR, Meehan E, Merrick N, et al. Comprehensive care programmes for children with medical complexity. Cochrane Database Syst Rev 2024 May 30;5(5):CD013329. [doi: 10.1002/14651858.CD013329.pub2] [Medline: 38813833]
28. Weier RC, Gardner W, Conkol K, Pajer K, Kelleher KJ. Partners for Kids Care Coordination: lessons from the field. Pediatrics 2017 May;139(Suppl 2):S109-S116. [doi: 10.1542/peds.2016-2786E] [Medline: 28562308]

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

Edited by M Balcarras; submitted 20.Nov.2025; peer-reviewed by S Sharma, YA Bisyuk; revised version received 30.Mar.2026; accepted 30.Mar.2026; published 22.Apr.2026.

Please cite as:
Juusola JL, Kumar S, Iragavarapu MS, Mueller L, Batlivala N, Ong MK, Ostrovsky A, Favini N
An Innovative Approach to Enhanced Care Management for High-Need Pediatric Medicaid Members: Retrospective Cohort Study
JMIR Pediatr Parent 2026;9:e88204
URL: https://pediatrics.jmir.org/2026/1/e88204
doi:10.2196/88204

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

Berhanu Fikadie Endehabtu[1,2], MPH; Kassahun Alemu[2,3], PhD; Shegaw Anagaw Mengiste[4], PhD; Meseret Zelalem[5], MD; Monika Knudsen Gullslett[6], PhD; Binyam Tilahun[1,2], PhD

[1]Department of Health Informatics, Institute of Public Health, College of Medicine and Health Sciences, University of Gondar, Gondar, Ethiopia
[2]Center for Digital Health and Implementation Science, University of Gondar, Gondar, Ethiopia
[3]Department of Epidemiology and Biostatistics, Institute of Public Health, College of Medicine and Health Sciences, University of Gondar, Gondar, Ethiopia
[4]School of Business, University of South-Eastern Norway, Drammen, Norway
[5]Department of Pediatrics and Child Health, University of Gondar, Gondar, Ethiopia
[6]Norwegian Centre for E-health Research, University Hospital of North Norway, Tromsø, Norway

Corresponding Author:
Berhanu Fikadie Endehabtu, MPH
Department of Health Informatics, Institute of Public Health, College of Medicine and Health Sciences, University of Gondar, Gondar, Ethiopia

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.

(JMIR Pediatr Parent 2026;9:e76712) doi:10.2196/76712

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, 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 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.

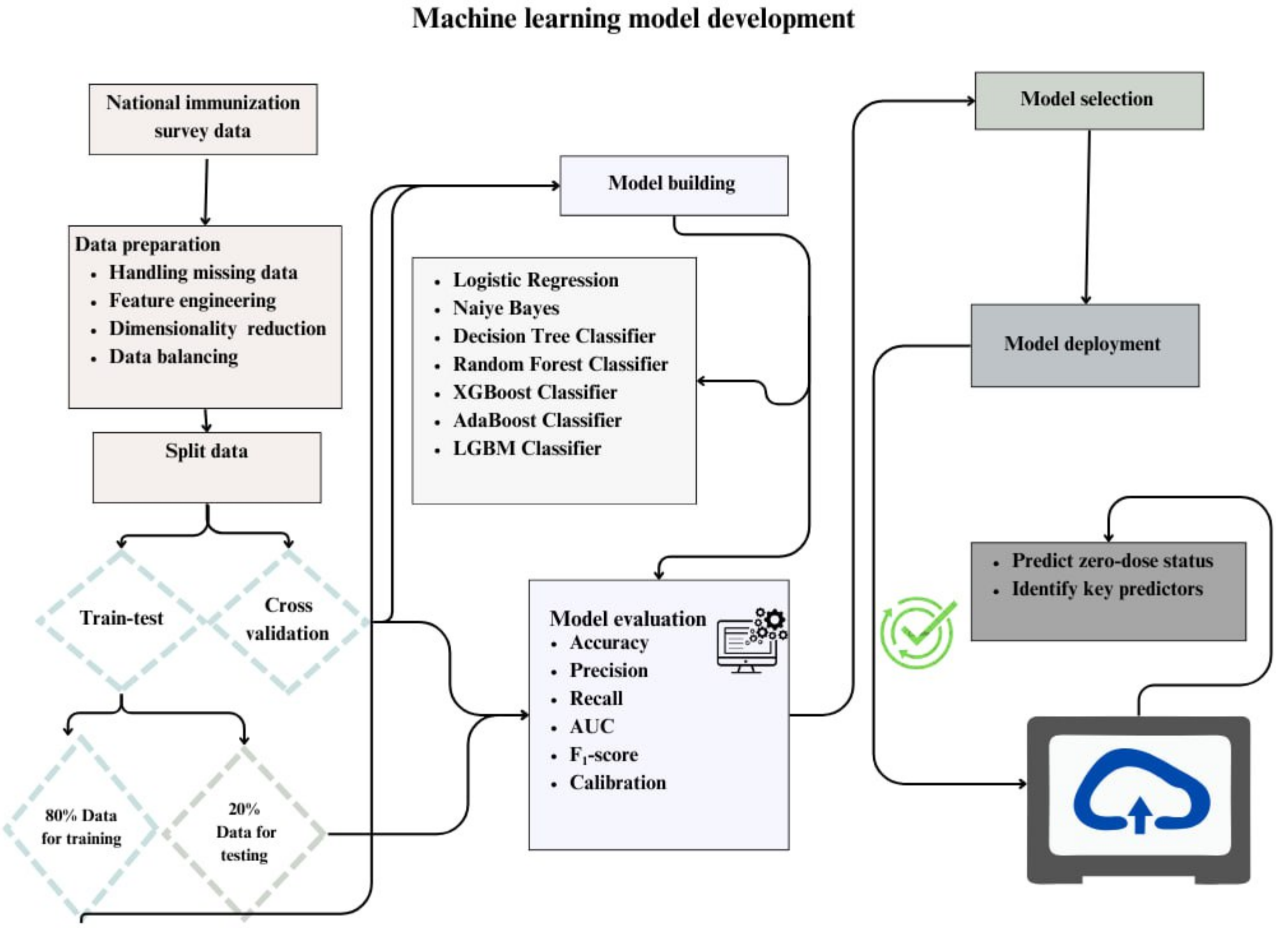
Category	Description	Response/type of data
Socioeconomic and demographic factor		
Residency	Type of living arrangement	Categorical (urban and rural)
Region	Geographic area of residence	Nominal (eg, Afar, Amhara...)
Religion	Cultural beliefs influencing health behaviors	Nominal or categorical (orthodox, 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).

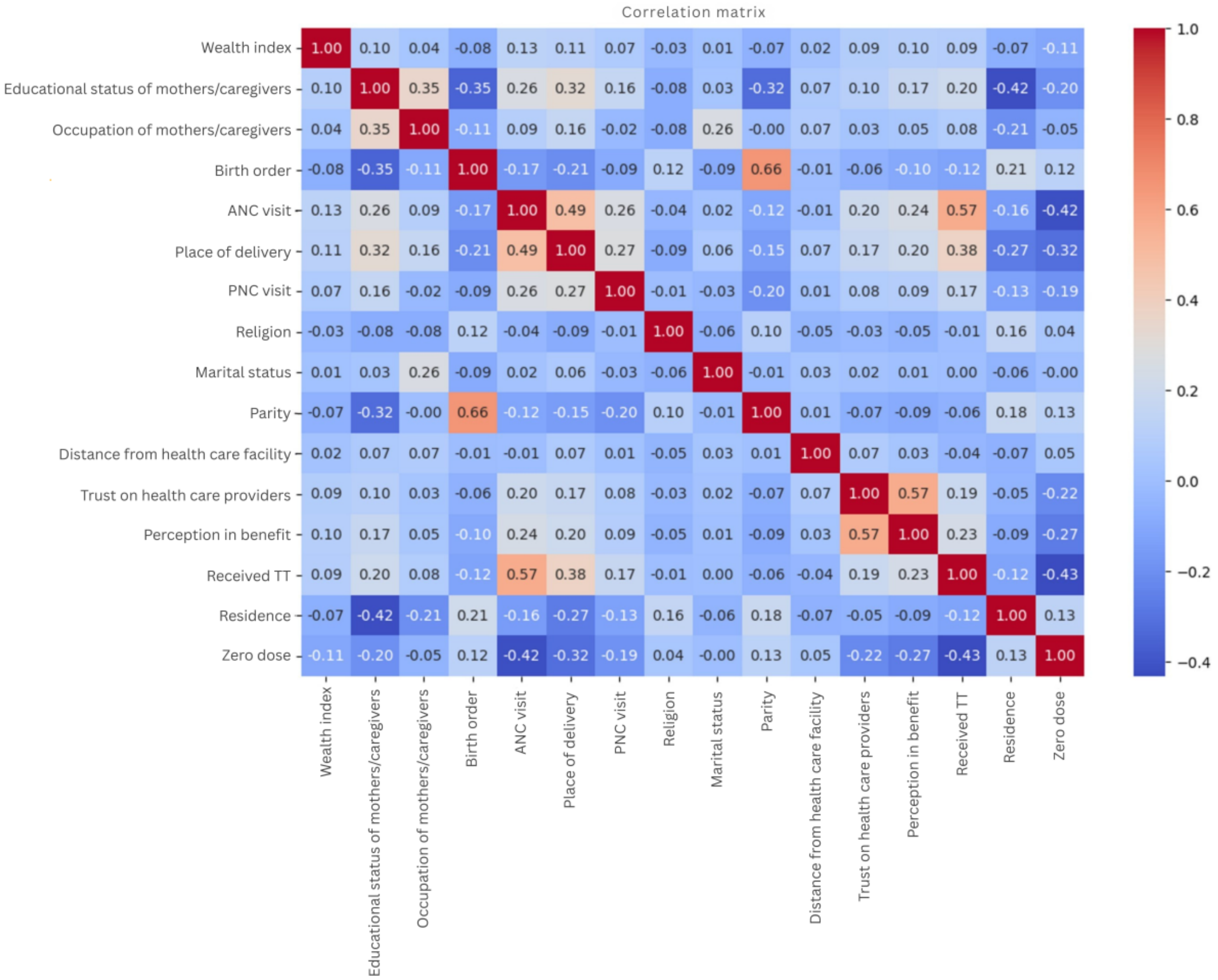
Figure 1. Data preparation and analysis steps for zero-dose children prediction. AUC: area under the curve; LGBM: Light Gradient Boosting Machine.



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.

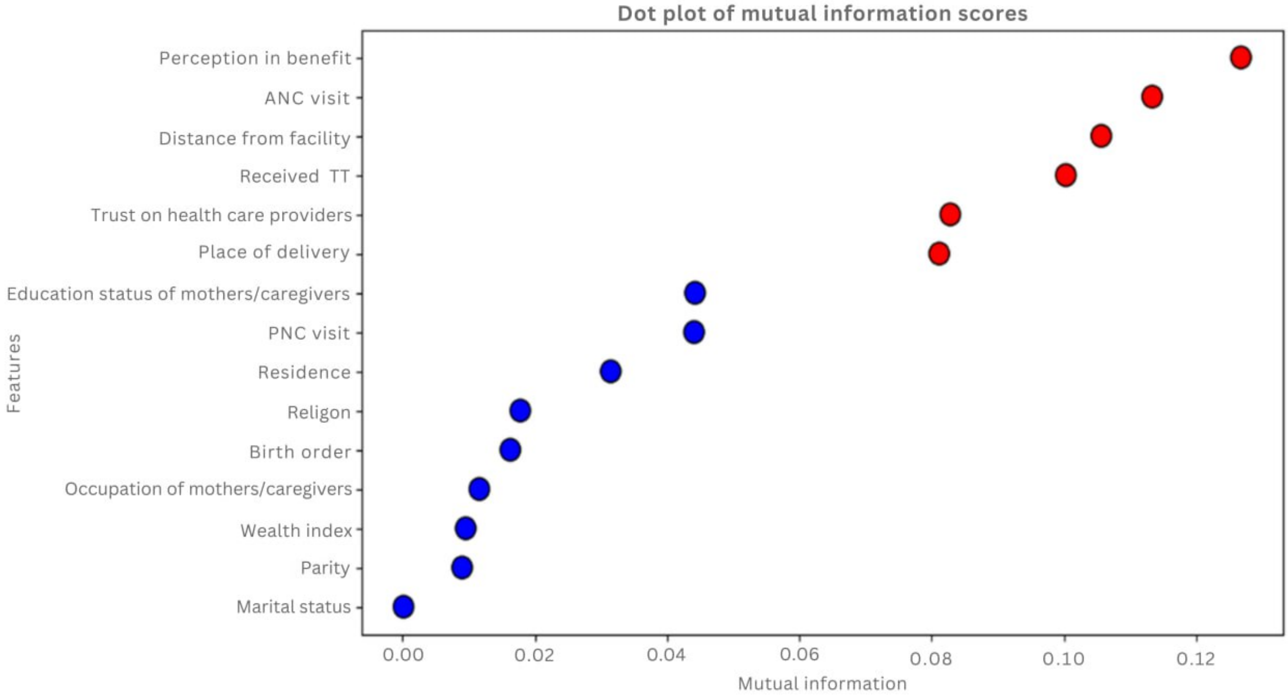
Next, we conducted a correlation analysis to identify and remove highly correlated features, thereby reducing multicollinearity and enhancing model robustness. Our correlation matrix showed a strong relation between parity and birth order (Figure 2), leading us to compute mutual information scores for 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.

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



	Wealth index	Educational status of mothers/caregivers	Occupation of mothers/caregivers	Birth order	ANC visit	Place of delivery	PNC visit	Religion	Marital status	Parity	Distance from health care facility	Trust on health care providers	Perception in benefit	Received TT	Residence	Zero dose
Wealth index	1.00	0.10	0.04	-0.08	0.13	0.11	0.07	-0.03	0.01	-0.07	0.02	0.09	0.10	0.09	-0.07	-0.11
Educational status of mothers/caregivers	0.10	1.00	0.35	-0.35	0.26	0.32	0.16	-0.08	0.03	-0.32	0.07	0.10	0.17	0.20	-0.42	-0.20
Occupation of mothers/caregivers	0.04	0.35	1.00	-0.11	0.09	0.16	-0.02	-0.08	0.26	-0.00	0.07	0.03	0.05	0.08	-0.21	-0.05
Birth order	-0.08	-0.35	-0.11	1.00	-0.17	-0.21	-0.09	0.12	-0.09	0.66	-0.01	-0.06	-0.10	-0.12	0.21	0.12
ANC visit	0.13	0.26	0.09	-0.17	1.00	0.49	0.26	-0.04	0.02	-0.12	-0.01	0.20	0.24	0.57	-0.16	-0.42
Place of delivery	0.11	0.32	0.16	-0.21	0.49	1.00	0.27	-0.09	0.06	-0.15	0.07	0.17	0.20	0.38	-0.27	-0.32
PNC visit	0.07	0.16	-0.02	-0.09	0.26	0.27	1.00	-0.01	-0.03	-0.20	0.01	0.08	0.09	0.17	-0.13	-0.19
Religion	-0.03	-0.08	-0.08	0.12	-0.04	-0.09	-0.01	1.00	-0.06	0.10	-0.05	-0.03	-0.05	-0.01	0.16	0.04
Marital status	0.01	0.03	0.26	-0.09	0.02	0.06	-0.03	-0.06	1.00	-0.01	0.03	0.02	0.01	0.00	-0.06	-0.00
Parity	-0.07	-0.32	-0.00	0.66	-0.12	-0.15	-0.20	0.10	-0.01	1.00	0.01	-0.07	-0.09	-0.06	0.18	0.13
Distance from health care facility	0.02	0.07	0.07	-0.01	-0.01	0.07	0.01	-0.05	0.03	0.01	1.00	0.07	0.03	-0.04	-0.07	0.05
Trust on health care providers	0.09	0.10	0.03	-0.06	0.20	0.17	0.08	-0.03	0.02	-0.07	0.07	1.00	0.57	0.19	-0.05	-0.22
Perception in benefit	0.10	0.17	0.05	-0.10	0.24	0.20	0.09	-0.05	0.01	-0.09	0.03	0.57	1.00	0.23	-0.09	-0.27
Received TT	0.09	0.20	0.08	-0.12	0.57	0.38	0.17	-0.01	0.00	-0.06	-0.04	0.19	0.23	1.00	-0.12	-0.43
Residence	-0.07	-0.42	-0.21	0.21	-0.16	-0.27	-0.13	0.16	-0.06	0.18	-0.07	-0.05	-0.09	-0.12	1.00	0.13
Zero dose	-0.11	-0.20	-0.05	0.12	-0.42	-0.32	-0.19	0.04	-0.00	0.13	0.05	-0.22	-0.27	-0.43	0.13	1.00

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



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.

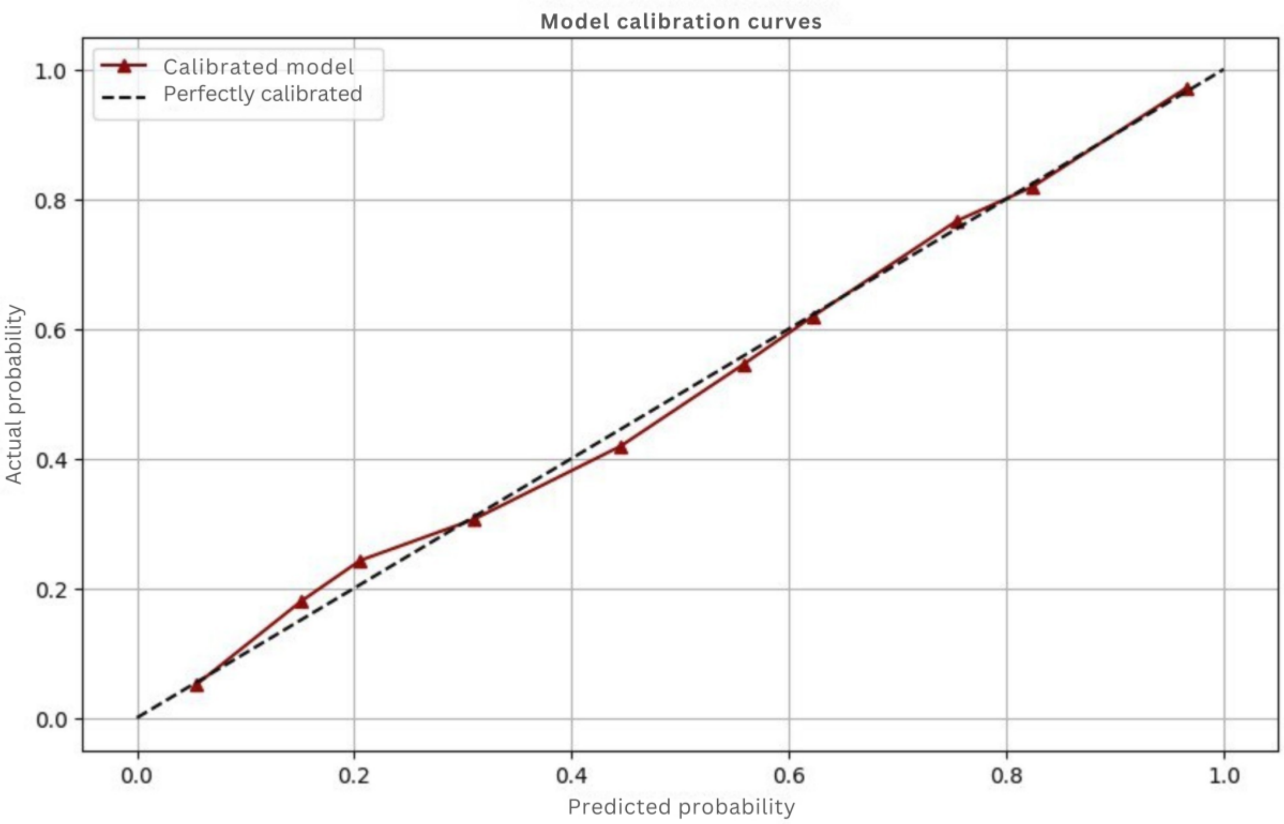
Given the categorical nature of the outcome variable, we used 7 classical classification algorithms: AdaBoost Classifier [32], Logistic Regression [33], Naive Bayes, Random Forest (RF) [34], Light Gradient Boosting Machine (LGBM) [35], Extreme Gradient Boosting (XGBoost) [35], and Decision Tree [36]. 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].

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.

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

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.

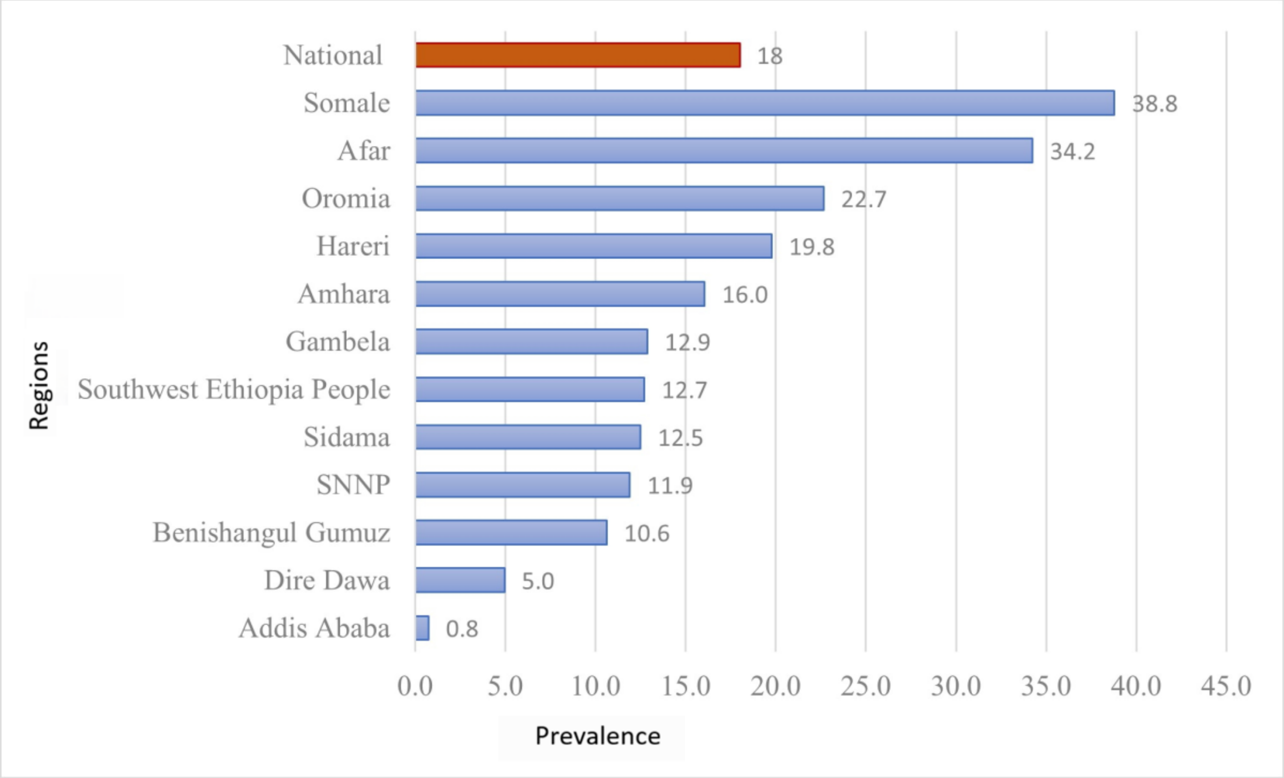
[b] ANC: antenatal care.

[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%).

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.

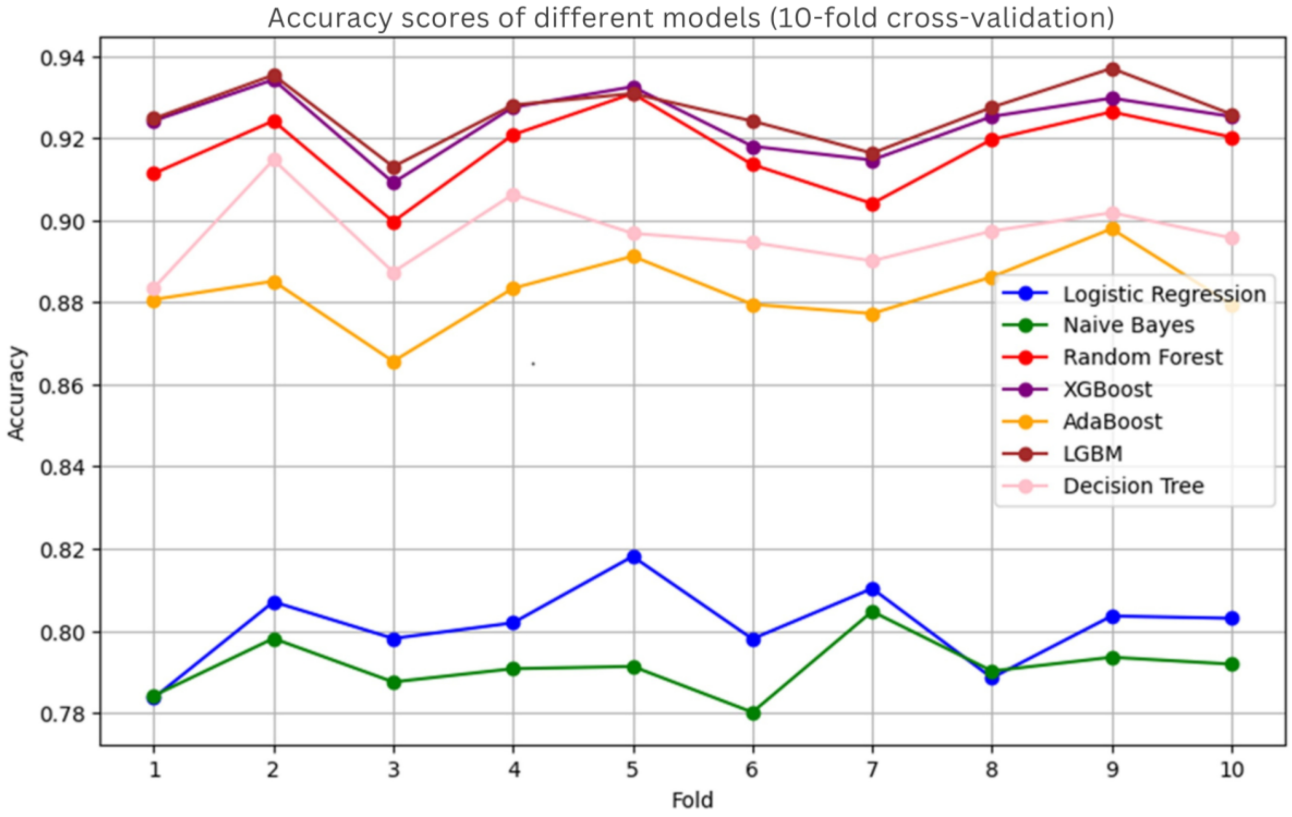
Model	Accuracy (%)	AUC[a] (%)	Precision (%)	Recall (%)	F_1-score (%)
Logistic Regression	80.8	89.1	82.5	76.9	79.6
Naive Bayes	79.1	87.3	82	73.1	77.3
Random Forest	91.6	96.7	91.9	90.6	91.3
XGBoost	92.2	97.3	93.9	89.8	91.8
AdaBoost	89.6	96.2	90.6	87.8	89.2
LGBM[b]	92.4	97.4	93.2	90.9	92.1
Decision Tree	89.9	94.5	89.5	89.7	89.6

[a] AUC: area under the curve.

[b] LGBM: Light Gradient Boosting Machine.

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.



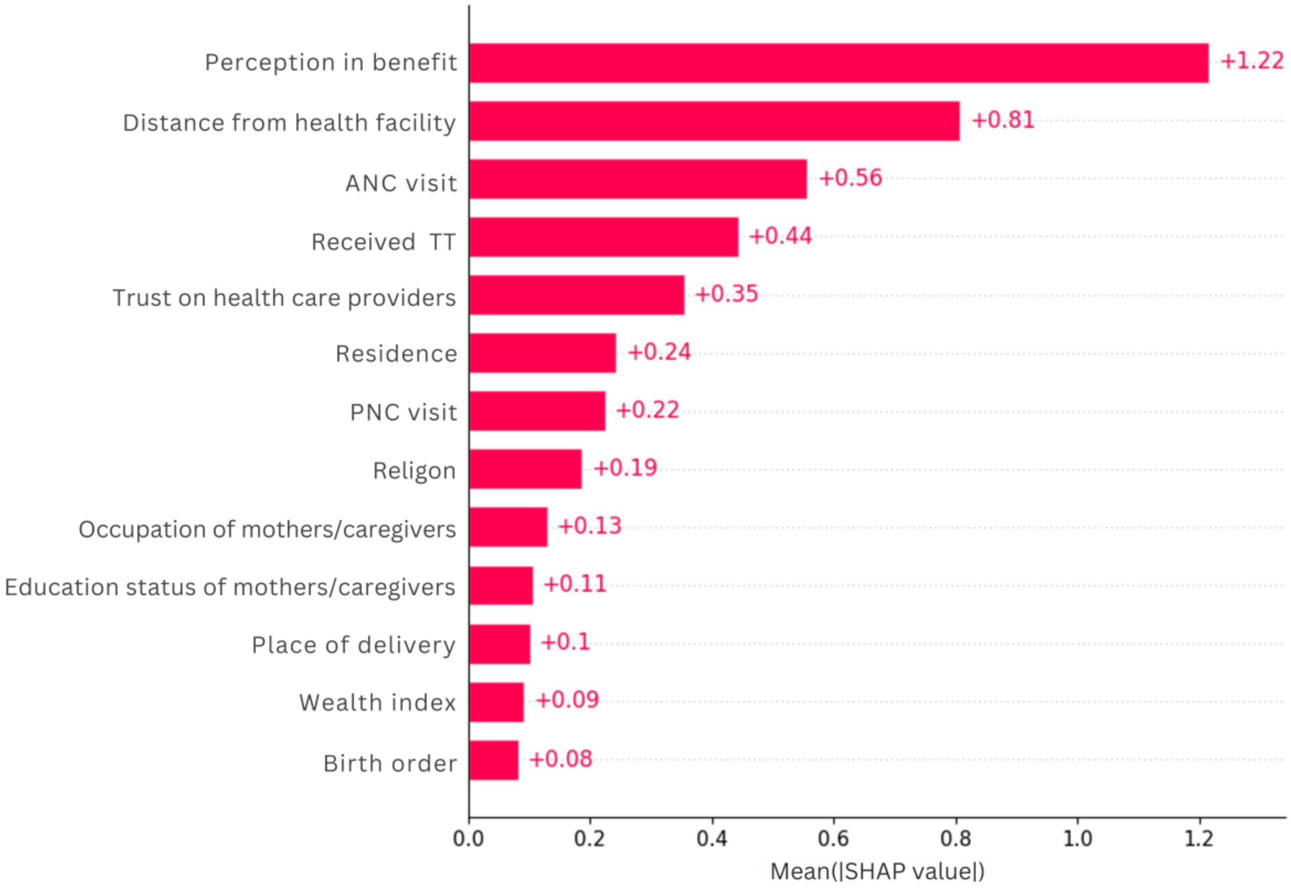
Predicting ZD

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

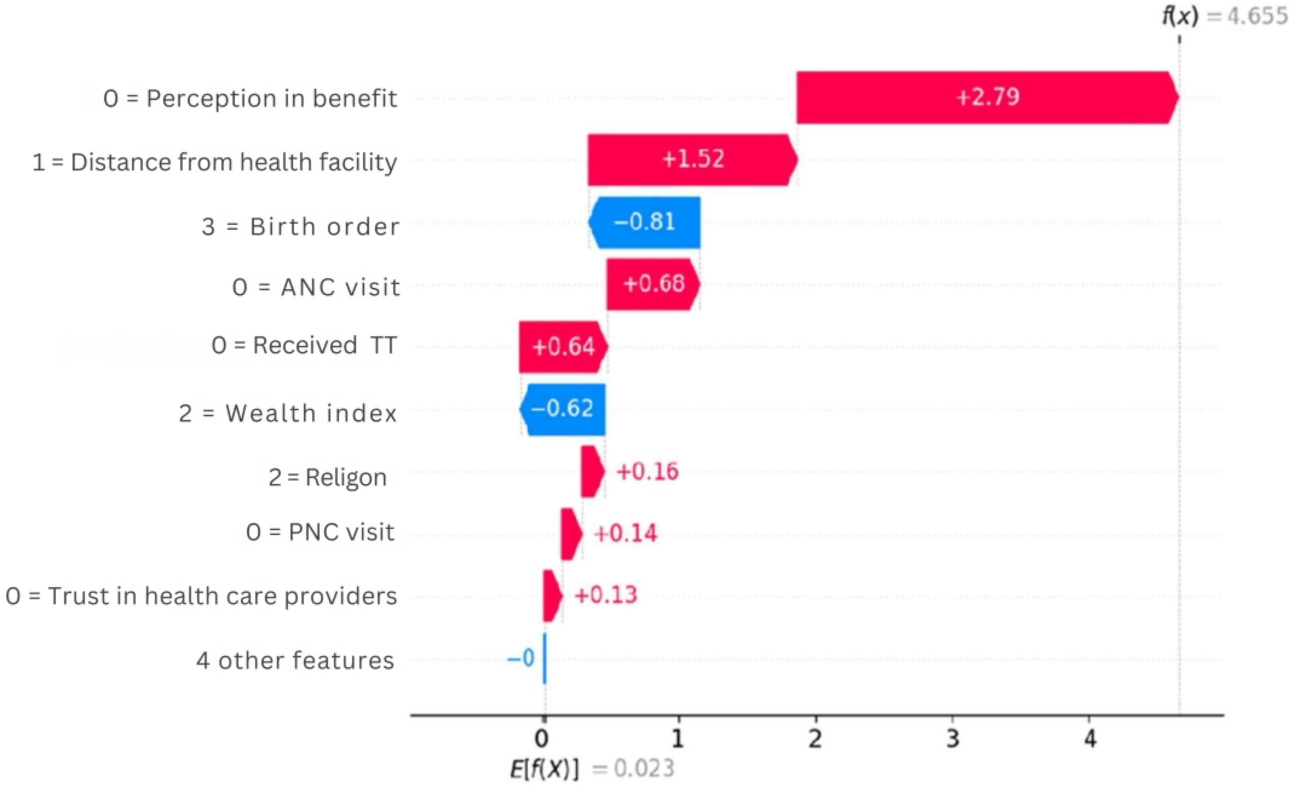
The Shapley Additive analysis identified that mother's or caregiver's perception of benefit of immunization (+1.13), with whether the distance to immunization site (+0.88), whether the mother received ANC (+0.55), whether the mother received TT (+0.42), and whether trust in health providers (0.41) were 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).

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).

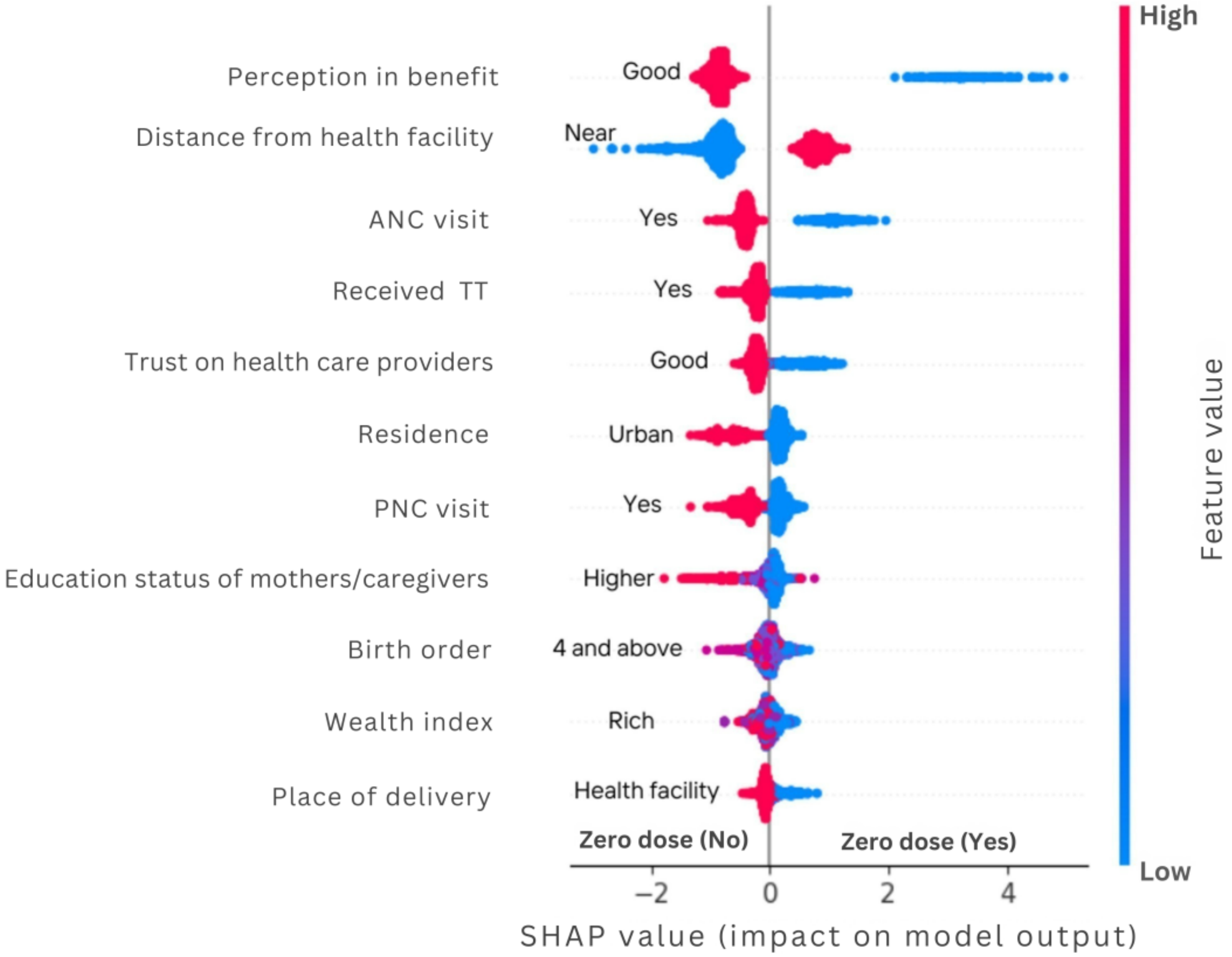
Figure 8. Waterfall plot of first observation value to predict zero-dose children in Ethiopia, 2023. ANC: antenatal care; PNC: postnatal care.



.

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).

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.

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 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.

Acknowledgments

The authors would like to thank the University of Gondar for the unwavering support. In addition, the authors extend their sincere thanks to the Ministry of Health of Ethiopia for granting them access to the data that were critical for their study.

Funding

No external financial support or grants were received from any public, commercial, or not-for-profit entities for the research, authorship, or publication of this article.

Data Availability

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

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]

References

1. Clark H, Coll-Seck AM, Banerjee A, et al. A future for the world's children? A WHO–UNICEF–Lancet Commission. Lancet 2020 Feb 22;395(10224):605-658. [doi: 10.1016/S0140-6736(19)32540-1] [Medline: 32085821]
2. Kaur G, Danovaro-Holliday MC, Mwinnyaa G, et al. Routine vaccination coverage—worldwide, 2022. MMWR Morb Mortal Wkly Rep 2023 Oct 27;72(43):1155-1161. [doi: 10.15585/mmwr.mm7243a1] [Medline: 37883326]
3. Sharrow D, Hug L, You D, et al. Global, regional, and national trends in under-5 mortality between 1990 and 2019 with scenario-based projections until 2030: a systematic analysis by the UN Inter-agency Group for Child Mortality Estimation. Lancet Glob Health 2022 Feb;10(2):e195-e206. [doi: 10.1016/S2214-109X(21)00515-5] [Medline: 35063111]
4. WHO/UNICEF estimates of national immunization coverage. World Health Organization. 2023 Sep. URL: https://www.who.int/news-room/questions-and-answers/item/who-unicef-estimates-of-national-immunization-coverage [accessed 2026-01-19]
5. Immunization Agenda 2030: a global strategy to leave no one behind. : World Health Organization; 2020 URL: https://www.who.int/publications/m/item/immunization-agenda-2030-a-global-strategy-to-leave-no-one-behind [accessed 2024-11-22]
6. Restrepo-Méndez MC, Barros AJ, Wong KL, et al. Inequalities in full immunization coverage: trends in low- and middle-income countries. Bull World Health Organ 2016 Nov 1;94(11):794-805B. [doi: 10.2471/BLT.15.162172] [Medline: 27821882]
7. Ozawa S, Yemeke TT, Evans DR, Pallas SE, Wallace AS, Lee BY. Defining hard-to-reach populations for vaccination. Vaccine (Auckl) 2019 Sep;37(37):5525-5534. [doi: 10.1016/j.vaccine.2019.06.081]
8. Johri M, Rajpal S, Subramanian SV. Progress in reaching unvaccinated (zero-dose) children in India, 1992-2016: a multilevel, geospatial analysis of repeated cross-sectional surveys. Lancet Glob Health 2021 Dec;9(12):e1697-e1706. [doi: 10.1016/S2214-109X(21)00349-1] [Medline: 34798029]
9. Johri M, Ng ES, Sharkey A, Bosson-Rieutort D, Kone GK, Subramanian SV. Effects of zero-dose vaccination status in early childhood and level of community socioeconomic development on learning attainment in preadolescence in India: a population-based cohort study. bmjph 2023 Nov;1(1):e000022. [doi: 10.1136/bmjph-2023-000022]
10. Chopra M, Bhutta Z, Chang Blanc D, et al. Addressing the persistent inequities in immunization coverage. Bull World Health Organ 2020 Feb 1;98(2):146-148. [doi: 10.2471/BLT.19.241620] [Medline: 32015586]
11. Teferi E. Factors influencing coverage and key challenges to achieving targets of routine immunization in Africa: a systematic review. Ethiop J Pediatr Child Health 2016;12(2):34-45 [FREE Full text]
12. Nour TY, Farah AM, Ali OM, Osman MO, Aden MA, Abate KH. Predictors of immunization coverage among 12–23 month old children in Ethiopia: systematic review and meta-analysis. BMC Public Health 2020 Dec;20(1):1-19. [doi: 10.1186/s12889-020-09890-0]
13. Tamir TT, Zegeye AF, Mekonen EG, et al. Prevalence, spatial variation and determinants of zero-dose children in Ethiopia: spatial and multilevel analyses. Public Health (Fairfax) 2024 Nov;236:365-372. [doi: 10.1016/j.puhe.2024.09.011]
14. Yadita ZS, Ayehubizu LM. Full immunization coverage and associated factors among children aged 12-23 months in Somali Region, Eastern Ethiopia. PLoS One 2021;16(12):e0260258. [doi: 10.1371/journal.pone.0260258] [Medline: 34874949]
15. Biset G, Woday A, Mihret S, Tsihay M. Full immunization coverage and associated factors among children age 12-23 months in Ethiopia: systematic review and meta-analysis of observational studies. Hum Vaccin Immunother 2021 Jul 3;17(7):2326-2335. [doi: 10.1080/21645515.2020.1870392]
16. Girmay A, Dadi AF. Full immunization coverage and associated factors among children aged 12-23 months in a hard-to-reach areas of Ethiopia. Int J Pediatr 2019;2019:1924941. [doi: 10.1155/2019/1924941] [Medline: 31263502]

17. Gurmu E, Etana D. Factors influencing children’s full immunization in Ethiopia. Afr Popul Stud 2016;30:2. [doi: 10.11564/30-2-813]
18. Asresie MB, Dagnew GW, Bekele YA. Changes in immunization coverage and contributing factors among children aged 12-23 months from 2000 to 2019, Ethiopia: multivariate decomposition analysis. PLoS One 2023;18(9):e0291499. [doi: 10.1371/journal.pone.0291499] [Medline: 37703252]
19. Nozaki I, Hachiya M, Kitamura T. Factors influencing basic vaccination coverage in Myanmar: secondary analysis of 2015 Myanmar demographic and health survey data. BMC Public Health 2019 Feb 28;19(1):242. [doi: 10.1186/s12889-019-6548-0] [Medline: 30819127]
20. Song X, Mitnitski A, Cox J, Rockwood K. Comparison of machine learning techniques with classical statistical models in predicting health outcomes. Stud Health Technol Inform 2004;107(Pt 1):736-740. [Medline: 15360910]
21. Bonaccorso G. Machine Learning Algorithms: Popular Algorithms for Data Science and Machine Learning: Packt Publishing Ltd; 2018. URL: https://cir.nii.ac.jp/crid/1130000794529220864 [accessed 2024-11-22]
22. Sarker IH. Machine learning: algorithms, real-world applications and research directions. SN Comput Sci 2021;2(3):160. [doi: 10.1007/s42979-021-00592-x] [Medline: 33778771]
23. Agrawal R, Imieliński T, Swami A. Mining association rules between sets of items in large databases. Presented at: Proceedings of the 1993 ACM SIGMOD International Conference on Management of Data; Jun 1, 1993; Washington, DC p. 207-216. [doi: 10.1145/170035.170072]
24. Cheong Q, Au-Yeung M, Quon S, Concepcion K, Kong JD. Predictive modeling of vaccination uptake in US counties: a machine learning-based approach. J Med Internet Res 2021 Nov 25;23(11):e33231. [doi: 10.2196/33231] [Medline: 34751650]
25. Carrieri V, Lagravinese R, Resce G. Predicting vaccine hesitancy from area-level indicators: a machine learning approach. Health Econ 2021 Dec;30(12):3248-3256. [doi: 10.1002/hec.4430] [Medline: 34523180]
26. Avirappattu G, Pach Iii A, Locklear CE, Briggs AQ. An optimized machine learning model for identifying socio-economic, demographic and health-related variables associated with low vaccination levels that vary across ZIP codes in California. Prev Med Rep 2022 Aug;28:101858. [doi: 10.1016/j.pmedr.2022.101858] [Medline: 35706686]
27. Zhang A, Xing L, Zou J, Wu JC. Shifting machine learning for healthcare from development to deployment and from models to data. Nat Biomed Eng 2022 Dec;6(12):1330-1345. [doi: 10.1038/s41551-022-00898-y] [Medline: 35788685]
28. National immunization program evaluation research in Ethiopia. : Consortium of CBMP Universities; 2024 URL: https://www.scribd.com/document/875138308 [accessed 2025-06-29]
29. World Health Organization vaccination coverage cluster surveys: reference manual. World Health Organization. 2018. URL: https://www.who.int/publications/i/item/WHO-IVB-18.09 [accessed 2024-11-23]
30. Wonodi C, Farrenkopf BA. Defining the zero dose child: a comparative analysis of two approaches and their impact on assessing the zero dose burden and vulnerability profiles across 82 low- and middle-income countries. Vaccines (Basel) 2023 Sep 28;11(10):1543. [doi: 10.3390/vaccines11101543] [Medline: 37896946]
31. Zero dose children and missed communities. Gavi. URL: https://www.gavi.org/our-alliance/strategy/phase-5-2021-2025/equity-goal/zero-dose-children-missed-communities [accessed 2026-01-19]
32. Schapire RE, Freund Y. Boosting: foundations and algorithms. Kybernetes 2013 Jan 4;42(1):164-166. [doi: 10.1108/03684921311295547]
33. Cessie SL, Houwelingen JCV. Ridge estimators in logistic regression. Appl Stat 1992;41(1):191. [doi: 10.2307/2347628]
34. Pal M. Random forest classifier for remote sensing classification. Int J Remote Sens 2005 Jan;26(1):217-222. [doi: 10.1080/01431160412331269698]
35. Chen T, Guestrin C. XGBoost: a scalable tree boosting system. Presented at: Proceedings of the 22nd ACM SIGKDD International Conference on Knowledge Discovery and Data Mining; Aug 13-17, 2016; San Francisco, CA p. 785-794. [doi: 10.1145/2939672.2939785]
36. Breiman L, Friedman J, Olshen RA, Stone CJ. Classification and Regression Trees: Routledge; 2017. [doi: 10.1201/9781315139470]
37. Šimundić AM. Measures of Diagnostic Accuracy: Basic Definitions. EJIFCC 2009 Jan;19(4):203-211. [Medline: 27683318]
38. Flach P, Kull M. Precision-recall-gain curves: PR analysis done right. Adv Neural Inf Process Syst 2015;28 [FREE Full text]
39. Santini A, Man A, Voidăzan S. Accuracy of diagnostic tests. J Crit Care Med 2021 Jul 1;7(3):241-248. [doi: 10.2478/jccm-2021-0022]
40. Kumar R, Indrayan A. Receiver operating characteristic (ROC) curve for medical researchers. Indian Pediatr 2011 Apr;48(4):277-287. [doi: 10.1007/s13312-011-0055-4] [Medline: 21532099]
41. Collins GS, Reitsma JB, Altman DG, Moons KGM, TRIPOD Group. Transparent reporting of a multivariable prediction model for individual prognosis or diagnosis (TRIPOD): the TRIPOD statement. The TRIPOD Group. Circulation 2015 Jan 13;131(2):211-219. [doi: 10.1161/CIRCULATIONAHA.114.014508] [Medline: 25561516]
42. Huang Y, Li W, Macheret F, Gabriel RA, Ohno-Machado L. A tutorial on calibration measurements and calibration models for clinical prediction models. J Am Med Inform Assoc 2020 Apr 1;27(4):621-633. [doi: 10.1093/jamia/ocz228]

43. Lundberg SM, Lee SI. A unified approach to interpreting model predictions. : Curran Associates Inc; 2017 Presented at: Proceedings of the 31st International Conference on Neural Information Processing Systems; Dec 4-9, 2017; Long Beach, CA p. 4768-4777 URL: https://proceedings.neurips.cc/paper/2017/hash/8a20a8621978632d76c43dfd28b67767-Abstract.html [accessed 2026-01-25]
44. Bifarin OO. Interpretable machine learning with tree-based SHapley Additive Explanations: application to metabolomics datasets for binary classification. PLoS One 2023;18(5):e0284315. [doi: 10.1371/journal.pone.0284315] [Medline: 37141218]
45. Altaf W, Shahbaz M, Guergachi A. Applications of association rule mining in health informatics: a survey. Artif Intell Rev 2017 Mar;47(3):313-340. [doi: 10.1007/s10462-016-9483-9]
46. Khare S, Gupta D. Association rule analysis in cardiovascular disease. Presented at: 2016 Second International Conference on Cognitive Computing and Information Processing (CCIP); Aug 12-13, 2016; Mysuru, India p. 1-6. [doi: 10.1109/CCIP.2016.7802881]
47. Agrawal R, Srikant R. Fast algorithms for mining association rules. 1994 Presented at: Proceedings of the 20th International Conference on Very Large Data Bases; Sep 12-15, 1994; San Francisco, CA, USA p. 487-499 URL: https://www.columbia.edu/~rd2537/docu/apriori(abstract).pdf [accessed 2024-11-24]
48. Tadese ZB, Nigatu AM, Yehuala TZ, Sebastian Y. Prediction of incomplete immunization among under-five children in East Africa from recent demographic and health surveys: a machine learning approach. Sci Rep 2024 May 21;14(1):11529. [doi: 10.1038/s41598-024-62641-8] [Medline: 38773175]
49. Chandir S, Siddiqi DA, Hussain OA, et al. Using predictive analytics to identify children at high risk of defaulting from a routine immunization program: feasibility study. JMIR Public Health Surveill 2018 Sep 4;4(3):e63. [doi: 10.2196/publichealth.9681] [Medline: 30181112]
50. Chambongo PE, Nguku P, Wasswa P, Semali I. Community vaccine perceptions and its role on vaccination uptake among children aged 12-23 months in the Ileje District, Tanzania: a cross section study. Pan Afr Med J 2016;23:162. [doi: 10.11604/pamj.2016.23.162.8925] [Medline: 27303578]
51. Puri YE, Murti B, Demartoto A. Analysis of the effect of maternal perception on completeness of child immunization status with health belief model. J Health Promot Behav 2016;01(3):211-222. [doi: 10.26911/thejhpb.2016.01.03.08]
52. Demsash AW, Chereka AA, Walle AD, Kassie SY, Bekele F, Bekana T. Machine learning algorithms' application to predict childhood vaccination among children aged 12–23 months in Ethiopia: evidence 2016 Ethiopian Demographic and Health Survey dataset. PLoS One 2023;18(10):e0288867. [doi: 10.1371/journal.pone.0288867]
53. Biswas A, Tucker J, Bauhoff S. Performance of predictive algorithms in estimating the risk of being a zero-dose child in India, Mali and Nigeria. BMJ Glob Health 2023 Oct;8(10):e012836. [doi: 10.1136/bmjgh-2023-012836] [Medline: 37821114]
54. Dixit P, Dwivedi LK, Ram F. Strategies to improve child immunization via antenatal care visits in India: a propensity score matching analysis. PLoS One 2013;8(6):e66175. [doi: 10.1371/journal.pone.0066175] [Medline: 23824555]
55. Jiao B, Iversen I, Sato R, et al. Association between achieving adequate antenatal care and health-seeking behaviors: a study of demographic and health surveys in 47 low- and middle-income countries. PLoS Med 2024 Jul;21(7):e1004421. [doi: 10.1371/journal.pmed.1004421] [Medline: 38968303]
56. Krishnamoorthy Y, Rehman T. Impact of antenatal care visits on childhood immunization: a propensity score-matched analysis using nationally representative survey. Fam Pract 2022 Jul 19;39(4):603-609. [doi: 10.1093/fampra/cmab124] [Medline: 34564727]
57. Ibrahim ZA, Sabahelzain MM, Elhadi YAM, Malande OO, Babiker S. Predictors of tetanus vaccine uptake among pregnant women in Khartoum State, Sudan: a hospital-based cross-sectional study. Vaccines (Basel) 2023 Jul 21;11(7):7. [doi: 10.3390/vaccines11071268] [Medline: 37515083]
58. Amin MB, Roy N, Meem AE, Hossain E, Aktarujjaman M. Trends and determinants of taking tetanus toxoid vaccine among women during last pregnancy in Bangladesh: country representative survey from 2006 to 2019. PLoS One 2022;17(10):e0276417. [doi: 10.1371/journal.pone.0276417]
59. Laryea DO, Abbeyquaye Parbie E, Frimpong E. Timeliness of childhood vaccine uptake among children attending a tertiary health service facility-based immunisation clinic in Ghana. BMC Public Health 2014 Jan 29;14:1-5. [doi: 10.1186/1471-2458-14-90] [Medline: 24476339]
60. Sarker AR, Akram R, Ali N, Chowdhury ZI, Sultana M. Coverage and determinants of full immunization: vaccination coverage among Senegalese children. Medicina 2019;55(8):480. [doi: 10.3390/medicina55080480]
61. Acharya P, Kismul H, Mapatano MA, Hatløy A. Individual- and community-level determinants of child immunization in the Democratic Republic of Congo: a multilevel analysis. PLoS One 2018;13(8):e0202742. [doi: 10.1371/journal.pone.0202742] [Medline: 30138459]
62. Rauniyar SK, Munkhbat E, Ueda P, Yoneoka D, Shibuya K, Nomura S. Timeliness of routine vaccination among children and determinants associated with age-appropriate vaccination in Mongolia. Heliyon 2020 Sep;6(9):e04898. [doi: 10.1016/j.heliyon.2020.e04898] [Medline: 32995607]
63. Budu E, Darteh EKM, Ahinkorah BO, Seidu AA, Dickson KS. Trend and determinants of complete vaccination coverage among children aged 12-23 months in Ghana: analysis of data from the 1998 to 2014 Ghana Demographic and Health Surveys. PLoS One 2020;15(10):e0239754. [doi: 10.1371/journal.pone.0239754]

64. Noh JW, Kim YM, Akram N, et al. Factors affecting complete and timely childhood immunization coverage in Sindh, Pakistan; a secondary analysis of cross-sectional survey data. PLoS One 2018;13(10):e0206766. [doi: 10.1371/journal.pone.0206766]
65. Sarker AR, Akram R, Ali N, Sultana M. Coverage and factors associated with full immunisation among children aged 12–59 months in Bangladesh: insights from the nationwide cross-sectional demographic and health survey. BMJ Open 2019 Jul;9(7):e028020. [doi: 10.1136/bmjopen-2018-028020]

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

Edited by S Badawy; submitted 29.Apr.2025; peer-reviewed by F Pabon-Rodriguez, M Adisu, N Meng; revised version received 18.Sep.2025; accepted 14.Oct.2025; published 02.Feb.2026.

Please cite as:
Endehabtu BF, Alemu K, Mengiste SA, Zelalem M, Gullslett MK, Tilahun B
Modeling Zero-Dose Children in Ethiopia: A Machine Learning Perspective on Model Performance and Predictor Variables
JMIR Pediatr Parent 2026;9:e76712
URL: https://pediatrics.jmir.org/2026/1/e76712
doi:10.2196/76712

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

Blaise Musoya Mumba[1], MPH; Fiston Ilunga Mbayo[2,3], MPH; Pacifique Kanku Wa Ilunga[4], MPH; Hermann Tamubango Kitoko[5], MPH; Pascal Geri Madragule[4], MPH; Jean Nyandwe Kyloka[1], MPH, PhD

[1]School of Public Health, University of Kinshasa, 11850, Kinshasa, Democratic Republic of the Congo
[2]Department of Public Health, Malemba Nkulu General Reference Hospital, Malemba Nkulu, Haut-Lomami, Democratic Republic of the Congo
[3]School of Public Health, University of Malemba Nkulu, P.O. Box 365, Malemba Nkulu, Haut-Lomami, Democratic Republic of the Congo
[4]School of Public Health, Faculty of Medicine, University of Kamina, Kamina, Haut-Lomami, Democratic Republic of the Congo
[5]Department of Public Health, Likasi Institute of Advanced Medical Techniques, Likasi, Haut-Katanga, Democratic Republic of the Congo

Corresponding Author:
Fiston Ilunga Mbayo, MPH
Department of Public Health, Malemba Nkulu General Reference Hospital, Malemba Nkulu, Haut-Lomami, Democratic Republic of the Congo

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.

(JMIR Pediatr Parent 2026;9:e88879) doi:10.2196/88879

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.

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.

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)

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

(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)

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).

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

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 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.

Acknowledgments

The authors thank the Kikula Health Zone management team, the heads of health areas, and the community health workers for their support during data collection. The authors also acknowledge the mothers and caregivers who generously participated in this study. All authors declared that they had insufficient or no funding to support open access publication of this manuscript, including from affiliated organizations or institutions, funding agencies, or other organizations. JMIR Publications provided article processing fee (APF) support for the publication of this paper.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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)

Visualization: HTK (lead), PKWI (supporting)
Writing—original draft: BMM (lead), FIM (supporting)
Writing—review and editing: all authors (equal)

Conflicts of Interest

None declared.

References

1. Immunization coverage. World Health Organization. 2025. URL: https://www.who.int/news-room/fact-sheets/detail/immunization-coverage [accessed 2026-03-04]
2. The state of the world's children 2023: for every child, vaccination. : UNICEF; 2023 URL: https://www.unicef.org/reports/state-worlds-children-2023 [accessed 2026-03-04]
3. Varied impact of COVID-19 on routine immunization in the European region. World Health Organization. 2021. URL: https://www.who.int/europe/news/item/16-07-2021-varied-impact-of-covid-19-on-routine-immunization-in-the-european-region [accessed 2026-03-18]
4. Annual progress report 2022. : Gavi, the Vaccine Alliance; 2022 URL: https://www.gavi.org/progress-report-2022 [accessed 2026-03-04]
5. Egondi T, Oyolola M, Mutua MK, Elung'ata P. Determinants of immunization inequality among urban poor children: evidence from Nairobi's informal settlements. Int J Equity Health 2015 Feb 27;14:24. [doi: 10.1186/s12939-015-0154-2] [Medline: 25889450]
6. Main results of the MICS-Palu survey 2017-2018. : UNICEF; 2019 URL: https://www.unicef.org/drcongo/en/reports/summary-mics-palu-2017-2018?utm_source=chatgpt.com [accessed 2026-03-04]
7. Rapport MICS RDC 2018. : Universite de Kinshasa; 2018 URL: https://espkinshasa.net/rapport-mics-2018/ [accessed 2026-03-04]
8. Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? J Health Soc Behav 1995 Mar;36(1):1-10. [Medline: 7738325]
9. Rosenstock IM. The health belief model and preventive health behavior. Health Educ Monogr 1974 Dec;2(4):354-386. [doi: 10.1177/109019817400200405]
10. Annual immunization report – Haut Katanga provincial health division. : World Health Organization; 2022 URL: https://espkinshasa.net/enquete-de-couverture-vaccinale-chez-les-enfants-de-6-23-mois-en-republique-democratique-du-congo/ [accessed 2026-03-18]
11. Immunization coverage survey 2020–2023, kikula health zone. : UNICEF; 2023 URL: https://www.cliniquesuniversitairekinshasa.net/wp-content/uploads/2024/08/Policy-Brief-ECV2023-4.pdf [accessed 2026-03-18]
12. Hosmer DWJ, Lemeshow S, Sturdivant RX. Applied Logistic Regression, 3rd edition: John Wiley & Sons; 2013. [doi: 10.1002/9781118548387]

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

Edited by M Balcarras, S Badawy; submitted 03.Dec.2025; peer-reviewed by G Gilano, M Kabamba; revised version received 11.Feb.2026; accepted 12.Feb.2026; published 31.Mar.2026.

Please cite as:
Musoya Mumba B, Ilunga Mbayo F, Kanku Wa Ilunga P, Tamubango Kitoko H, Geri Madragule P, Nyandwe Kyloka J
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
JMIR Pediatr Parent 2026;9:e88879
URL: https://pediatrics.jmir.org/2026/1/e88879
doi:10.2196/88879

Health System Community Partnership to Design an Online Resource to Address Perinatal Information Needs for Black Families: Action Research Study

Yhenneko J Taylor[1,2], PhD; Alicia Dahl[3], MS, PhD; McKenzie Isreal[1], MPH; Chelse Spinner[4], PhD; Lisa Sammons[5], MSW; Daniel Fesperman[6], MA; Racquel Washington[7], MA; Shivani Mehta[8], MD; Candace Howell[8], MD; Jennifer Stamp[9], MSW; Henry Bundy[2], PhD; Pamela Cobb[10], MD; Bridges Community Partner Group[11,12]

[1]Center for Health System Sciences, Atrium Health, 1300 Scott Ave, Charlotte, NC, United States
[10]Department of Obstetrics and Gynecology, Atrium Health, Charlotte, NC, United States
[11]See Acknowledgments
[12]
[2]Department of Social Sciences and Health Policy, Wake Forest University School of Medicine, Winston Salem, NC, United States
[3]Department of Epidemiology and Community Health, University of North Carolina at Charlotte, Charlotte, NC, United States
[4]Department of Pediatrics, Stanford Medicine, Stanford, CA, United States
[5]Mecklenburg County Health Department, Mecklenburg County Government, Charlotte, NC, United States
[6]Division on Community Health, Advocate Health, Charlotte, NC, United States
[7]The Queen's Collective Birthing, Charlotte, NC, United States
[8]Department of Pediatrics, Levine Children's Hospital, Atrium Health, Charlotte, NC, United States
[9]Smart Start of Mecklenburg County, Charlotte, NC, United States

Corresponding Author:
Yhenneko J Taylor, PhD
Center for Health System Sciences, Atrium Health, 1300 Scott Ave, Charlotte, NC, United States

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 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.

(JMIR Pediatr Parent 2026;9:e71161) doi:10.2196/71161

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 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).

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.

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.

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.

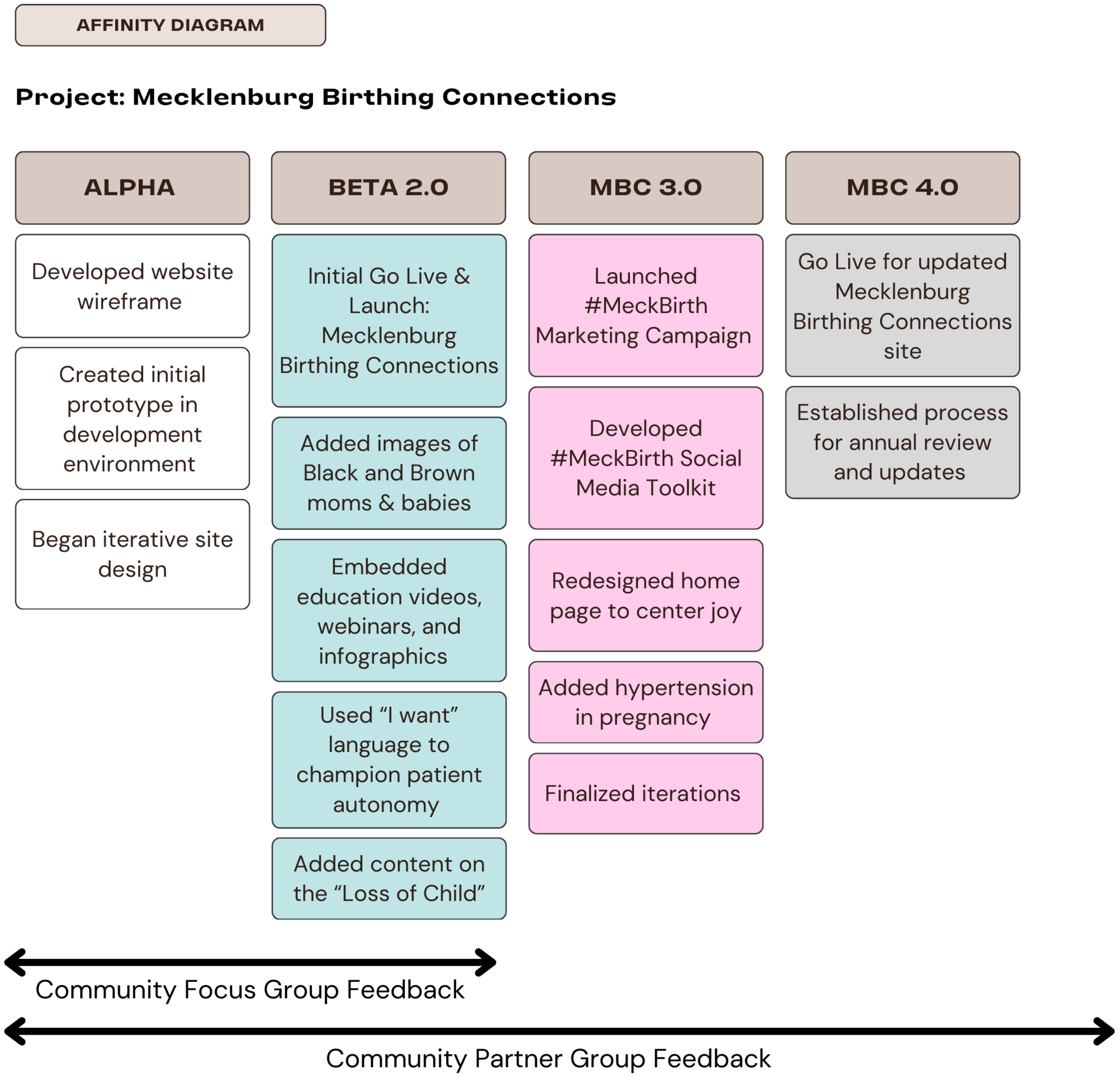
Theme	Representative quote
Have vetted and distilled information, as to not overwhelm.	"You don't want to go too crazy on the Internet. Because I have tried to diagnose myself with certain stuff, and you'll get scared."
Include current and updated information.	"With my third daughter, it had been a while, 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.

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 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.

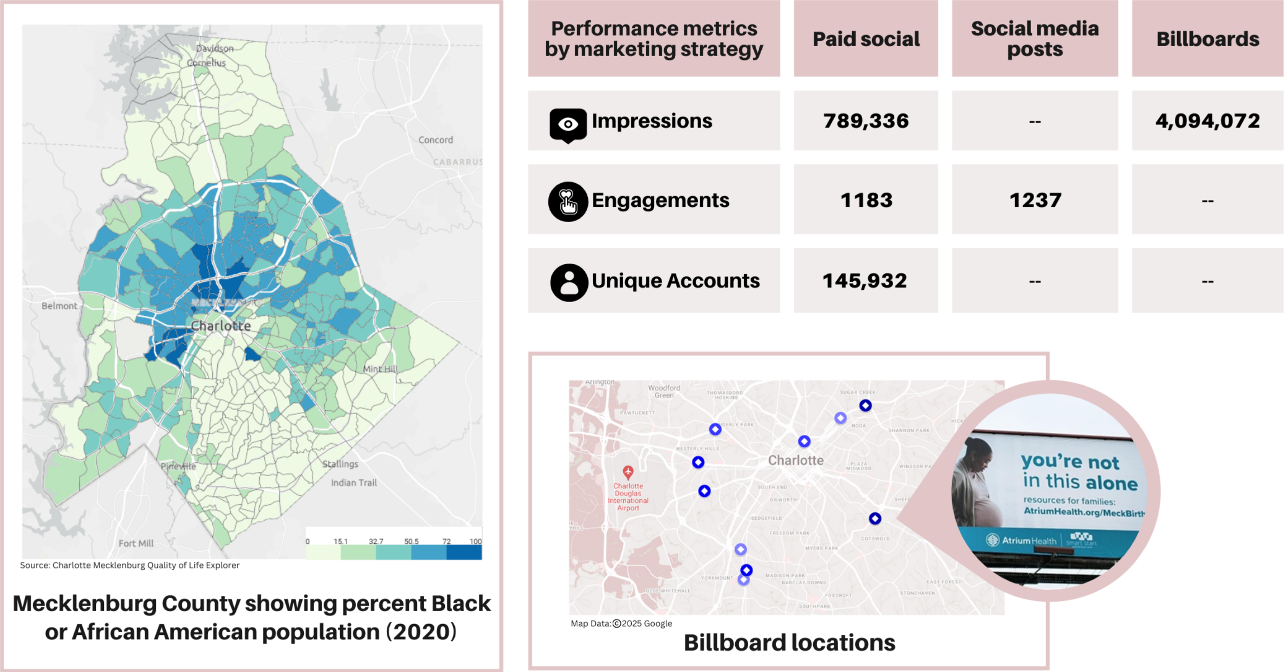
Event title	Date	Type of event	Host	Numerical reach, n
Atrium Health Nurses Meeting	March 27, 2024	Clinical Leaders Meeting	Atrium Health	60+
MBC[a] Community Forum	April 17, 2024	Community Outreach	MBC Project Team	60+
Community Health Worker-Resource Fair	April 20, 2024	Community Outreach	Atrium Health	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.

Figure 2. Reach of the Mecklenburg Birthing Connections marketing campaign.



Source: Charlotte Mecklenburg Quality of Life Explorer

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 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 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.

Acknowledgments

The project team would like to acknowledge Matt Britt and Kara Barner for developing the marketing strategy for the website, Whitney Rossman for administrative support, Ebony Cloud for her input on website and marketing content, Payton Davenport for contributions to the design of website infographics, and the Atrium Health Web Design Team for web design. Thanks to community members who participated in focus groups and meetings informing this project.

Members of the *Bridges Community Partner Group*: Audrey Ray, Brandy Foreman, C. Danielle Connor, Candace Howell, Chris Westveer, Daniel Fesperman, Ed Dunlow, Henry Bundy, Jamall Kinkard, James Jones, Jennifer Barnhart, Jennifer Stamp, Karen Clark, Kealin Coffin, Kris Elle, LaMonya Meeks, Libby Safrit, Lisa Sammons, Lori Elks, McKenzie Isreal, Morgan Walls, Ngina Connors, Noellee Clarke, Pam Hurley, Pamela Fahrenkrog, Racquel Washington, Roger Suculpe, Shamona Conner, Shivani Mehta, Sydney Primis, TaHysha McClain, Tchernavia Montgomery, Tina Schoen, Veronica Kirkland, Alicia Dahl, Andrew

Heling, Ashley Carr, Bernard Meeks, Danette McLaurin Glass, Elizabeth Borders, Karla Escobar, Kelly Musante, Lyn Nuse, Pamela Cobb, Rachel Davis, Sherresa Falls, William Minor, and Yhenneko Taylor.

Funding

This work was supported in part by Smart Start of Mecklenburg County (award no. FY22-23 PSC).

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.

References

1. Hoyert DL. Maternal mortality rates in the United States, 2022. Centers for Disease Control and Prevention. 2024. URL: https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2022/maternal-mortality-rates-2022.htm [accessed 2024-12-06]
2. Ely DM, Driscoll AK. Infant Mortality in the United States, 2021: Data From the Period Linked Birth/Infant Death File. Natl Vital Stat Rep 2023 Sep;72(11):1-19. [doi: 10.15620/cdc:131356] [Medline: 37748084]
3. Hill L, Rao A, Artiga S. Racial disparities in maternal and infant health: current status and efforts to address them. KFF. 2024. URL: https://www.kff.org/racial-equity-and-health-policy/issue-brief/racial-disparities-in-maternal-and-infant-health-current-status-and-efforts-to-address-them/ [accessed 2024-12-27]
4. Mooney JT, Dahl AA, Quinlan MM, et al. Expand and extend postpartum Medicaid to support maternal and child health. Transl Behav Med 2024 Apr 29;14(5):298-300. [doi: 10.1093/tbm/ibae007] [Medline: 38417096]
5. Guglielminotti J, Samari G, Friedman AM, Lee A, Landau R, Li G. Nurse workforce diversity and reduced risk of severe adverse maternal outcomes. Am J Obstet Gynecol MFM 2022 Sep;4(5):100689. [doi: 10.1016/j.ajogmf.2022.100689] [Medline: 35830955]
6. Kozhimannil KB, Almanza J, Hardeman R, Karbeah J. Racial and ethnic diversity in the nursing workforce: a focus on maternity care. Policy Polit Nurs Pract 2021 Aug;22(3):170-179. [doi: 10.1177/15271544211005719] [Medline: 33775170]
7. Escarne JG, Atrash HK, de la Cruz DS, Baker B, Reyes M. Introduction to the special issue on Healthy Start. Matern Child Health J 2017 Dec;21(Suppl 1):1-3. [doi: 10.1007/s10995-017-2404-y] [Medline: 29190009]
8. Healthy start. Health Resources & Services Administration (HRSA). 2010. URL: http://mchb.hrsa.gov/programs/healthystart/index.html [accessed 2011-08-08]
9. McKelvey LM, Lewis KN, Beavers J, Casey PH, Irby C, Goudie A. Home visiting for NICU graduates: impacts of Following Baby Back Home. Pediatrics 2021 Jul;148(1):e2020029397. [doi: 10.1542/peds.2020-029397] [Medline: 34083358]
10. Meghea CI, Raffo JE, Yu X, et al. Community health worker home visiting, birth outcomes, maternal care, and disparities among birthing individuals with Medicaid insurance. JAMA Pediatr 2023 Sep 1;177(9):939-946. [doi: 10.1001/jamapediatrics.2023.2310] [Medline: 37486641]
11. Schnitman G, Wang T, Kundu S, et al. The role of digital patient education in maternal health: a systematic review. Patient Educ Couns 2022 Mar;105(3):586-593. [doi: 10.1016/j.pec.2021.06.019] [Medline: 34183217]
12. Ledford CJW, Canzona MR, Cafferty LA, Hodge JA. Mobile application as a prenatal education and engagement tool: a randomized controlled pilot. Patient Educ Couns 2016 Apr;99(4):578-582. [doi: 10.1016/j.pec.2015.11.006] [Medline: 26610389]
13. Rothwell E, Johnson E, Wong B, et al. The use of a game-based decision aid to educate pregnant women about prenatal screening: a randomized controlled study. Am J Perinatol 2019 Feb;36(3):322-328. [doi: 10.1055/s-0038-1667371] [Medline: 30107621]
14. Shorten A, Shorten B, Fagerlin A, et al. A study to assess the feasibility of implementing a web-based decision aid for birth after cesarean to increase opportunities for shared decision making in ethnically diverse settings. J Midwifery Womens Health 2019 Jan;64(1):78-87. [doi: 10.1111/jmwh.12908] [Medline: 30334330]

15. Skar JB, Garnweidner-Holme LM, Lukasse M, Terragni L. Women’s experiences with using a smartphone app (the Pregnant+ app) to manage gestational diabetes mellitus in a randomised controlled trial. Midwifery 2018 Mar;58:102-108. [doi: 10.1016/j.midw.2017.12.021] [Medline: 29329023]
16. Hall J, Chawla M, Watson D, et al. Addressing reproductive health needs across the life course: an integrated, community-based model combining contraception and preconception care. Lancet Public Health 2023 Jan;8(1):e76-e84. [doi: 10.1016/S2468-2667(22)00254-7] [Medline: 36603914]
17. Hickmann E, Richter P, Schlieter H. All together now—patient engagement, patient empowerment, and associated terms in personal healthcare. BMC Health Serv Res 2022 Sep 2;22(1):1116. [doi: 10.1186/s12913-022-08501-5] [Medline: 36056354]
18. Chen J, Mullins CD, Novak P, Thomas SB. Personalized strategies to activate and empower patients in health care and reduce health disparities. Health Educ Behav 2016 Feb;43(1):25-34. [doi: 10.1177/1090198115579415]
19. Henrich N, Brinson A, Arnold A, Jahnke HR. Digital health needs and preferences during pregnancy and the postpartum period: mixed methods study. JMIR Form Res 2024 Jan 12;8:e48960. [doi: 10.2196/48960] [Medline: 38214971]
20. Li B, Jin N, Wang Y, Hou X, Meng J, Zhang Y. Perinatal women’s perception of maternal health information quality on digital media: scoping review. J Med Internet Res 2025 Jul 2;27:e67620. [doi: 10.2196/67620] [Medline: 40600605]
21. Mobile fact sheet. Pew Research Center. 2024. URL: https://www.pewresearch.org/internet/fact-sheet/mobile/ [accessed 2024-12-06]
22. Jack BW, Bickmore T, Yinusa-Nyahkoon L, et al. Improving the health of young African American women in the preconception period using health information technology: a randomised controlled trial. Lancet Digit Health 2020 Sep;2(9):e475-e485. [doi: 10.1016/S2589-7500(20)30189-8] [Medline: 33328115]
23. Centers for Disease Control and Prevention. Principles of Community Engagement, 2nd edition: U.S. Department of Health and Human Services; 2011. URL: https://ictr.johnshopkins.edu/wp-content/uploads/2015/10/CTSAPrinciplesofCommunityEngagement.pdf [accessed 2024-12-06]
24. QuickFacts: Mecklenburg County, North Carolina. US Census Bureau. URL: https://www.census.gov/quickfacts/fact/table/mecklenburgcountynorthcarolina/PST045223 [accessed 2024-12-06]
25. 2021 North Carolina infant mortality report, table 1B. North Carolina State Center for Health Statistics. 2023. URL: https://schs.dph.ncdhhs.gov/data/vital/ims/2021/2021-IMR-TABLE-1B-FINAL.html [accessed 2025-01-01]
26. Johnson JL, Cobb SM, Pettiford B. North Carolina’s 2022-2026 perinatal health strategic plan: addressing perinatal health inequities across the life-course. N C Med J 2022;83(5):330-336. [doi: 10.18043/ncm.83.5.330] [Medline: 37158542]
27. Public health; Maternal and child health. Mecklenburg County Health Department. URL: https://health.mecknc.gov/Maternal-and-Child-Health [accessed 2024-12-06]
28. Creating healthier lives for all. Atrium Health. URL: https://atriumhealth.org/community/health [accessed 2024-12-06]
29. Valerio MA, Rodriguez N, Winkler P, et al. Comparing two sampling methods to engage hard-to-reach communities in research priority setting. BMC Med Res Methodol 2016 Oct 28;16(1):146. [doi: 10.1186/s12874-016-0242-z] [Medline: 27793191]
30. O’Haire C, McPheeters M, Nakamoto E, et al. Engaging Stakeholders to Identify and Prioritize Future Research Needs: Agency for Healthcare Research and Quality (US); 2011. [Medline: 21977526]
31. Lu MC, Halfon N. Racial and ethnic disparities in birth outcomes: a life-course perspective. Matern Child Health J 2003 Mar;7(1):13-30. [doi: 10.1023/a:1022537516969] [Medline: 12710797]
32. Lu MC, Kotelchuck M, Hogan V, Jones L, Wright K, Halfon N. Closing the Black-White gap in birth outcomes: a life-course approach. Ethn Dis 2010;20(1 Suppl 2):S2-62. [Medline: 20629248]
33. Malawa Z, Gaarde J, Spellen S. Racism as a root cause approach: a new framework. Pediatrics 2021 Jan;147(1):e2020015602. [doi: 10.1542/peds.2020-015602] [Medline: 33386339]
34. Mollard E, Hatton-Bowers H, Tippens J. Finding strength in vulnerability: ethical approaches when conducting research with vulnerable populations. J Midwifery Womens Health 2020 Nov;65(6):802-807. [doi: 10.1111/jmwh.13151] [Medline: 32881276]
35. Charlotte-Mecklenburg quality of life explorer. Mecklenburg County, City of Charlotte, UNC Charlotte Urban Institute. URL: https://maps.mecklenburgcountync.gov/qol/ [accessed 2025-01-11]
36. Reach effectiveness adoption implementation maintenance. RE-AIM. URL: http://www.re-aim.org/ [accessed 2019-08-15]
37. Mecklenburg birthing connections. Atrium Health. 2025. URL: https://atriumhealth.org/meckbirth [accessed 2025-01-11]
38. Falako S, Okoli N, Boateng MO, et al. Utilizing community-centered approaches to address black maternal mortality. Health Educ Behav 2023 Aug;50(4):500-504. [doi: 10.1177/10901981231177078]
39. Crear-Perry J, Correa-de-Araujo R, Lewis Johnson T, McLemore MR, Neilson E, Wallace M. Social and structural determinants of health inequities in maternal health. J Womens Health (Larchmt) 2021 Feb 1;30(2):230-235. [doi: 10.1089/jwh.2020.8882]
40. Plevock Haase KM, Price CA, Wei GS, et al. Establishing NIH Community Implementation Programs to improve maternal health. Implement Sci Commun 2024 Dec;5(1):1-7. [doi: 10.1186/s43058-024-00634-4]
41. Health care transformation task force. Maternal Health Hub. URL: https://maternalhealthhub.org/resources/ [accessed 2024-12-27]

42. Bower KM, Arrington LA, Kramer BE, Jeffers NK, Ogunwole SM, Harris TL. Development of a community‐ and patient‐engaged maternal health equity toolkit for hospitals. J Midwife Womens Health 2025 Sep;70(5):800-806. [doi: 10.1111/jmwh.13771]
43. Amore AD, Britt A, Arconada Alvarez SJ, Greenleaf MN. A web-based intervention to address risk factors for Maternal Morbidity and Mortality (MAMA LOVE): development and evaluation study. JMIR Pediatr Parent 2023 Aug 18;6:e44615. [doi: 10.2196/44615] [Medline: 37623373]
44. Chandler R, Guillaume D, Parker A, Wells J, Hernandez ND. Developing culturally tailored mHealth tools to address sexual and reproductive health outcomes among Black and Latina women: a systematic review. Health Promot Pract 2022 Jul;23(4):619-630. [doi: 10.1177/15248399211002831] [Medline: 33771045]
45. Kathuria-Prakash N, Moser DK, Alshurafa N, Watson K, Eastwood JA. Young African American women’s participation in an m-Health study in cardiovascular risk reduction: feasibility, benefits, and barriers. Eur J Cardiovasc Nurs 2019 Oct;18(7):569-576. [doi: 10.1177/1474515119850009] [Medline: 31088306]
46. McFarlane SJ, Callands T, Francis DB, Swartzendruber A, S D. Feasibility and acceptability of a multimedia childbirth education intervention for Black women and birthing people and their birth companions. Healthcare (Basel) 2025 May 9;13(10):1106. [doi: 10.3390/healthcare13101106]
47. Chinekezi O, Andress L, Agonafer EP, et al. From the national to the local: issues of trust and a model for community-academic-engagement. Front Public Health 2023;11:1068425. [doi: 10.3389/fpubh.2023.1068425] [Medline: 36908463]
48. Quiñones AR, Talavera GA, Castañeda SF, Saha S. Interventions that reach into communities--promising directions for reducing racial and ethnic disparities in healthcare. J Racial Ethn Health Disparities 2015 Sep;2(3):336-340. [doi: 10.1007/s40615-014-0078-3] [Medline: 26413456]
49. Spencer MRT, Chen J. Revisiting patient engagement and empowerment within the NIMHD health disparity framework. Am J Public Health 2023 Feb;113(2):141-143. [doi: 10.2105/AJPH.2022.307170] [Medline: 36480774]
50. Hernandez-Green N, Davis MV, Farinu O, et al. Using mHealth to reduce disparities in Black maternal health: perspectives from Black rural postpartum mothers. Womens Health (Lond Engl) 2024 Jan;20:17455057241239769. [doi: 10.1177/17455057241239769]

Abbreviations

AIAN: American Indian and Alaska Native

Edited by J Zhang; submitted 17.Jan.2025; peer-reviewed by AG Bauer, L Furman, X Ding; revised version received 11.Aug.2025; accepted 05.Dec.2025; published 24.Feb.2026.

Please cite as:
Taylor YJ, Dahl A, Isreal M, Spinner C, Sammons L, Fesperman D, Washington R, Mehta S, Howell C, Stamp J, Bundy H, Cobb P, Bridges Community Partner Group
Health System Community Partnership to Design an Online Resource to Address Perinatal Information Needs for Black Families: Action Research Study
JMIR Pediatr Parent 2026;9:e71161
URL: https://pediatrics.jmir.org/2026/1/e71161
doi:10.2196/71161

Dental Health in Pediatric Patients With Different Types of Mucopolysaccharidosis: Retrospective Cross-Sectional Study

Mengxing Wang[1], MSc; Rong Liu[2], BSc; Tian Xia[1], BSc; Ying Wang[1], MSc

[1]Department of Stomatology, Capital Center for Children’s Health, Capital Medical University, No. 2 Yabao Road, Chaoyang District, Beijing, China
[2]Department of Hematology, Capital Center for Children’s Health, Capital Medical University, Beijing, China

Corresponding Author:
Mengxing Wang, MSc
Department of Stomatology, Capital Center for Children’s Health, Capital Medical University, No. 2 Yabao Road, Chaoyang District, Beijing, China

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

(JMIR Pediatr Parent 2026;9:e87430) doi:10.2196/87430

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 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 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.

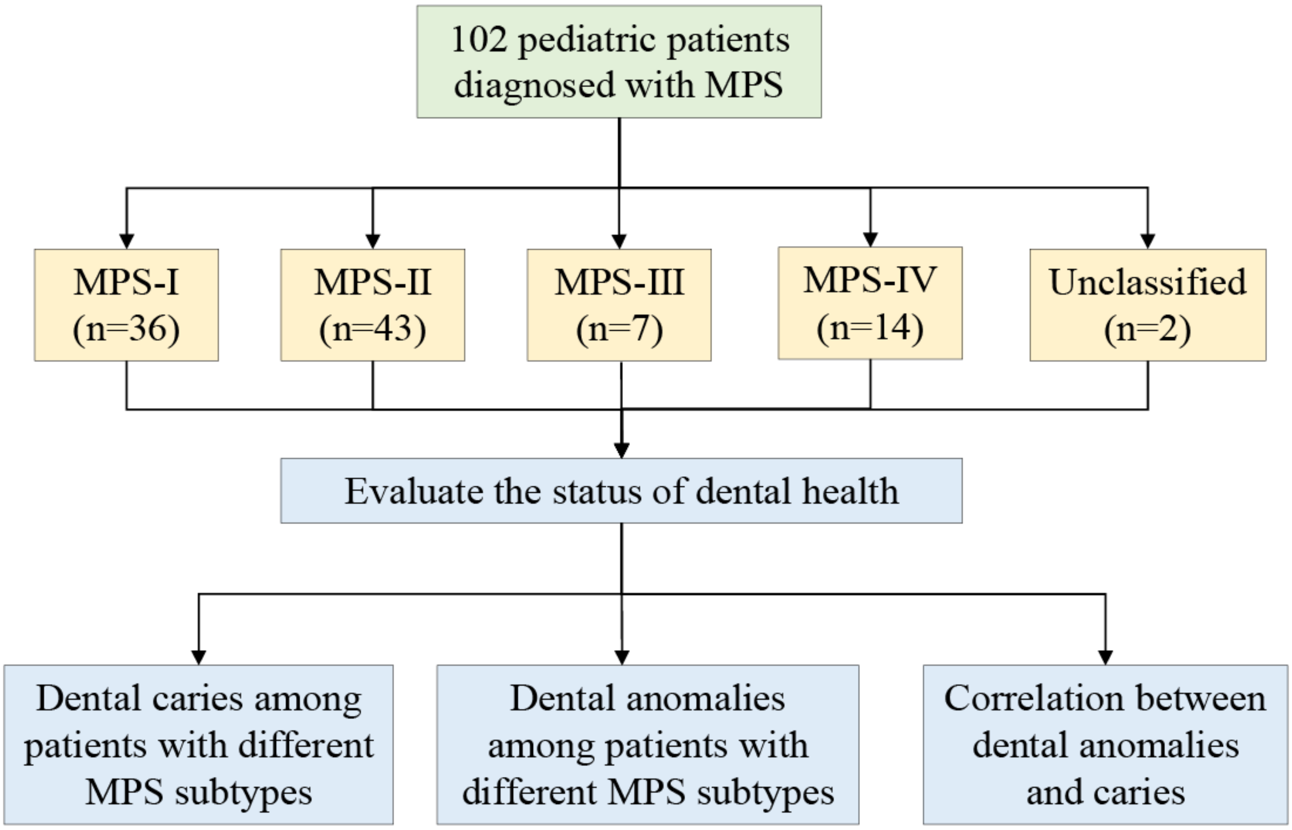


Table . Demographic and clinical characteristics of patients with mucopolysaccharidosis (MPS; N=102).

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).

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.

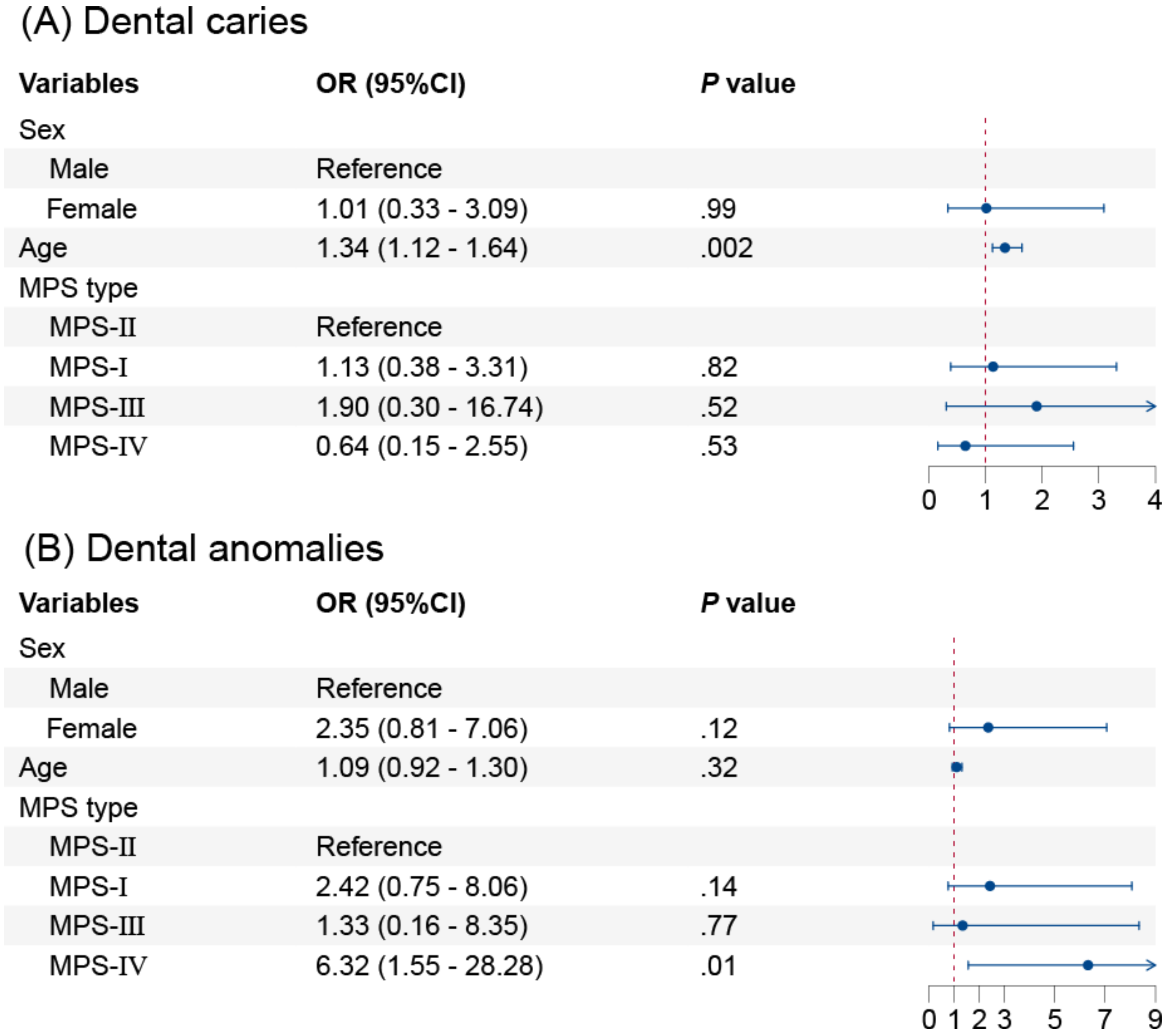
Developmental anomalies were the most common type observed in patients with MPS-I (9/36, 25%), while morphological anomalies were notably frequent in patients with MPS-IV (4/14, 28.6%). Patients with developmental anomalies primarily exhibited the following 4 manifestations: delayed or retained eruption, 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).

Figure 2. Multivariable analysis of the association of mucopolysaccharidosis (MPS) subtypes with dental health: (A) dental caries and (B) dental anomalies. OR: odds ratio.



(A) Dental caries

Variables	OR (95%CI)	*P* value
Sex		
Male	Reference	
Female	1.01 (0.33 - 3.09)	.99
Age	1.34 (1.12 - 1.64)	.002
MPS type		
MPS-II	Reference	
MPS-I	1.13 (0.38 - 3.31)	.82
MPS-III	1.90 (0.30 - 16.74)	.52
MPS-IV	0.64 (0.15 - 2.55)	.53

(B) Dental anomalies

Variables	OR (95%CI)	*P* value
Sex		
Male	Reference	
Female	2.35 (0.81 - 7.06)	.12
Age	1.09 (0.92 - 1.30)	.32
MPS type		
MPS-II	Reference	
MPS-I	2.42 (0.75 - 8.06)	.14
MPS-III	1.33 (0.16 - 8.35)	.77
MPS-IV	6.32 (1.55 - 28.28)	.01

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.

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 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

The authors declared no financial support was received for this work.

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.

References

1. Nagpal R, Goyal RB, Priyadarshini K, et al. Mucopolysaccharidosis: a broad review. Indian J Ophthalmol 2022 Jul;70(7):2249-2261. [doi: 10.4103/ijo.IJO_425_22] [Medline: 35791104]
2. Bhakthaganesh K, Vanathi M, Ahmed S, Gupta N, Tandon R. Mucopolysaccharidosis. Taiwan J Ophthalmol 2023;13(4):443-450. [doi: 10.4103/tjo.TJO-D-23-00137] [Medline: 38249505]
3. Zhou J, Lin J, Leung WT, Wang L. A basic understanding of mucopolysaccharidosis: incidence, clinical features, diagnosis, and management. Intractable Rare Dis Res 2020 Feb;9(1):1-9. [doi: 10.5582/irdr.2020.01011] [Medline: 32201668]
4. Tylki-Szymańska A, Almássy Z, Christophidou-Anastasiadou V, et al. The landscape of mucopolysaccharidosis in Southern and Eastern European countries: a survey from 19 specialistic centers. Orphanet J Rare Dis 2022 Mar 24;17(1):136. [doi: 10.1186/s13023-022-02285-x] [Medline: 35331284]
5. Çelik B, Tomatsu SC, Tomatsu S, Khan SA. Epidemiology of mucopolysaccharidoses update. Diagnostics (Basel) 2021 Feb 10;11(2):273. [doi: 10.3390/diagnostics11020273] [Medline: 33578874]
6. Chen X, Qiu W, Ye J, Han L, Gu X, Zhang H. Demographic characteristics and distribution of lysosomal storage disorder subtypes in Eastern China. J Hum Genet 2016 Apr;61(4):345-349. [doi: 10.1038/jhg.2015.155] [Medline: 26740238]
7. Hp C, Harjai G, Doddawad VG, S M. Comprehensive preventive and therapeutic oral health care: a case report of mucopolysaccharidosis type IV A in a pediatric patient. P R Health Sci J 2023 Dec;42(4):332-334. [Medline: 38104293]
8. Carneiro NC, Abreu LG, Milagres RM, et al. Dental and maxillomandibular incidental findings in panoramic radiography among individuals with mucopolysaccharidosis: a cross-sectional study. J Appl Oral Sci 2021;29:e20200978. [doi: 10.1590/1678-7757-2020-0978] [Medline: 33886944]
9. Hirst L, Mubeen S, Abou-Ameira G, Chakrapani A. Mucopolysaccharidosis (MPS): review of the literature and case series of five pediatric dental patients. Clin Case Rep 2021 Feb;9(3):1704-1710. [doi: 10.1002/ccr3.3885] [Medline: 33768919]
10. de Bode CJ, Dogterom EJ, Rozeboom AV, et al. Orofacial abnormalities in mucopolysaccharidosis and mucolipidosis type II and III: a systematic review. JIMD Rep 2022 Sep;63(6):621-629. [doi: 10.1002/jmd2.12331] [Medline: 36341168]
11. Costi S, Caporali RF, Marino A. Mucopolysaccharidosis: what pediatric rheumatologists and orthopedics need to know. Diagnostics (Basel) 2022 Dec 27;13(1):75. [doi: 10.3390/diagnostics13010075] [Medline: 36611367]
12. Oussoren E, Wagenmakers MA, Link B, et al. Hip disease in mucopolysaccharidoses and mucolipidoses: a review of mechanisms, interventions and future perspectives. Bone 2021 Feb;143:115729. [doi: 10.1016/j.bone.2020.115729] [Medline: 33130340]
13. Guffon N, Journeau P, Brassier A, Leger J, Chevallier B. Growth impairment and limited range of joint motion in children should raise suspicion of an attenuated form of mucopolysaccharidosis: expert opinion. Eur J Pediatr 2019 Apr;178(4):593-603. [doi: 10.1007/s00431-019-03330-x] [Medline: 30740618]
14. Galimberti C, Madeo A, Di Rocco M, Fiumara A. Mucopolysaccharidoses: early diagnostic signs in infants and children. Ital J Pediatr 2018 Nov 16;44(Suppl 2):133. [doi: 10.1186/s13052-018-0550-5] [Medline: 30442162]
15. Sawamoto K, Álvarez González JV, Piechnik M, et al. Mucopolysaccharidosis IVA: diagnosis, treatment, and management. Int J Mol Sci 2020 Feb 23;21(4):1517. [doi: 10.3390/ijms21041517] [Medline: 32102177]

16. de Almeida-Barros RQ, de Medeiros PF, de Almeida Azevedo MQ, et al. Evaluation of oral manifestations of patients with mucopolysaccharidosis IV and VI: clinical and imaging study. Clin Oral Investig 2018 Jan;22(1):201-208. [doi: 10.1007/s00784-017-2100-8] [Medline: 28315965]
17. James A, Hendriksz CJ, Addison O. The oral health needs of children, adolescents and young adults affected by a mucopolysaccharide disorder. JIMD Rep 2012;2:51-58. [doi: 10.1007/8904_2011_46] [Medline: 23430854]
18. Gugnani N, Pandit IK, Srivastava N, Gupta M, Sharma M. International caries detection and assessment system (ICDAS): a new concept. Int J Clin Pediatr Dent 2011;4(2):93-100. [doi: 10.5005/jp-journals-10005-1089] [Medline: 27672245]
19. Moradi G, Mohamadi Bolbanabad A, Moinafshar A, Adabi H, Sharafi M, Zareie B. Evaluation of oral health status based on the decayed, missing and filled teeth (DMFT) index. Iran J Public Health 2019 Nov;48(11):2050-2057. [Medline: 31970104]
20. Talukdar L, Saha S, Dhinsa K, Rai A, Tiwari V, Trivedi H. Comparison of craniofacial morphology characteristics along with dental caries status and salivary properties of operated cleft lip and palate patients with noncleft patients. J Indian Soc Pedod Prev Dent 2022;40(3):265-273. [doi: 10.4103/jisppd.jisppd_278_22] [Medline: 36260467]
21. de Santana Sarmento DJ, de Carvalho SH, Melo SL, et al. Mucopolysaccharidosis: radiographic findings in a series of 16 cases. Oral Surg Oral Med Oral Pathol Oral Radiol 2015 Dec;120(6):e240-e246. [doi: 10.1016/j.oooo.2015.08.009] [Medline: 26455293]
22. Anju V, Raj NS. Caries assessment and salivary microbial analysis in patients diagnosed with mucopolysaccharidosis. J Indian Soc Pedod Prev Dent 2024 Apr 1;42(2):83-90. [doi: 10.4103/jisppd.jisppd_28_24] [Medline: 38957904]
23. Prado HV, Carneiro NC, Perazzo MF, de Abreu MH, Martins CC, Borges-Oliveira AC. Assessing a possible vulnerability to dental caries in individuals with rare genetic diseases that affect the skeletal development. Orphanet J Rare Dis 2019 Jun 18;14(1):145. [doi: 10.1186/s13023-019-1114-5] [Medline: 31215497]

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

Edited by S Badawy; submitted 09.Nov.2025; peer-reviewed by K Baghlaf, SK Ucar; revised version received 08.Feb.2026; accepted 04.Mar.2026; published 04.May.2026.

Please cite as:
Wang M, Liu R, Xia T, Wang Y
Dental Health in Pediatric Patients With Different Types of Mucopolysaccharidosis: Retrospective Cross-Sectional Study
JMIR Pediatr Parent 2026;9:e87430
URL: https://pediatrics.jmir.org/2026/1/e87430
doi:10.2196/87430

The Pattern and Characteristics of Childhood Unintentional Injuries in Abha Maternity and Children Hospital, KSA: Prospective Descriptive Study

Ihab Mohammed Ibrahim Elsorogy[1], MD; Niemat Mohammed Tahir Ali[2], MD; Alam Eldin Musa Mustafa[2,3], MD; Ibrahim Alhelali[1], MD; Ibrahim AL-Benhassan[1], MD; Ahmed Alhijab A Alhazmi[1], MD; Safa Ahmed Ali Fadoul[4], MD; Emad Mohammed Mosaad Mohammed[1], MD; Mohammed Mahmoud Mohammed Almusdi[4], MD

[1]Pediatric Intensive Care Unit, Abha Maternity and Children Hospital, Abha, Saudi Arabia

[2]Department of Child Health, College of Medicine, King Khalid University, P.O. Box 641, Abha, Saudi Arabia

[3]Department of Pediatrics, Faculty of Medicine, University of Kordofan, Al Ubayyid, Sudan

[4]Pediatric Intensive Care Unit, Khamis Mushait Maternity and Children Hospital, Khamis Mushait, Saudi Arabia

Corresponding Author:
Alam Eldin Musa Mustafa, MD
Department of Child Health, College of Medicine, King Khalid University, P.O. Box 641, Abha, Saudi Arabia

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.

(JMIR Pediatr Parent 2026;9:e83867) doi:10.2196/83867

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 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.

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).

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.

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

Figure 1. Kaplan and Meier curve representing time to discharge for the whole group.

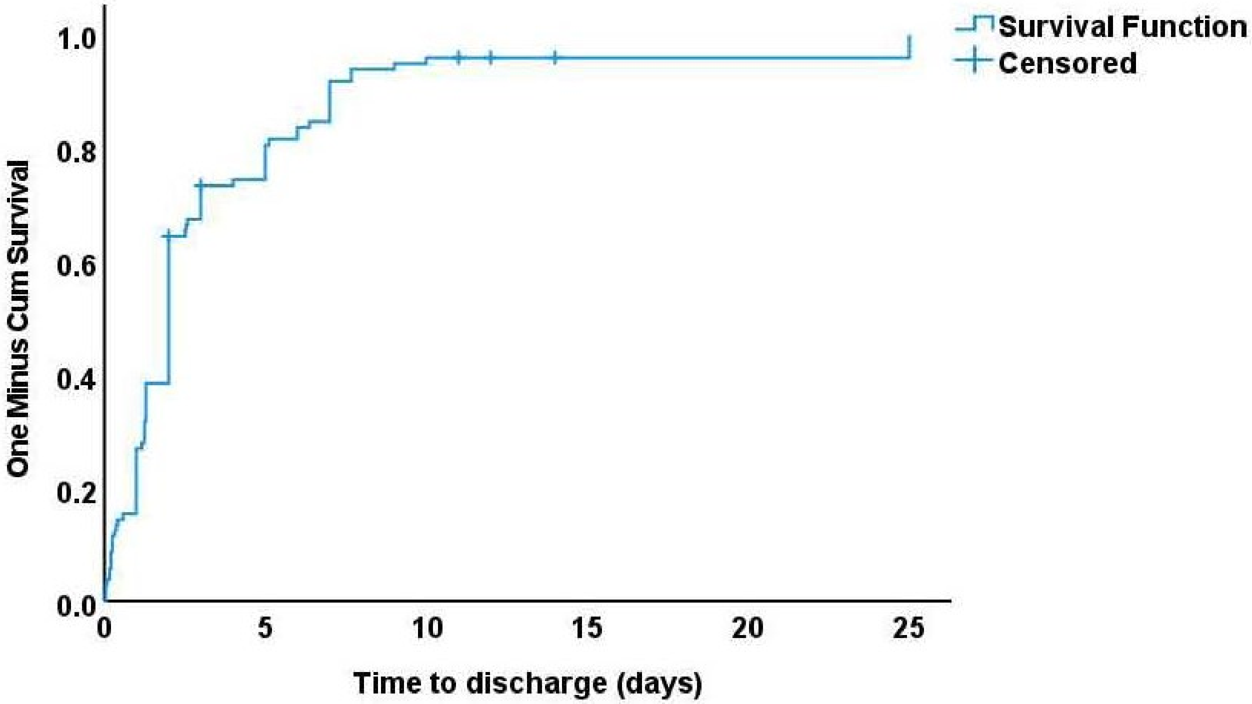


Figure 2. Kaplan and Meier curve representing time to discharge by type of trauma.

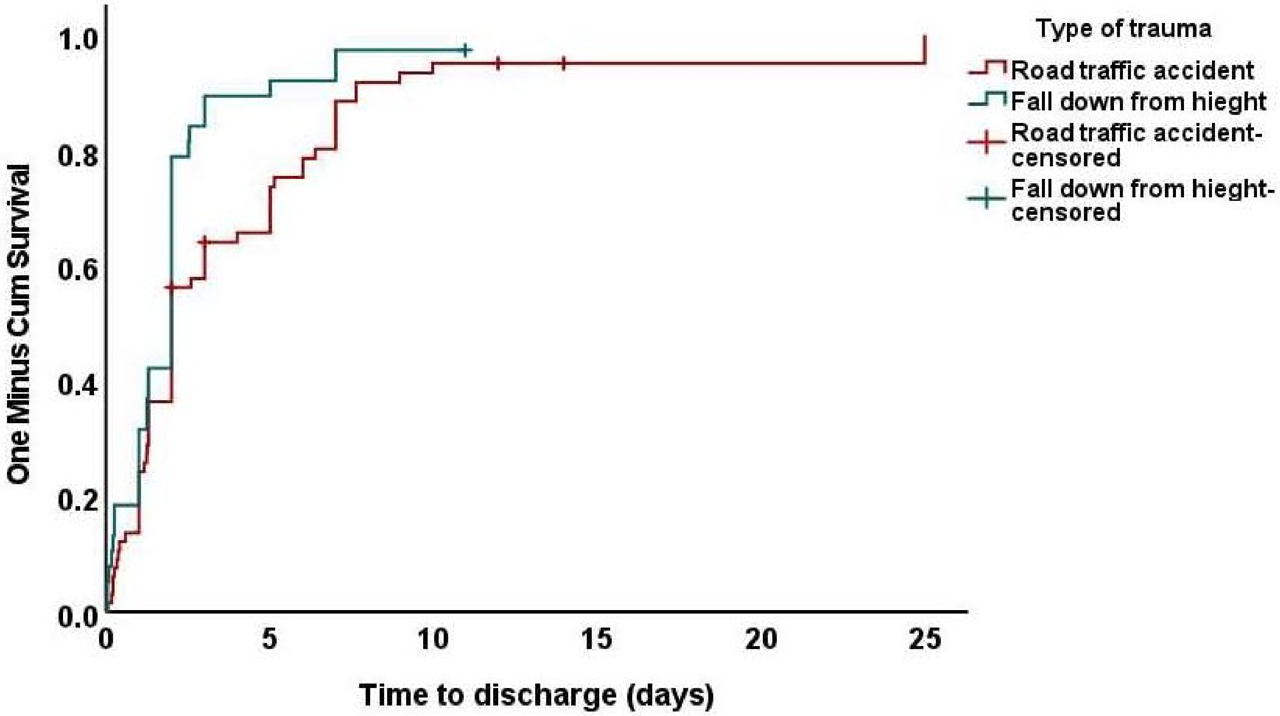


Table . Time to discharge concerning different factors.

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).

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 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.

Acknowledgments

Artificial intelligence (AI) applications were not used in the generation of any portion of this study.

Funding

No funding was received from any source for this study in any part of it.

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.

References

1. Almalki MM, Almalki ME, Alsulaimani N, et al. Epidemiology of pediatric trauma in Makkah, Kingdom of Saudi Arabia. SMJ 2023 Aug;44(8):808-814. [doi: 10.15537/smj.2023.44.8.20230292]
2. Wei W, Lyu W, Zhang Y. Global patterns and health impact of unintentional injuries among children and adolescents, 1990-2021. Front Public Health 2025;13:1626739. [doi: 10.3389/fpubh.2025.1626739] [Medline: 41069815]
3. Rosenblum S, Nardi-Moses T, Goez H, Demeter N. Children who experience unintentional injuries: their functional profiles. Occup Ther Int 2022;2022:6731339. [doi: 10.1155/2022/6731339] [Medline: 36419546]

4. Xiang H, Wheeler KK, Stallones L. Disability status: a risk factor in injury epidemiologic research. Ann Epidemiol 2014 Jan;24(1):8-16. [doi: 10.1016/j.annepidem.2013.10.014] [Medline: 24268995]
5. Alkhamis KN, Abdulkader RS. Assessment of unintentional childhood injuries and associated factors in the pediatric clinics of a tertiary care hospital in Riyadh, Saudi Arabia. J Family Community Med 2020;27(3):168-177. [doi: 10.4103/jfcm.JFCM_75_20] [Medline: 33354147]
6. Global Burden of Disease Child and Adolescent Health Collaboration, Kassebaum N, Kyu HH, et al. Child and Adolescent Health From 1990 to 2015: Findings From the Global Burden of Diseases, Injuries, and Risk Factors 2015 Study. JAMA Pediatr 2017 Jun 1;171(6):573-592. [doi: 10.1001/jamapediatrics.2017.0250] [Medline: 28384795]
7. GBD 2016 Disease and Injury Incidence and Prevalence Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet 2017 Sep 16;390(10100):1211-1259. [doi: 10.1016/S0140-6736(17)32154-2] [Medline: 28919117]
8. Peden M, McGee K, Krug E. Injury: A Leading Cause of the Global Burden of Disease, 2000.
9. He S, Lunnen JC, Puvanachandra P, Zia N, Hyder AA. Global childhood unintentional injury study: multisite surveillance data. Am J Public Health 2014 Mar;104(3):e79-e84. [doi: 10.2105/AJPH.2013.301607] [Medline: 24432924]
10. Global burden of disease, 2004 update WHO library cataloguing-in-publication data. World Health Organization. 2008. URL: https://www.who.int/publications/i/item/9789241563710 [accessed 2026-03-18]
11. Zhang X, Xiang H, Jing R, Tu Z. Road traffic injuries in the People’s Republic of China, 1951-2008. Traffic Inj Prev 2011 Dec;12(6):614-620. [doi: 10.1080/15389588.2011.609925] [Medline: 22133338]
12. Peden M, Oyegbite K, Ozanne-Smith J, Hyder AA. World Report on Child Injury Prevention: World Health Organization; 2008. URL: https://pubmed.ncbi.nlm.nih.gov/26269872/
13. Lao Z, Gifford M, Dalal K. Economic cost of childhood unintentional injuries. Int J Prev Med 2012 May;3(5):303-312. [Medline: 22708026]
14. Moghadam N, Rahil G. Survey of under-5-year-old children injury and accident mortality causes in the City of Kerman in 2013 [in Arabic]. Journal of Health-Based Research 2015;1(1):1-12 [FREE Full text]
15. Sridharan L, Crandall M. Injury and health among children in vulnerable families. J Trauma Acute Care Surg 2011;70(6):1539-1545. [doi: 10.1097/TA.0b013e3182190b94]
16. Yu X, Wang Y, He C, et al. The trend of unintentional injury-related mortality among children aged under-five years in China, 2010-2020: a retrospective analysis from a national surveillance system. BMC Public Health 2023 Apr 11;23(1):673. [doi: 10.1186/s12889-023-15546-6] [Medline: 37041562]
17. Alomani H, Fareed A, Ibrahim H, et al. Pediatric trauma at a single center in the Qassim region of Saudi Arabia. Ann Saudi Med 2021;41(3):165-170. [doi: 10.5144/0256-4947.2021.165] [Medline: 34085544]
18. Almalki MM, Almalki ME, Alsulaimani N, et al. Epidemiology of pediatric trauma in Makkah, Kingdom of Saudi Arabia: An observational cohort study. Saudi Med J 2023 Aug;44(8):808-814. [doi: 10.15537/smj.2023.44.8.20230292] [Medline: 37582569]
19. Albedewi H, Al-Saud N, Kashkary A, Al-Qunaibet A, AlBalawi SM, Alghnam S. Epidemiology of childhood injuries in Saudi Arabia: a scoping review. BMC Pediatr 2021 Sep 25;21(1):424. [doi: 10.1186/s12887-021-02886-8] [Medline: 34563167]
20. Otters H, Schellevis FG, Damen J, van der Wouden JC, van Suijlekom-Smit LWA, Koes BW. Epidemiology of unintentional injuries in childhood: a population-based survey in general practice. Br J Gen Pract 2005 Aug;55(517):630-633. [Medline: 16105373]
21. Ansari S, Akhdar F, Mandoorah M, Moutaery K. Causes and effects of road traffic accidents in Saudi Arabia. Public Health 2000 Jan;114(1):37-39. [doi: 10.1038/sj.ph.1900610] [Medline: 10787024]
22. Gong H, Lu G, Ma J, et al. Causes and characteristics of children unintentional injuries in emergency department and its implications for prevention. Front Public Health 2021;9(August):1-8. [doi: 10.3389/fpubh.2021.669125]
23. Sharma SL, N SR, Ramanujam K, et al. PW 2288 prevalence and risk factors of unintentional injuries among children aged 1–5 years in urban slums of Vellore, South India. 2018 Nov Presented at: Safety 2018 abstracts p. A1392-AA139. [doi: 10.1136/injuryprevention-2018-safety.386]
24. Pathak P, Joshi SK. Epidemiology of unintentional childhood injuries in urban and rural areas of Nepal- A comparative study. PLoS ONE 2023;18(10):e0287487. [doi: 10.1371/journal.pone.0287487] [Medline: 37847700]

Abbreviations

MCH: Maternity and Children Hospital
PICU: pediatric intensive care unit
RTA: road traffic accident

Edited by S Badawy; submitted 09.Sep.2025; peer-reviewed by AE Tadevosyan, MA Jatt; accepted 16.Feb.2026; published 27.Mar.2026.

Please cite as:
Elsorogy IMI, Ali NMT, Mustafa AEM, Alhelali I, AL-Benhassan I, Alhazmi AAA, Fadoul SAA, Mohammed EMM, Almusdi MMM
The Pattern and Characteristics of Childhood Unintentional Injuries in Abha Maternity and Children Hospital, KSA: Prospective Descriptive Study
JMIR Pediatr Parent 2026;9:e83867
URL: https://pediatrics.jmir.org/2026/1/e83867
doi:10.2196/83867

Family Engagement in a Digital Intervention Targeting Risk for Anxiety in Parent-Child Dyads: Mixed Methods Study

Isaac A Mirzadegan[1,2,3], BA, MS, PhD; Ericka M Lewis[4], LMSW, PhD; Sally L Cole[1], MA; Alexandria M Meyer[5], BA, MA, PhD

[1]Department of Psychology, Florida State University, Tallahassee, FL, United States
[2]San Francisco VA Medical Center, 4150 Clement St (116B), San Francisco, CA, United States
[3]Department of Psychiatry and Behavioral Sciences, University of California, San Francisco, San Francisco, CA, United States
[4]School of Social Work, University of Maryland, Baltimore, Maryland, United States
[5]School of Education and Counseling Psychology, Santa Clara University, Santa Clara, United States

Corresponding Author:
Isaac A Mirzadegan, BA, MS, PhD
Department of Psychology, Florida State University, Tallahassee, FL, United States

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.

(JMIR Pediatr Parent 2026;9:e79898) doi:10.2196/79898

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

[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 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 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).

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)

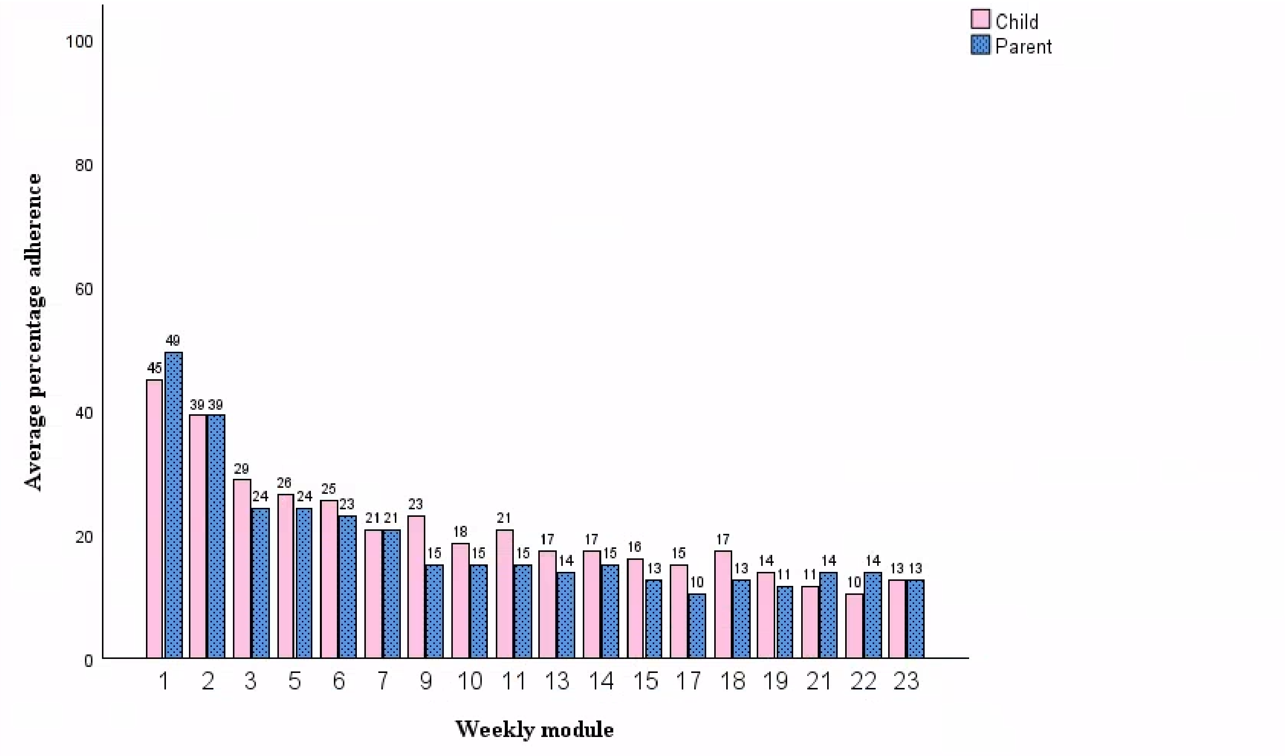
[a] $n=83$ for relationship status and parent age ($n_{missing}=4$). Full sample: mean parent age 36.6 (SD 6.0; range 22-52) years; mean child age 6.2 (SD 0.8; range 5-8) years. Interview sample: mean parent age 36.4 (SD 6.3; range 25-48); mean child age 6.2 (SD 0.9; range 5-8).

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 $\chi^2_2=4.36$; $P=.11$), 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 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 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 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 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, 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.

Acknowledgments

We thank Drs Anne Barrett, Michael Kofler, Lyndsay Jenkins, and Walter Boot for their insightful comments and support on an earlier draft of this manuscript, as well as Drs Ryan Coker, Jillian Volpe-White, and Karl Wissemann for their consultations. We deeply appreciate each of the families that participated in our research, especially those who completed qualitative interviews. Finally, we are grateful to the many research assistants who made this work possible, including but not limited to Mia Mantei, Madison Poisall, Sarah Conley, Catalina Borges, Cara Dillhyon, and Mateo Roldan. IAM and AMM were affiliated with Florida State University at the time of data collection. IAM is currently affiliated with the Department of Veterans Affairs/UCSF. AMM is currently affiliated with Santa Clara University.

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.

Funding

This work was funded by the National Institute of Mental Health (grant ID NIMH K01MH117366) and supported by the Department of Veterans Affairs, Office of Academic Affiliations VA Quality Scholars Advanced Fellowship Program (Program Award Number 3Q082019C). The views expressed in this paper are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States Government.

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.

Multimedia Appendix 1
Supplemental data and access to Making Mistakes program.
[DOCX File, 31 KB - pediatrics_v9i1e79898_app1.docx]

References

1. Hollis C, Falconer CJ, Martin JL, et al. Annual research review: digital health interventions for children and young people with mental health problems—a systematic and meta ‐ review. Child Psychology Psychiatry 2017 Apr;58(4):474-503. [doi: 10.1111/jcpp.12663]
2. Eysenbach G. The law of attrition. J Med Internet Res 2005 Mar 31;7(1):e11. [doi: 10.2196/jmir.7.1.e11] [Medline: 15829473]
3. Nahum-Shani I, Shaw SD, Carpenter SM, Murphy SA, Yoon C. Engagement in digital interventions. Am Psychol 2022 Oct;77(7):836-852. [doi: 10.1037/amp0000983] [Medline: 35298199]
4. Cole-Lewis H, Ezeanochie N, Turgiss J. Understanding health behavior technology engagement: pathway to measuring digital behavior change interventions. JMIR Form Res 2019 Oct 10;3(4):e14052. [doi: 10.2196/14052] [Medline: 31603427]
5. Boucher EM, Raiker JS. Engagement and retention in digital mental health interventions: a narrative review. BMC Digit Health 2024 Aug 8;2(1):52. [doi: 10.1186/s44247-024-00105-9]
6. Molloy A, Anderson PL. Engagement with mobile health interventions for depression: a systematic review. Internet Interv 2021 Dec;26:100454. [doi: 10.1016/j.invent.2021.100454] [Medline: 34621626]
7. Gan DZQ, McGillivray L, Han J, Christensen H, Torok M. Effect of engagement with digital interventions on mental health outcomes: a systematic review and meta-analysis. Front Digit Health 2021;3:764079. [doi: 10.3389/fdgth.2021.764079] [Medline: 34806079]
8. Nardi W, Roy A, Dunsiger S, Brewer J. Analyzing the impact of mobile app engagement on mental health outcomes: secondary analysis of the unwinding anxiety program. J Med Internet Res 2022 Aug 15;24(8):e33696. [doi: 10.2196/33696] [Medline: 35969440]
9. Palinkas LA, Aarons GA, Horwitz S, Chamberlain P, Hurlburt M, Landsverk J. Mixed method designs in implementation research. Adm Policy Ment Health 2011 Jan;38(1):44-53. [doi: 10.1007/s10488-010-0314-z] [Medline: 20967495]
10. Bergin AD, Vallejos EP, Davies EB, et al. Preventive digital mental health interventions for children and young people: a review of the design and reporting of research. NPJ Digit Med 2020;3(1):133. [doi: 10.1038/s41746-020-00339-7] [Medline: 33083568]
11. Haine-Schlagel R, Dickson KS, Lind T, et al. Caregiver participation engagement in child mental health prevention programs: a systematic review. Prev Sci 2022 Feb;23(2):321-339. [doi: 10.1007/s11121-021-01303-x] [Medline: 34936045]
12. Chacko A, Jensen SA, Lowry LS, et al. Engagement in behavioral parent training: review of the literature and implications for practice. Clin Child Fam Psychol Rev 2016 Sep;19(3):204-215. [doi: 10.1007/s10567-016-0205-2] [Medline: 27311693]
13. Garvey C, Julion W, Fogg L, Kratovil A, Gross D. Measuring participation in a prevention trial with parents of young children. Res Nurs Health 2006 Jun;29(3):212-222. [doi: 10.1002/nur.20127] [Medline: 16676341]
14. Finan SJ, Swierzbiolek B, Priest N, Warren N, Yap M. Parental engagement in preventive parenting programs for child mental health: a systematic review of predictors and strategies to increase engagement. PeerJ 2018;6(4):e4676. [doi: 10.7717/peerj.4676] [Medline: 29719737]
15. Meyer A. On the relationship between the error-related negativity and anxiety in children and adolescents: from a neural marker to a novel target for intervention. Psychophysiology 2022 Jun;59(6):e14050. [doi: 10.1111/psyp.14050] [Medline: 35324015]
16. Moser JS. The nature of the relationship between anxiety and the error-related negativity across development. Curr Behav Neurosci Rep 2017 Dec;4(4):309-321. [doi: 10.1007/s40473-017-0132-7] [Medline: 35475020]
17. Tan JXY, Hamm JM, Liu P. Age and anxiety symptoms jointly moderated the curvilinear changes in trial-level ERN following repeated errors on a Go/No-Go task during early adolescence. Dev Psychopathol 2025:1-8. [doi: 10.1017/S0954579424001925]
18. Meyer A, Hajcak G, Torpey-Newman DC, Kujawa A, Klein DN. Enhanced error-related brain activity in children predicts the onset of anxiety disorders between the ages of 6 and 9. J Abnorm Psychol 2015 May;124(2):266-274. [doi: 10.1037/abn0000044] [Medline: 25643204]
19. Chong LJ, Meyer A. Understanding the link between anxiety and a neural marker of anxiety (the error-related negativity) in 5 to 7 year-old children. Dev Neuropsychol 2019;44(1):71-87. [doi: 10.1080/87565641.2018.1528264] [Medline: 30407088]
20. Tozzi F, Aggen SH, Neale BM, et al. The structure of perfectionism: a twin study. Behav Genet 2004 Sep;34(5):483-494. [doi: 10.1023/B:BEGE.0000038486.47219.76] [Medline: 15319571]
21. Meyer A, Chong L, Wissemann K, Mehra L, Mirzadegan I. An experimental therapeutics approach to the development of a novel computerized treatment targeting error-related brain activity in young children. Behav Ther 2023 Jul;54(4):652-665. [doi: 10.1016/j.beth.2023.01.005] [Medline: 37330255]
22. National Research Council (US) and Institute of Medicine (US) Committee on the Prevention of Mental Disorders and Substance Abuse Among Children, Youth, and Young Adults: Research Advances and Promising Interventions, O'Connell

ME, Boat T, Warner KE. Defining the scope of prevention. In: Preventing Mental, Emotional, and Behavioral Disorders Among Young People: Progress and Possibilities: National Academies Press; 2009:59-70. [doi: 10.17226/12480]

23. Flett GL, Hewitt PL, Oliver JM, Macdonald S. Perfectionism in children and their parents: a developmental analysis. In: Flett GL, Hewitt PL, editors. Perfectionism: Theory, Research, and Treatment American Psychological Association: American Psychological Association; 2002:89-132. [doi: 10.1037/10458-004]
24. Smith MM, Hewitt PL, Sherry SB, Flett GL, Ray C. Parenting behaviors and trait perfectionism: a meta-analytic test of the social expectations and social learning models. J Res Pers 2022 Feb;96:104180. [doi: 10.1016/j.jrp.2021.104180]
25. Affrunti NW, Woodruff-Borden J. Parental perfectionism and overcontrol: examining mechanisms in the development of child anxiety. J Abnorm Child Psychol 2015 Apr;43(3):517-529. [doi: 10.1007/s10802-014-9914-5] [Medline: 25030793]
26. Affrunti NW, Woodruff-Borden J. Perfectionism in pediatric anxiety and depressive disorders. Clin Child Fam Psychol Rev 2014 Sep;17(3):299-317. [doi: 10.1007/s10567-014-0164-4] [Medline: 24481881]
27. Cook LC. The influence of parent factors on child perfectionism: a cross-sectional study [Doctoral Dissertation]. : University of Nevada; 2012. [doi: 10.34917/4332532]
28. Harvey BC. Distinguishing two dimensions of perfectionism: the antecedents and outcomes associated with each [Doctoral Thesis]. : McGill University; 2019 URL: https://escholarship.mcgill.ca/concern/theses/jd473156b [accessed 2026-03-24]
29. Mitchell JH, Broeren S, Newall C, Hudson JL. An experimental manipulation of maternal perfectionistic anxious rearing behaviors with anxious and non-anxious children. J Exp Child Psychol 2013 Sep;116(1):1-18. [doi: 10.1016/j.jecp.2012.12.006] [Medline: 23419410]
30. Morris L, Lomax C. Review: assessment, development, and treatment of childhood perfectionism: a systematic review. Child Adolesc Ment Health 2014 Nov;19(4):225-234. [doi: 10.1111/camh.12067] [Medline: 32878354]
31. Rasmussen KE, Troilo J. “It has to be perfect!”: The development of perfectionism and the family system. J Fam Theory Rev 2016 Jun;8(2):154-172. [doi: 10.1111/jftr.12140]
32. Fairweather-Schmidt AK, Wade TD. Piloting a perfectionism intervention for pre-adolescent children. Behav Res Ther 2015 Oct;73:67-73. [doi: 10.1016/j.brat.2015.07.004] [Medline: 26255173]
33. Shu CY, Watson HJ, Anderson RA, Wade TD, Kane RT, Egan SJ. A randomized controlled trial of unguided internet cognitive behaviour therapy for perfectionism in adolescents: impact on risk for eating disorders. Behav Res Ther 2019 Sep;120:103429. [doi: 10.1016/j.brat.2019.103429] [Medline: 31279221]
34. Mirzadegan IA. Perceived acceptability, appropriateness, and participation fidelity in a web-based intervention for error sensitivity in 5-7-year-olds: a mixed-methods evaluation [Doctoral Dissertation]. : Florida State University; 2023 URL: https://repository.lib.fsu.edu/islandora/object/fsu:954575 [accessed 2026-03-24]
35. Mitchell JH, Newall C, Broeren S, Hudson JL. The role of perfectionism in cognitive behaviour therapy outcomes for clinically anxious children. Behav Res Ther 2013 Sep;51(9):547-554. [doi: 10.1016/j.brat.2013.05.015] [Medline: 23850630]
36. Flett GL, Hewitt PL. A proposed framework for preventing perfectionism and promoting resilience and mental health among vulnerable children and adolescents. Psychol Sch 2014 Nov;51(9):899-912. [doi: 10.1002/pits.21792]
37. Czymoniewicz-Klippel MT, Chesnut RP, DiNallo JM, Perkins DF. Understanding the implementation of the parenting program: findings from a mixed methods pilot study. Child Youth Serv Rev 2017 Nov;82:99-107. [doi: 10.1016/j.childyouth.2017.09.016]
38. Hickey G, McGilloway S, Leckey Y, Stokes A, Bywater T, Donnelly M. “Putting meat on the bones”: understanding the implementation of a community-based early intervention and prevention programme-contextual, person, and programme influences. Prev Sci 2021 Jan;22(1):113-129. [doi: 10.1007/s11121-020-01170-y] [Medline: 33057874]
39. Leckey Y, Stokes A, Hickey G, McGilloway S. Engagement with a multi-component, preventative program to reduce child maltreatment: program satisfaction and acceptability. Clin Soc Work J 2022 Dec;50(4):358-376. [doi: 10.1007/s10615-021-00789-w]
40. Lewis EM, Feely M, Seay KD, Fedoravicis N, Kohl PL. Child welfare involved parents and Pathways Triple P: perceptions of program acceptability and appropriateness. J Child Fam Stud 2016 Dec;25(12):3760-3770. [doi: 10.1007/s10826-016-0526-2] [Medline: 27909390]
41. Lewis EM, Hooley C, Feely M, Lanier P, Korff SJ, Kohl PL. Engaging child welfare–involved families in evidence-based interventions to address child disruptive behavior disorders. J Emot Behav Disord 2020 Mar;28(1):43-51. [doi: 10.1177/1063426618806253]
42. Liverpool S, Edbrooke-Childs J. Feasibility and acceptability of a digital intervention to support shared decision-making in children’s and young people’s mental health: mixed methods pilot randomized controlled trial. JMIR Form Res 2021 Mar 2;5(3):e25235. [doi: 10.2196/25235] [Medline: 33650973]
43. O’Byrne R, Thompson R, Friedmann JS, Lumley MN. Parent engagement with an online, school-based, character strengths promotion program. Int J Appl Posit Psychol 2022;7(3):355-377. [doi: 10.1007/s41042-022-00072-4] [Medline: 35971433]
44. Guest G, Namey E, McKenna K. How many focus groups are enough? Building an evidence base for nonprobability sample sizes. Field methods 2017 Feb;29(1):3-22. [doi: 10.1177/1525822X16639015]
45. Mirzadegan IA, Lewis EM, Cole SL, Meyer A. Perceived acceptability and appropriateness of a web-based program targeting risk for anxiety in young children and their parents. J Pediatr Psychol 2025 Jan 1;50(1):6-17. [doi: 10.1093/jpepsy/jsae040] [Medline: 38857450]

46. Creswell JW, Clark VLP. Designing and Conducting Mixed Methods Research, 3rd edition: SAGE Publications; 2017. URL: https://collegepublishing.sagepub.com/products/designing-and-conducting-mixed-methods-research-3-241842 [accessed 2026-03-24]
47. Shenton AK. Strategies for ensuring trustworthiness in qualitative research projects. Educ Inf 2004;22(2):63-75. [doi: 10.3233/EFI-2004-22201]
48. Brinkmann S, Kvale S. Conducting an interview. In: Doing Interviews, 2nd edition: SAGE Publications Ltd; 2018:57-72. [doi: 10.4135/9781529716665.n5]
49. Malterud K. Qualitative research: standards, challenges, and guidelines. Lancet 2001 Aug 11;358(9280):483-488. [doi: 10.1016/S0140-6736(01)05627-6] [Medline: 11513933]
50. Miles MB, Huberman AM. Qualitative Data Analysis: A Methods Sourcebook, 4th edition: SAGE Publications; 2018. URL: https://collegepublishing.sagepub.com/products/qualitative-data-analysis-4-246128 [accessed 2026-03-24]
51. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
52. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. BMJ 2000 Jan 8;320(7227):114-116. [doi: 10.1136/bmj.320.7227.114] [Medline: 10625273]
53. Proctor E, Silmere H, Raghavan R, et al. Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. Adm Policy Ment Health 2011 Mar;38(2):65-76. [doi: 10.1007/s10488-010-0319-7] [Medline: 20957426]
54. Guba EG. Criteria for assessing the trustworthiness of naturalistic inquiries. ECTJ 1981 Jun;29(2):75-91. [doi: 10.1007/BF02766777]
55. Linardon J, Cuijpers P, Carlbring P, Messer M, Fuller-Tyszkiewicz M. The efficacy of app-supported smartphone interventions for mental health problems: a meta-analysis of randomized controlled trials. World Psychiatry 2019 Oct;18(3):325-336. [doi: 10.1002/wps.20673] [Medline: 31496095]
56. Lipschitz JM, Pike CK, Hogan TP, Murphy SA, Burdick KE. The engagement problem: a review of engagement with digital mental health interventions and recommendations for a path forward. Curr Treat Options Psychiatry 2023 Sep;10(3):119-135. [doi: 10.1007/s40501-023-00297-3] [Medline: 38390026]
57. Collins LM, Nahum-Shani I, Guastaferro K, Strayhorn JC, Vanness DJ, Murphy SA. Intervention optimization: a paradigm shift and its potential implications for clinical psychology. Annu Rev Clin Psychol 2024 Jul;20(1):21-47. [doi: 10.1146/annurev-clinpsy-080822-051119] [Medline: 38316143]
58. Borghouts J, Eikey E, Mark G, et al. Barriers to and facilitators of user engagement with digital mental health interventions: systematic review. J Med Internet Res 2021 Mar 24;23(3):e24387. [doi: 10.2196/24387] [Medline: 33759801]
59. Zainal NH, Liu X, Leong U, Yan X, Chakraborty B. Bridging innovation and equity: advancing public health through just-in-time adaptive interventions. Annu Rev Public Health 2025 Apr;46(1):43-68. [doi: 10.1146/annurev-publhealth-071723-103909] [Medline: 39656954]
60. Mirzadegan IA, Blanton AC, Meyer A. Measuring and enhancing initial parent engagement in parenting education: experiment and psychometric analysis. JMIR Pediatr Parent 2022 Sep 30;5(3):e37449. [doi: 10.2196/37449] [Medline: 36178725]
61. Gonzalez C, Morawska A, Haslam DM. The role of health behavior theories in parents' initial engagement with parenting interventions. J Consult Clin Psychol 2023 Aug;91(8):485-495. [doi: 10.1037/ccp0000816] [Medline: 37141031]
62. Chorpita BF, Becker KD. Dimensions of treatment engagement among youth and caregivers: structural validity of the REACH framework. J Consult Clin Psychol 2022 Mar;90(3):258-271. [doi: 10.1037/ccp0000711] [Medline: 35099207]
63. Becker KD, Chorpita BF. Future directions in youth and family treatment engagement: finishing the bridge between science and service. J Clin Child Adolesc Psychol 2023 Mar 4;52(2):284-309. [doi: 10.1080/15374416.2023.2169926]
64. Tozzi F, Nicolaidou I, Galani A, Antoniades A. eHealth interventions for anxiety management targeting young children and adolescents: exploratory review. JMIR Pediatr Parent 2018 May 10;1(1):e5. [doi: 10.2196/pediatrics.7248] [Medline: 31518330]
65. d'Halluin A, Costa M, Morgiève M, Sebbane D. Attitudes of children, adolescents, and their parents toward digital health interventions: scoping review. J Med Internet Res 2023 May 2;25:e43102. [doi: 10.2196/43102] [Medline: 37129931]
66. Donovan CL, March S. Online CBT for preschool anxiety disorders: a randomised control trial. Behav Res Ther 2014 Jul;58:24-35. [doi: 10.1016/j.brat.2014.05.001] [Medline: 24927471]
67. Morgan AJ, Rapee RM, Salim A, et al. Internet-delivered parenting program for prevention and early intervention of anxiety problems in young children: randomized controlled trial. J Am Acad Child Adolesc Psychiatry 2017 May;56(5):417-425.e1. [doi: 10.1016/j.jaac.2017.02.010]
68. Salari R, Enebrink P. Role of universal parenting programs in prevention. In: Sanders M, Morawska A, editors. Handbook of Parenting and Child Development Across the Lifespan: Springer; 2018:713-743. [doi: 10.1007/978-3-319-94598-9_32]
69. Yap MBH, Morgan AJ, Cairns K, Jorm AF, Hetrick SE, Merry S. Parents in prevention: a meta-analysis of randomized controlled trials of parenting interventions to prevent internalizing problems in children from birth to age 18. Clin Psychol Rev 2016 Dec;50:138-158. [doi: 10.1016/j.cpr.2016.10.003] [Medline: 27969003]

70. Jensen-Doss A, Douglas S, Phillips DA, Gencdur O, Zalman A, Gomez NE. Measurement-based care as a practice improvement tool: clinical and organizational applications in youth mental health. Evid Based Pract Child Adolesc Ment Health 2020;5(3):233-250. [doi: 10.1080/23794925.2020.1784062] [Medline: 33732875]
71. Gardner F. Methodological issues in the direct observation of parent-child interaction: do observational findings reflect the natural behavior of participants? Clin Child Fam Psychol Rev 2000 Sep;3(3):185-198. [doi: 10.1023/a:1009503409699] [Medline: 11225753]
72. Reyes LI, Johnson SL, Oke S, Carmona BA, Bellows LL. Understanding parents' digital use and preferences for an mHealth intervention in low-income, rural settings. Health Educ Res 2025 Jun 26;40(4):cyaf024. [doi: 10.1093/her/cyaf024] [Medline: 40590678]
73. Tongol NAC, McHardy RJW, Simpson KM, et al. Parent and caregiver preferences for eHealth programs. BMC Public Health 2025 Jul 3;25(1):2307. [doi: 10.1186/s12889-025-22612-8] [Medline: 40610958]
74. Sung JY, Mumper E, Schleider JL. Empowering anxious parents to manage child avoidance behaviors: randomized control trial of a single-session intervention for parental accommodation. JMIR Ment Health 2021 Jul 6;8(7):e29538. [doi: 10.2196/29538] [Medline: 34255718]
75. van Mierlo T, Rondina R, Fournier R. Nudges and prompts increase engagement in self-guided digital health treatment for depression and anxiety: results from a 3-arm randomized controlled trial. JMIR Form Res 2024 Apr 9;8(1):e52558. [doi: 10.2196/52558] [Medline: 38592752]
76. Dunn A, Alvarez J, Arbon A, et al. Effectiveness of an unguided modular online intervention for highly anxious parents in preventing anxiety in their children: a parallel group randomised controlled trial. Lancet Reg Health Eur 2024 Oct;45:101038. [doi: 10.1016/j.lanepe.2024.101038] [Medline: 39291249]

Abbreviations

CPE: caregiver participation engagement
DHP: digital health program
ERN: error-related negativity
RCT: randomized controlled trial

Edited by A Serlachius; submitted 02.Jul.2025; peer-reviewed by H Sabbineni, K Hasan, S Sawesi; revised version received 30.Jan.2026; accepted 08.Mar.2026; published 09.Apr.2026.

Please cite as:
Mirzadegan IA, Lewis EM, Cole SL, Meyer AM
Family Engagement in a Digital Intervention Targeting Risk for Anxiety in Parent-Child Dyads: Mixed Methods Study
JMIR Pediatr Parent 2026;9:e79898
URL: https://pediatrics.jmir.org/2026/1/e79898
doi:10.2196/79898

Increasing Use of a Postpartum and Newborn Chatbot among Birthing Individuals and Caregivers: Development and Implementation Study

Jessica N Rivera Rivera[1], PhD, MPH; Marjanna Smith[1], MPH; Shrey Mathur[2], MS; Katarina E AuBuchon[3], PhD; Angela D Thomas[1], DrPH, MPH, MBA; Hannah Arem[1,4], PhD, MHS

[1]Healthcare Delivery Research, MedStar Health Research Institute, 100 Irving St. NW, Washington, DC, United States
[2]Center for Biostatistics, Informatics and Data Science, MedStar Health Research Institute, Washington, DC, United States
[3]Palliative Care Research Group, MedStar Health Research Institute, Washington, DC, United States
[4]Department of Oncology, Georgetown University, Washington, DC, United States

Corresponding Author:
Jessica N Rivera Rivera, PhD, MPH
Healthcare Delivery Research, MedStar Health Research Institute, 100 Irving St. NW, Washington, DC, United States

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.

(JMIR Pediatr Parent 2026;9:e81844) doi:10.2196/81844

KEYWORDS

postpartum period; newborn care; health information; chatbot; implementation

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 postpartum chatbot; for instance, birthing individuals who had a C-section received information about wound care.

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)

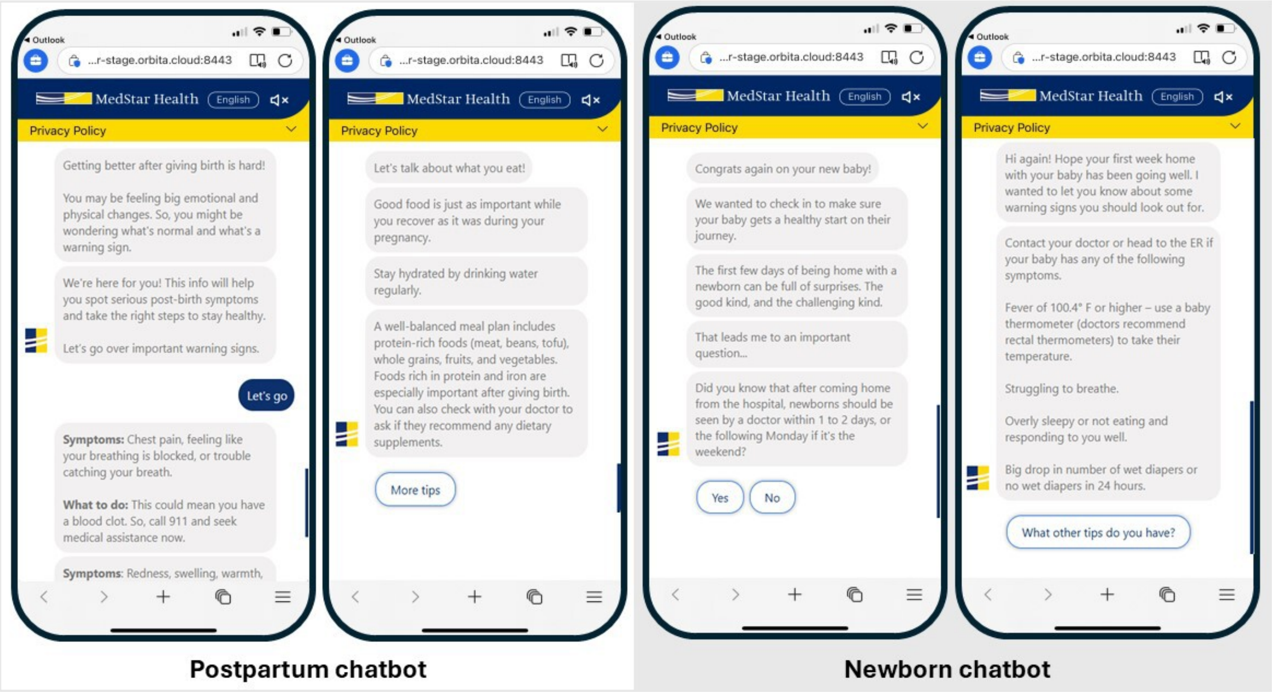
Experiences and topics covered in the chatbot[a]	General reach by experience, n/N (%)
Revised: family planning and sex after birth	706/2777 (25.4)
Experience 6 (day 28)	
Original: pelvic floor - Kegel exercises	656/3660 (17.9)
Revised: physical activity; Pelvic floor - Kegel exercises	511/2845 (18)
Experience 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.



Getting better after giving birth is hard!

You may be feeling big emotional and physical changes. So, you might be wondering what's normal and what's a warning sign.

We're here for you! This info will help you spot serious post-birth symptoms and take the right steps to stay healthy.

Let's go over important warning signs.

Symptoms: Chest pain, feeling like your breathing is blocked, or trouble catching your breath.

What to do: This could mean you have a blood clot. So, call 911 and seek medical assistance now.

Symptoms: Redness, swelling, warmth,

Let's talk about what you eat!

Good food is just as important while you recover as it was during your pregnancy.

Stay hydrated by drinking water regularly.

A well-balanced meal plan includes protein-rich foods (meat, beans, tofu), whole grains, fruits, and vegetables. Foods rich in protein and iron are especially important after giving birth. You can also check with your doctor to ask if they recommend any dietary supplements.

Postpartum chatbot

Congrats again on your new baby!

We wanted to check in to make sure your baby gets a healthy start on their journey.

The first few days of being home with a newborn can be full of surprises. The good kind, and the challenging kind.

That leads me to an important question...

Did you know that after coming home from the hospital, newborns should be seen by a doctor within 1 to 2 days, or the following Monday if it's the weekend?

Hi again! Hope your first week home with your baby has been going well. I wanted to let you know about some warning signs you should look out for.

Contact your doctor or head to the ER if your baby has any of the following symptoms.

Fever of 100.4° F or higher – use a baby thermometer (doctors recommend rectal thermometers) to take their temperature.

Struggling to breathe.

Overly sleepy or not eating and responding to you well.

Big drop in number of wet diapers or no wet diapers in 24 hours.

Newborn chatbot

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 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

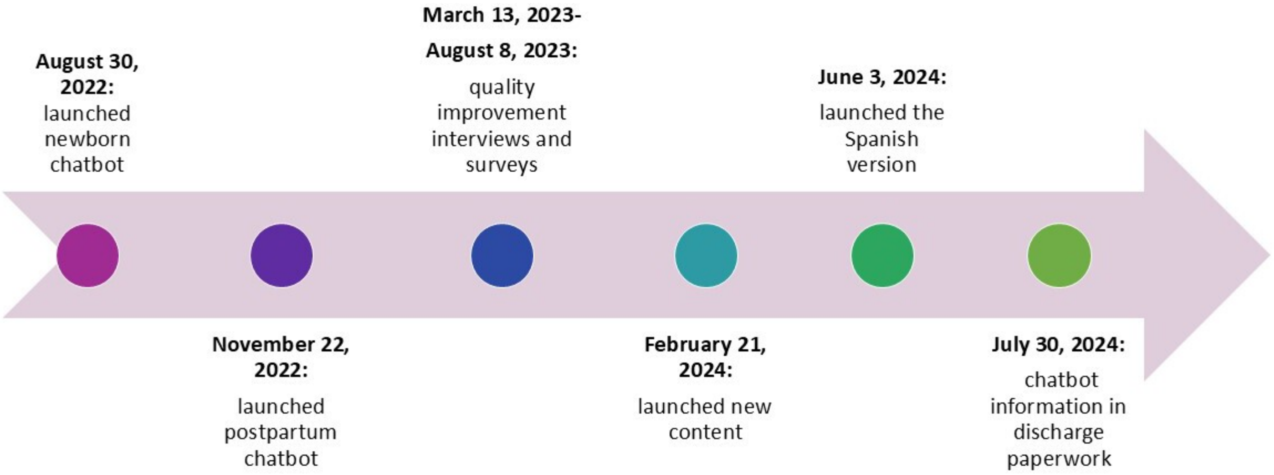
Before developing the chatbot, we met with the clinical leaders in labor and delivery, including physicians, nurses, and administrators. We also consulted with our community partners on key content and outreach strategies, as two-thirds of those delivering at the target hospital seek prenatal and postpartum 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.

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 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).

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[f,g]				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[f,g]				N/A				.003
<37 weeks	N/A	N/A	N/A		738	452	61.3	

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 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).

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).

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 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 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.

Acknowledgments

We want to acknowledge the support of the DC Safe Babies Safe Moms Team, Doriun Brown, Christine Laccay, Dr Amalia Londono Tobon for reviewing the Spanish version of the chatbots, and Orbita, the company that ran the chatbots.

Funding

This project was funded by the A James and Alice B Clark Foundation. The funder had no involvement in the study design, data collection, analysis, interpretation, or the writing of the article.

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]

References

1. Tully KP, Stuebe AM, Verbiest SB. The fourth trimester: a critical transition period with unmet maternal health needs. Am J Obstet Gynecol 2017 Jul;217(1):37-41. [doi: 10.1016/j.ajog.2017.03.032] [Medline: 28390671]
2. WHO recommendations on maternal and newborn care for a positive postnatal experience. : World Health Organization; 2022 URL: https://iris.who.int/server/api/core/bitstreams/73dec697-c033-449c-8323-1cd04a8d8f20/content [accessed 2025-12-23]
3. Dol J, Hughes B, Bonet M, et al. Timing of maternal mortality and severe morbidity during the postpartum period: a systematic review. JBI Evid Synth 2022 Sep 1;20(9):2119-2194. [doi: 10.11124/JBIES-20-00578] [Medline: 35916004]
4. Pregnancy-related deaths: data from maternal mortality review committees. CDC. URL: https://www.cdc.gov/maternal-mortality/php/data-research/mmrc/?CDC_AAref_Val=https%3A%2F%2Fwww.cdc.gov%2Fmaternal-mortality%2Fphp%2Fdata-research%2Findex.html&cove-tab=3 [accessed 2025-12-23]
5. Infant mortality. CDC. URL: https://www.cdc.gov/maternal-infant-health/infant-mortality/index.html [accessed 2025-12-11]
6. Chen J, Cox S, Kuklina EV, Ferre C, Barfield W, Li R. Assessment of incidence and factors associated with severe maternal morbidity after delivery discharge among women in the US. JAMA Netw Open 2021 Feb 1;4(2):e2036148. [doi: 10.1001/jamanetworkopen.2020.36148] [Medline: 33528553]
7. Ladley A, Hieger AW, Arthur J, Broom M. Educational text messages decreased emergency department utilization among infant caregivers: a randomized trial. Acad Pediatr 2018 Aug;18(6):636-641. [doi: 10.1016/j.acap.2018.02.003] [Medline: 29432907]
8. Whittaker R, Matoff-Stepp S, Meehan J, et al. Text4baby: development and implementation of a national text messaging health information service. Am J Public Health 2012 Dec;102(12):2207-2213. [doi: 10.2105/AJPH.2012.300736] [Medline: 23078509]
9. Text4baby. Alabama Public Health. 2023. URL: https://www.alabamapublichealth.gov/perinatal/text4baby.html [accessed 2025-12-30]
10. Marko KI, Krapf JM, Meltzer AC, et al. Testing the feasibility of remote patient monitoring in prenatal care using a mobile app and connected devices: a prospective observational trial. JMIR Res Protoc 2016 Nov 18;5(4):e200. [doi: 10.2196/resprot.6167] [Medline: 27864167]
11. About us. BabyScripts. 2025. URL: https://babyscripts.com/about-us [accessed 2025-12-11]
12. Suharwardy S, Ramachandran M, Leonard SA, et al. Feasibility and impact of a mental health chatbot on postpartum mental health: a randomized controlled trial. AJOG Glob Rep 2023 Aug;3(3):100165. [doi: 10.1016/j.xagr.2023.100165] [Medline: 37560011]
13. Nguyen QC, Aparicio EM, Jasczynski M, et al. Rosie, a health education question-and-answer chatbot for new mothers: randomized pilot study. JMIR Form Res 2024 Jan 12;8:e51361. [doi: 10.2196/51361] [Medline: 38214963]
14. Mane HY, Channell Doig A, Marin Gutierrez FX, et al. Practical guidance for the development of rosie, a health education question-and-answer chatbot for new mothers. J Public Health Manag Pract 2023;29(5):663-670. [doi: 10.1097/PHH.0000000000001781] [Medline: 37478093]
15. Chung K, Cho HY, Park JY. A chatbot for perinatal women’s and partners’ obstetric and mental health care: development and usability evaluation study. JMIR Med Inform 2021 Mar 3;9(3):e18607. [doi: 10.2196/18607] [Medline: 33656442]
16. Perrin Franck C, Babington-Ashaye A, Dietrich D, et al. iCHECK-DH: guidelines and checklist for the reporting on digital health implementations. J Med Internet Res 2023 May 10;25:e46694. [doi: 10.2196/46694] [Medline: 37163336]
17. Thomas AD, Biel M, Rethy J, et al. D.C. safe babies safe moms: a novel, multigenerational model to reduce maternal and infant health disparities. NEJM Catalyst 2025 Jan 15;6(2). [doi: 10.1056/CAT.24.0161]
18. Rivera Rivera JN, AuBuchon KE, Smith M, et al. Development and refinement of a chatbot for birthing individuals and newborn caregivers: mixed methods study. JMIR Pediatr Parent 2024 Nov 14;7:e56807. [doi: 10.2196/56807] [Medline: 39541147]
19. Lawson A, Dalfen A, Murphy KE, Milligan N, Lancee W. Use of text messaging for postpartum depression screening and information provision. Psychiatr Serv 2019 May 1;70(5):389-395. [doi: 10.1176/appi.ps.201800269] [Medline: 30717643]
20. Abd-Alrazaq AA, Alajlani M, Ali N, Denecke K, Bewick BM, Househ M. Perceptions and opinions of patients about mental health chatbots: scoping review. J Med Internet Res 2021 Jan 13;23(1):e17828. [doi: 10.2196/17828] [Medline: 33439133]
21. Chua JYX, Choolani M, Chee CYI, et al. Insights of parents and parents ‐ to ‐ be in using chatbots to improve their preconception, pregnancy, and postpartum health: a mixed studies review. J Midwifery Womens Health 2023;68(4):480-489. [doi: 10.1111/jmwh.13472] [Medline: 36734375]
22. Arkerson BJ, Finneran MM, Harris SR, et al. Remote monitoring compared with in-office surveillance of blood pressure in patients with pregnancy-related hypertension. Obstet Gynecol 2023 Oct 1;142(4):855-861. [doi: 10.1097/AOG.0000000000005327] [Medline: 37734091]
23. Litman EA, Kavathekar T, Amdur R, Sebastian A, Marko K. Remote gestational weight gain monitoring in a large low-risk US population. Obes Sci Pract 2022 Apr;8(2):147-152. [doi: 10.1002/osp4.554] [Medline: 35388344]
24. Abroms LC, Boal AL, Simmens SJ, Mendel JA, Windsor RA. A randomized trial of Text2Quit: a text messaging program for smoking cessation. Am J Prev Med 2014 Sep;47(3):242-250. [doi: 10.1016/j.amepre.2014.04.010] [Medline: 24913220]

25. Aggarwal A, Tam CC, Wu D, Li X, Qiao S. Artificial intelligence-based chatbots for promoting health behavioral changes: systematic review. J Med Internet Res 2023 Feb 24;25:e40789. [doi: 10.2196/40789] [Medline: 36826990]
26. Leitner K, Cutri-French C, Mandel A, et al. A conversational agent using natural language processing for postpartum care for new mothers: development and engagement analysis. JMIR AI 2025 Apr 22;4:e58454. [doi: 10.2196/58454] [Medline: 40605798]
27. Khadjesari Z, Brown TJ, Ramsey AT, et al. Novel implementation strategy to electronically screen and signpost patients to health behavior apps: mixed methods implementation study (optimine study). JMIR Form Res 2022 Jul 11;6(7):e34271. [doi: 10.2196/34271] [Medline: 35816374]
28. Kruse GR, Kelley JHK, Chase K, Rigotti NA. Feasibility of a proactive text messaging intervention for smokers in community health centers: pilot study. JMIR Form Res 2018;2(1):e11. [doi: 10.2196/formative.9608] [Medline: 30506038]
29. Ahmed N, Boxley C, Dixit R, et al. Evaluation of a text message-based COVID-19 vaccine outreach program among older patients: cross-sectional study. JMIR Form Res 2022 Jul 18;6(7):e33260. [doi: 10.2196/33260] [Medline: 35724339]
30. Keyworth C, Quinlivan L, Leather JZ, O'Connor RC, Armitage CJ. Does refining an intervention based on participant feedback increase acceptability? An experimental approach. BMC Public Health 2023 Aug 22;23(1):1598. [doi: 10.1186/s12889-023-16344-w] [Medline: 37608317]

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

Edited by S Badawy; submitted 04.Aug.2025; peer-reviewed by J Xie, R Garcia-Fernandez; accepted 27.Nov.2025; published 09.Jan.2026.

Please cite as:
Rivera Rivera JN, Smith M, Mathur S, AuBuchon KE, Thomas AD, Arem H
Increasing Use of a Postpartum and Newborn Chatbot among Birthing Individuals and Caregivers: Development and Implementation Study
JMIR Pediatr Parent 2026;9:e81844
URL: https://pediatrics.jmir.org/2026/1/e81844
doi:10.2196/81844

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

Susana R Patton[1], PhD; Nicole Kahhan[2], PhD; Holly O'Donnell[3], PhD; David D Williams[4], MPH; Mark Clements[5], MD, PhD; Kimberly Driscoll[6], PhD

[1]Center for Healthcare Delivery Science, Nemours Children's Clinic, 807 Children's Way, Jacksonville, FL, United States
[2]Division of Psychology, Nemours Children's Clinic, Jacksonville, FL, United States
[3]Barbara Davis Center for Diabetes, University of Colorado Anschutz Medical Campus, Aurora, CO, United States
[4]Health Services and Outcomes Research, Children's Mercy Kansas City, Kansas City, MO, United States
[5]Division of Pediatric Endocrinology, Children's Mercy Kansas City, Kansas City, MO, United States
[6]Department of Clinical and Health Psychology, University of Florida Health Science Center, Gainesville, FL, United States

Corresponding Author:
Susana R Patton, PhD
Center for Healthcare Delivery Science, Nemours Children's Clinic, 807 Children's Way, Jacksonville, FL, United States

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

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

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].

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.

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.

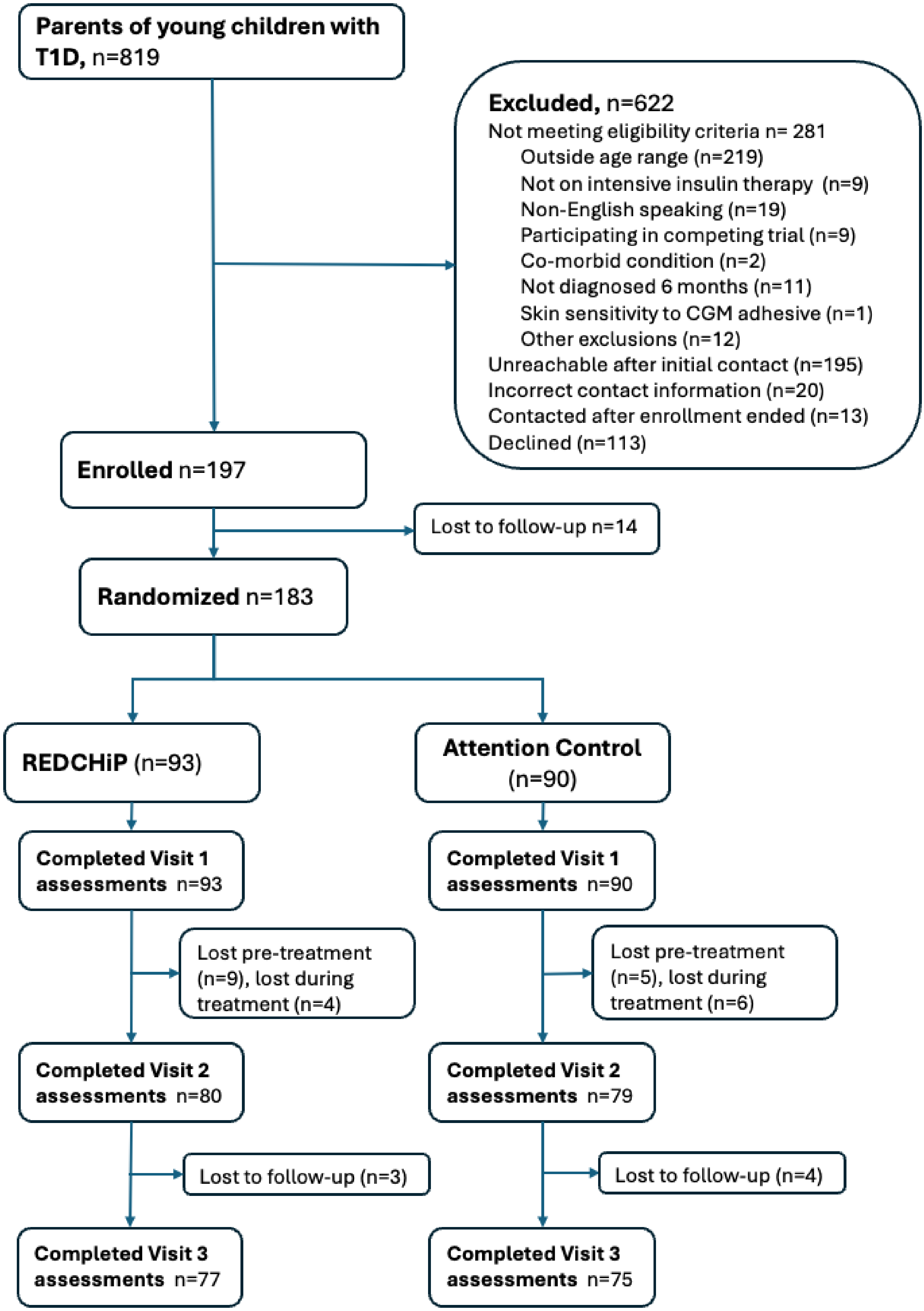
[c] HbA_{1c}: hemoglobin A_{1c}.

[d] Not applicable.

[e] CGM: continuous glucose monitor.

[f] AID: automated insulin delivery.

Figure 1. CONSORT (Consolidated Standards of Reporting Trials) diagram. REDCHiP: Reducing Emotional Distress for Childhood Hypoglycemia in Parents.



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.

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) 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 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

We thank the families who participated in the trial. We also acknowledge the contributions of Ms Amy Milkes, Ms Emily Shaffer, Ms Bailey Tanner, Ms. Ashlee Ernst, Mr Andrew McConville, Dr Alexandra Monzon, Dr Paige Trojanowski, Dr Alicia Pardon, Dr Cheyenne Reynolds, and Dr Sara Wetter-Wren whose efforts made the trial possible.

Funding

The trial was supported by a grant (PI: SRP) from the National Institutes of Health/National Institute of Diabetes and Digestive and Kidney Diseases (R01 DK118514).

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]

References

1. Urakami T. Severe hypoglycemia: is it still a threat for children and adolescents with type 1 diabetes? Front Endocrinol (Lausanne) 2020;11:609. [doi: 10.3389/fendo.2020.00609] [Medline: 33042005]
2. Lan YY, Kovinthapillai R, Kędzia A, Niechciał E. Age-based challenges to type 1 diabetes management in the pediatric population. Front Pediatr 2024;12:1434276. [doi: 10.3389/fped.2024.1434276] [Medline: 39286453]
3. Patton SR, Monzon AD, Noser AE, Clements MA. Physical activity, glycemic variability, and parental hypoglycemia fear in preschoolers with type 1 diabetes. Pediatr Exerc Sci 2022 Aug 1;34(3):135-140. [doi: 10.1123/pes.2021-0046] [Medline: 35045389]
4. Driscoll KA, Raymond J, Naranjo D, Patton SR. Fear of hypoglycemia in children and adolescents and their parents with type 1 diabetes. Curr Diab Rep 2016 Aug;16(8):77. [doi: 10.1007/s11892-016-0762-2] [Medline: 27370530]
5. Shalitin S, Phillip M. Hypoglycemia in type 1 diabetes: a still unresolved problem in the era of insulin analogs and pump therapy. Diabetes Care 2008 Feb;31 Suppl 2:S121-S124. [doi: 10.2337/dc08-s228] [Medline: 18227471]
6. Patton SR, Noser AE, Clements MA, Dolan LM, Powers SW. Reexamining the hypoglycemia fear survey for parents of young children in a sample of children using insulin pumps. Diabetes Technol Ther 2017 Feb;19(2):103-108. [doi: 10.1089/dia.2016.0389]
7. Barnard K, Thomas S, Royle P, Noyes K, Waugh N. Fear of hypoglycaemia in parents of young children with type 1 diabetes: a systematic review. BMC Pediatr 2010 Jul 15;10:50. [doi: 10.1186/1471-2431-10-50] [Medline: 20633252]

8. Herbert LJ, Clary L, Owen V, Monaghan M, Alvarez V, Streisand R. Relations among school/daycare functioning, fear of hypoglycaemia and quality of life in parents of young children with type 1 diabetes. J Clin Nurs 2015 May;24(9-10):1199-1209. [doi: 10.1111/jocn.12658] [Medline: 25047499]
9. Glocker V, Bachmann S, Hess M, Szinnai G, Burckhardt MA. Fear of hypoglycemia and quality of life in young people with type 1 diabetes and their parents in the era of sensor glucose monitoring. Front Endocrinol (Lausanne) 2022;13:958671. [doi: 10.3389/fendo.2022.958671] [Medline: 35966066]
10. Patton SR, Dolan LM, Smith LB, Thomas IH, Powers SW. Pediatric parenting stress and its relation to depressive symptoms and fear of hypoglycemia in parents of young children with type 1 diabetes mellitus. J Clin Psychol Med Settings 2011 Dec;18(4):345-352. [doi: 10.1007/s10880-011-9256-1] [Medline: 21643962]
11. Van Name MA, Hilliard ME, Boyle CT, et al. Nighttime is the worst time: parental fear of hypoglycemia in young children with type 1 diabetes. Pediatr Diabetes 2018 Feb;19(1):114-120. [doi: 10.1111/pedi.12525] [Medline: 28429581]
12. Patton SR, Clements MA, Marker AM, Nelson EL. Intervention to reduce hypoglycemia fear in parents of young kids using video-based telehealth (REDCHiP). Pediatr Diabetes 2020 Feb;21(1):112-119. [doi: 10.1111/pedi.12934] [Medline: 31610073]
13. Patton SR, McConville A, Marker AM, Monzon AD, Driscoll KA, Clements MA. Reducing Emotional Distress for Childhood Hypoglycemia in Parents (REDCHiP): protocol for a randomized clinical trial to test a video-based telehealth intervention. JMIR Res Protoc 2020 Aug 18;9(8):e17877. [doi: 10.2196/17877] [Medline: 32808936]
14. Vallis M, Jones A, Pouwer F. Managing hypoglycemia in diabetes may be more fear management than glucose management: a practical guide for diabetes care providers. Curr Diabetes Rev 2014;10(6):364-370. [doi: 10.2174/1573399810666141113115026] [Medline: 25394991]
15. O’Donnell HK, Berget C, Wooldridge JS, Driscoll KA. Graduated exposure to treat fear of hypoglycemia in a young adult with type 1 diabetes: a case study. Pediatr Diabetes 2019 Feb;20(1):113-118. [doi: 10.1111/pedi.12791] [Medline: 30370639]
16. Liu S, Xiao H, Duan Y, et al. CBT treatment delivery formats for generalized anxiety disorder: a systematic review and network meta-analysis of randomized controlled trials. Transl Psychiatry 2025 Jun 12;15(1):197. [doi: 10.1038/s41398-025-03414-3] [Medline: 40506439]
17. Niec LN, Barnett ML, Prewett MS, Shanley Chatham JR. Group parent-child interaction therapy: a randomized control trial for the treatment of conduct problems in young children. J Consult Clin Psychol 2016 Aug;84(8):682-698. [doi: 10.1037/a0040218] [Medline: 27018531]
18. ElSayed NA, Aleppo G, Aroda VR, et al. 14. Children and adolescents: standards of care in diabetes—2023. Diabetes Care 2023 Jan 1;46(Supplement_1):S230-S253. [doi: 10.2337/dc23-S014]
19. Exner B, Frielitz-Wagner IV, Frielitz FS. Telemedicine and digital health for chronic conditions in pediatrics: a systematic review. J Telemed Telecare 2026 Apr;32(3):165-211. [doi: 10.1177/1357633X251334423] [Medline: 40329670]
20. Kessler EA, Sherman AK, Becker ML. Decreasing patient cost and travel time through pediatric rheumatology telemedicine visits. Pediatr Rheumatol Online J 2016 Sep 20;14(1):54. [doi: 10.1186/s12969-016-0116-2] [Medline: 27646340]
21. Hjelm NM. Benefits and drawbacks of telemedicine. J Telemed Telecare 2005;11(2):60-70. [doi: 10.1258/1357633053499886] [Medline: 15829049]
22. Macwilliam J, Hennessey I, Cleary G. Telemedicine: improving clinical care and medical education in paediatrics. Paediatr Child Health (Oxford) 2021 Oct;31(10):388-396. [doi: 10.1016/j.paed.2021.07.004] [Medline: 34603488]
23. Czajkowski SM, Powell LH, Adler N, et al. From ideas to efficacy: the ORBIT model for developing behavioral treatments for chronic diseases. Health Psychol 2015 Oct;34(10):971-982. [doi: 10.1037/hea0000161] [Medline: 25642841]
24. Marker AM, Monzon AD, Nelson EL, Clements MA, Patton SR. An intervention to reduce hypoglycemia fear in parents of young kids with type 1 diabetes through video-based telemedicine (REDCHiP): trial design, feasibility, and acceptability. Diabetes Technol Ther 2020 Jan;22(1):25-33. [doi: 10.1089/dia.2019.0244] [Medline: 31517512]
25. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform 2009 Apr;42(2):377-381. [doi: 10.1016/j.jbi.2008.08.010] [Medline: 18929686]
26. Markowitz JT, Volkening LK, Butler DA, Antisdel-Lomaglio J, Anderson BJ, Laffel LMB. Re-examining a measure of diabetes-related burden in parents of young people with type 1 diabetes: the Problem Areas in Diabetes Survey - Parent Revised version (PAID-PR). Diabet Med 2012 Apr;29(4):526-530. [doi: 10.1111/j.1464-5491.2011.03434.x] [Medline: 21883443]
27. Tinsley LJ, Commissariat PV, Volkening L, Anderson B, Katz M, Laffel LM. Establishing a clinically meaningful cut-point for the PAID-PR (Problem Areas in Diabetes-Parent Revised) survey. Diabetes 2018 Jul 1;67(Supplement_1). [doi: 10.2337/db18-1395-P]
28. Radloff LS. The CES-D Scale. Appl Psychol Meas 1977 Jun;1(3):385-401. [doi: 10.1177/014662167700100306]
29. Eaton W, Smith C, Ybarra M, Muntaner C, Tien A. Center for epidemiologic studies depression scale: review and revision (CES-d and CES-d-r). In: Maruish ME, editor. The Use of Psychological Testing for Treatment Planning and Outcomes Assessment: Lawrence Erlbaum Associates; 2004:363-377.

30. McConville A, Noser AE, Nelson EL, Clements MA, Majidi S, Patton SR. Depression as a predictor of hypoglycemia worry in parents of youth with recent-onset type 1 diabetes. Pediatr Diabetes 2020 Aug;21(5):909-916. [doi: 10.1111/pedi.13039] [Medline: 32410305]
31. Noser AE, Dai H, Marker AM, et al. Parental depression and diabetes-specific distress after the onset of type 1 diabetes in children. Health Psychol 2019 Feb;38(2):103-112. [doi: 10.1037/hea0000699] [Medline: 30570283]
32. Jacobsen LM, Bocchino LE, Lum JW, et al. Accuracy of three commercial home-use hemoglobin A1c tests. Diabetes Technol Ther 2022 Nov;24(11):789-796. [doi: 10.1089/dia.2022.0187] [Medline: 35763337]
33. Khuu HM, Robinson CA, Goolsby K, Hardy RW, Konrad RJ. Evaluation of a fully automated high-performance liquid chromatography assay for hemoglobin A1c. Arch Pathol Lab Med 1999 Sep;123(9):763-767. [doi: 10.5858/1999-123-0763-EOAFAH] [Medline: 10458820]
34. Hopewell S, Chan AW, Collins GS, et al. CONSORT 2025 explanation and elaboration: updated guideline for reporting randomised trials. BMJ 2025 Apr 14;389:e081124. [doi: 10.1136/bmj-2024-081124] [Medline: 40228832]
35. Feingold A. Effect sizes for growth-modeling analysis for controlled clinical trials in the same metric as for classical analysis. Psychol Methods 2009 Mar;14(1):43-53. [doi: 10.1037/a0014699] [Medline: 19271847]
36. Lyons N, Cooper C, Lloyd-Evans B. A systematic review and meta-analysis of group peer support interventions for people experiencing mental health conditions. BMC Psychiatry 2021 Jun 23;21(1):315. [doi: 10.1186/s12888-021-03321-z] [Medline: 34162340]
37. Monaghan M, Bryant BL, Inverso H, Moore HR, Streisand R. Young children with type 1 diabetes: recent advances in behavioral research. Curr Diab Rep 2022 Jun;22(6):247-256. [doi: 10.1007/s11892-022-01465-0] [Medline: 35435615]
38. Lupini F, Hilliard ME, Thurston IB, et al. Rigor and equity in intervention study design in pediatric psychology: a focus on comparator conditions from diabetes research. J Pediatr Psychol 2025 Nov 1;50(11):992-1003. [doi: 10.1093/jpepsy/jsaf069] [Medline: 40880256]
39. Freedland KE, Mohr DC, Davidson KW, Schwartz JE. Usual and unusual care: existing practice control groups in randomized controlled trials of behavioral interventions. Psychosom Med 2011 May;73(4):323-335. [doi: 10.1097/PSY.0b013e318218e1fb] [Medline: 21536837]
40. Price J, Lewis AM, Pierce JS, Enlow PT, Okonak K, Kazak AE. Psychosocial staffing and implementation of the International Society for Pediatric and Adolescent Diabetes Psychological Care Guidelines in U.S. Pediatric Diabetes Clinics. Diabetes Spectr 2023;36(3):219-227. [doi: 10.2337/ds22-0047] [Medline: 37583560]
41. de Beaufort C, Schierloh U, Thankamony A, et al. Cambridge hybrid closed-loop system in very young children with type 1 diabetes reduces caregivers’ fear of hypoglycemia and improves their well-being. Diabetes Care 2022 Sep 16;45(12):3050-3053. [doi: 10.2337/dc22-0693] [Medline: 36350787]
42. Cobry EC, Kanapka LG, Cengiz E, et al. Health-related quality of life and treatment satisfaction in parents and children with type 1 diabetes using closed-loop control. Diabetes Technol Ther 2021 Jun;23(6):401-409. [doi: 10.1089/dia.2020.0532] [Medline: 33404325]
43. Muradoğlu S, Yeşiltepe Mutlu G, Gökçe T, Can E, Hatun Ş. An evaluation of Glucagon Injection Anxiety and its association with the fear of hypoglycemia among the parents of children with type 1 diabetes. J Clin Res Pediatr Endocrinol 2021 Aug 23;13(3):285-292. [doi: 10.4274/jcrpe.galenos.2021.2020.0191] [Medline: 33491925]
44. Gruszka P, Ganahl K, Stasch N, Burger C, Haberlandt E, Bauer SM. Parental anxiety and depression are associated with adverse mental health in children with special needs during the COVID-19 pandemic. Front Public Health 2023;11:1254277. [doi: 10.3389/fpubh.2023.1254277] [Medline: 38074710]
45. Uphoff E, Ekers D, Robertson L, et al. Behavioural activation therapy for depression in adults. Cochrane Database Syst Rev 2020 Jul 6;7(7):CD013305. [doi: 10.1002/14651858.CD013305.pub2] [Medline: 32628293]
46. Srijan S, Rajagopalan IR. Best practices for handling missing data. Ann Surg Oncol 2024 Jan;31(1):12-13. [doi: 10.1245/s10434-023-14471-7] [Medline: 37865943]

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

REDCap: Research Electronic Data Capture
REDCHiP: Reducing Emotional Distress for Childhood Hypoglycemia in Parents
T1D: type 1 diabetes

Edited by A Serlachius; submitted 28.Oct.2025; peer-reviewed by K Bebbington, VD Jewell; revised version received 21.Jan.2026; accepted 04.Mar.2026; published 30.Apr.2026.

Please cite as:
Patton SR, Kahhan N, O'Donnell H, Williams DD, Clements M, Driscoll K
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
JMIR Pediatr Parent 2026;9:e86616
URL: https://pediatrics.jmir.org/2026/1/e86616
doi:10.2196/86616

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

Xinmiao Cui, RN, MSN; Tae Kawahara, RN, PhD; Akemi Yamazaki, RN, PhD

Division of Health Sciences, Department of Pediatric and Family Nursing, Graduate School of Medicine, The University of Osaka, 1-7 Yamadaoka, Suita, Osaka, Japan

Corresponding Author:
Tae Kawahara, RN, PhD
Division of Health Sciences, Department of Pediatric and Family Nursing, Graduate School of Medicine, The University of Osaka, 1-7 Yamadaoka, Suita, Osaka, Japan

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.

(JMIR Pediatr Parent 2026;9:e74069) doi:10.2196/74069

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 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.

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

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 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

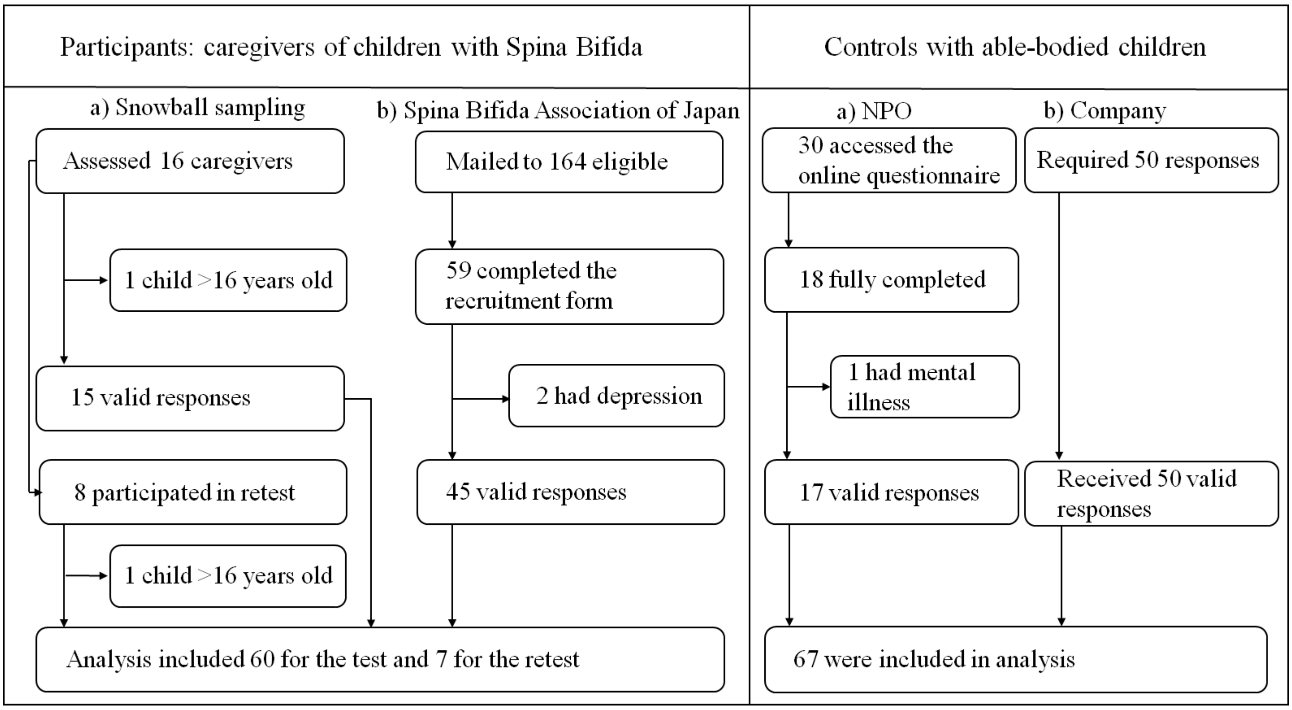
Due to the unique needs of children with SB, caregivers found it necessary to make more detailed plans for the future, particularly regarding schooling and other key aspects of their child’s development:

> *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.

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.

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

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).

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).

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 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.

Acknowledgments

The authors would like to thank all the caregivers who participated in this study, as well as the research team, the Spina Bifida Association of Japan, NPO famireli, and Tomakomai Neurosurgical Hospital for their support.

Funding

This study was financially supported by the Japan Society for the Promotion of Science (JSPS) KAKENHI (Grant-in-Aid for Early-Career Scientists [grant number: 23K16456]).

Data Availability

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

Conflicts of Interest

None declared.

References

1. Koch VH, Lopes M, Furusawa E, Vaz K, Barroso U. Multidisciplinary management of people with spina bifida across the lifespan. Pediatr Nephrol 2024 Mar;39(3):681-697. [doi: 10.1007/s00467-023-06067-w] [Medline: 37501019]
2. Szymanski KM, Cain MP, Whittam B, Kaefer M, Rink RC, Misseri R. All incontinence is not created equal: impact of urinary and fecal incontinence on quality of life in adults with spina bifida. J Urol 2017 Mar;197(3 Pt 2):885-891. [doi: 10.1016/j.juro.2016.08.117] [Medline: 28131501]
3. Winning AM, Ridosh M, Wartman E, et al. Parents' school-related concerns and perceived strengths in youth with spina bifida. Child Care Health Dev 2022 Jul;48(4):623-633. [doi: 10.1111/cch.12969] [Medline: 35043413]
4. Greenley RN, Holmbeck GN, Rose BM. Predictors of parenting behavior trajectories among families of young adolescents with and without spina bifida. J Pediatr Psychol 2006;31(10):1057-1071. [doi: 10.1093/jpepsy/jsj011] [Medline: 17090551]
5. Driscoll CFB, Buscemi J, Holmbeck GN. Parental distress and stress in association with health-related quality of life in youth with spina bifida: a longitudinal study. J Dev Behav Pediatr 2018 Dec;39(9):744-753. [doi: 10.1097/DBP.0000000000000603] [Medline: 30204623]
6. Pinquart M. Parenting stress in caregivers of children with chronic physical condition-a meta-analysis. Stress Health 2018 Apr;34(2):197-207. [doi: 10.1002/smi.2780] [Medline: 28834111]
7. Ong LC, Norshireen NAR, Chandran V. A comparison of parenting stress between mothers of children with spina bifida and able-bodied controls. Dev Neurorehabil 2011;14(1):22-28. [doi: 10.3109/17518423.2010.523057] [Medline: 21241175]
8. Macias MM, Saylor CF, Haire KB, Bell NL. Predictors of paternal versus maternal stress in families of children with neural tube defects. Child Health Care 2007 May 31;36(2):99-115. [doi: 10.1080/02739610701334558]
9. Macias MM, Saylor CF, Rowe BP, Bell NL. Age-related parenting stress differences in mothers of children with spina bifida. Psychol Rep 2003 Dec;93(3 Pt 2):1223-1232. [doi: 10.2466/pr0.2003.93.3f.1223] [Medline: 14765594]
10. Macias MM, Clifford SC, Saylor CF, Kreh SM. Predictors of parenting stress in families of children with spina bifida. Child Health Care 2001 Mar;30(1):57-65. [doi: 10.1207/S15326888CHC3001_5]
11. Kanaheswari Y, Razak NNA, Chandran V, Ong LC. Predictors of parenting stress in mothers of children with spina bifida. Spinal Cord 2011 Mar;49(3):376-380. [doi: 10.1038/sc.2010.125] [Medline: 20838404]
12. Vermaes IPR, Janssens J, Mullaart RA, Vinck A, Gerris JRM. Parents' personality and parenting stress in families of children with spina bifida. Child Care Health Dev 2008 Sep;34(5):665-674. [doi: 10.1111/j.1365-2214.2008.00868.x] [Medline: 18796058]
13. Horton TV, Wallander JL. Hope and social support as resilience factors against psychological distress of mothers who care for children with chronic physical conditions. Rehabil Psychol 2001;46(4):382-399. [doi: 10.1037//0090-5550.46.4.382]
14. Wallander JL, Varni JW, Babani L, DeHaan CB, Wilcox KT, Banis HT. The social environment and the adaptation of mothers of physically handicapped children. J Pediatr Psychol 1989 Sep;14(3):371-387. [doi: 10.1093/jpepsy/14.3.371] [Medline: 2677297]
15. Barakat LP, Linney JA. Children with physical handicaps and their mothers: the interrelation of social support, maternal adjustment, and child adjustment. J Pediatr Psychol 1992 Dec;17(6):725-739. [doi: 10.1093/jpepsy/17.6.725] [Medline: 1484335]
16. Feldman M, McDonald L, Serbin L, Stack D, Secco ML, Yu CT. Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay. J Intellect Disabil Res 2007 Aug;51(Pt 8):606-619. [doi: 10.1111/j.1365-2788.2006.00941.x] [Medline: 17598874]

17. Keniş-Coşkun Ö, Atabay CE, Şekeroğlu A, et al. The relationship between caregiver burden and resilience and quality of life in a Turkish pediatric rehabilitation facility. J Pediatr Nurs 2020;52:e108-e113. [doi: 10.1016/j.pedn.2019.10.014] [Medline: 31676209]
18. Slattery É, McMahon J, Gallagher S. Optimism and benefit finding in parents of children with developmental disabilities: the role of positive reappraisal and social support. Res Dev Disabil 2017 Jun;65:12-22. [doi: 10.1016/j.ridd.2017.04.006] [Medline: 28432893]
19. Riley K. Benefit finding. In: Gellman MD, Turner JR, editors. Encyclopedia of Behavioral Medicine: Springer; 2013:208-210. [doi: 10.1007/978-1-4419-1005-9_628]
20. Herts KL, Jorge-Miller A, Beran TM, McCannel TA, Wiley JF, Stanton AL. A prospective study of cancer-related benefit finding in uveal melanoma patients. J Behav Med 2021 Feb;44(1):131-137. [doi: 10.1007/s10865-020-00175-w] [Medline: 32939680]
21. Qian Y, Zheng L, Li J. Benefit finding and its influencing factors in patients with thyroid cancer: a retrospective study. Asia Pac J Oncol Nurs 2024 Nov;11(11):100584. [doi: 10.1016/j.apjon.2024.100584] [Medline: 39411575]
22. Zimmaro LA, Deng M, Handorf E, Fang CY, Denlinger CS, Reese JB. Understanding benefit finding among patients with colorectal cancer: a longitudinal study. Support Care Cancer 2021 May;29(5):2355-2362. [doi: 10.1007/s00520-020-05758-6] [Medline: 32918129]
23. Prikken S, Raymaekers K, Lemiere J, Vercruysse T, Uyttebroeck A, Luyckx K. Worries and benefit finding in cancer survivors and parents: a longitudinal study. J Pediatr Psychol 2022 Jun 7;47(6):641-651. [doi: 10.1093/jpepsy/jsab130] [Medline: 34918083]
24. Vitale SR, Schneider H, Gardner L, Alessandri M, Marker C. Challenging behavior and parental depression: the effects of everyday stressors and benefit finding for parents of children with autism spectrum disorder. J Autism Dev Disord 2023 Sep;53(9):3356-3368. [doi: 10.1007/s10803-022-05627-7] [Medline: 35749002]
25. Glazebrook A, Burke KJ, Shakespeare‐Finch J. Benefit‐finding process development in families raising children with chronic food hypersensitivity. Fam Relat 2022 Apr;71(2):707-723 [FREE Full text] [doi: 10.1111/fare.12648]
26. Kritikos TK, Stiles-Shields C, Shapiro JB, Holmbeck GN. Benefit-finding among young adults with spina bifida. J Health Psychol 2022 Apr;27(5):1176-1186. [doi: 10.1177/1359105321990804] [Medline: 33541148]
27. Kritikos TK, Smith ZR, Stiles-Shields C, et al. Inclusive measure development: amplifying the voices of adolescents and young adults with spina bifida in a new measure of benefit-finding and growth. J Pediatr Psychol 2024 Nov 1;49(11):802-811. [doi: 10.1093/jpepsy/jsae072] [Medline: 39311883]
28. Kojo K, Fukumaru Y. Depression and related factors in parents of children with spina bifida: a focus on differences between fathers and mothers. The Journal of Child Health 2015;74:638-645 [FREE Full text]
29. Yamane T. Stress-buffering effects of benefit finding on the psychological stress' response in mothers of children with developmental disorders. Shinrigaku Kenkyu 2014 Oct;85(4):335-344. [doi: 10.4992/jjpsy.85.13053] [Medline: 25486840]
30. Amtmann D, Liljenquist KS, Bamer A, et al. Development and validation of the University of Washington caregiver stress and benefit scales for caregivers of children with or without serious health conditions. Qual Life Res 2020 May;29(5):1361-1371. [doi: 10.1007/s11136-019-02409-0] [Medline: 31902052]
31. Mokkink LB, de Vet HCW, Prinsen CAC, et al. COSMIN risk of bias checklist for systematic reviews of patient-reported outcome measures. Qual Life Res 2018 May;27(5):1171-1179. [doi: 10.1007/s11136-017-1765-4] [Medline: 29260445]
32. Wild D, Grove A, Martin M, et al. Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: report of the ISPOR Task Force for Translation and Cultural Adaptation. Value Health 2005;8(2):94-104. [doi: 10.1111/j.1524-4733.2005.04054.x] [Medline: 15804318]
33. Terwee CB, Prinsen CAC, Chiarotto A, et al. COSMIN methodology for evaluating the content validity of patient-reported outcome measures: a Delphi study. Qual Life Res 2018 May;27(5):1159-1170. [doi: 10.1007/s11136-018-1829-0] [Medline: 29550964]
34. Amtmann D, Bamer AM, Salem R, Gammaitoni AR, Galer BS, Jensen MP. Translation and cultural validation of the University of Washington Caregiver Stress and Benefit Scales. J Patient Rep Outcomes 2021 Oct 30;5(1):113. [doi: 10.1186/s41687-021-00394-y] [Medline: 34718901]
35. Kanematsu Y, Araki A, Asano M, Arayashiki A, Shirahata N. Parenting Stress Index (PSI). In: Narama M, editor. Koyomondaikenkyukai. 2015. URL: https://www.saccess55.co.jp/untitled83.html [accessed 2026-03-12]
36. Loyd BH, Abidin RR. Revision of the Parenting Stress Index. J Pediatr Psychol 1985 Jun;10(2):169-177. [doi: 10.1093/jpepsy/10.2.169] [Medline: 4020601]
37. Iwasa H, Gondou Y, Masui Y, Hiroki I, Chieko K, Rika O, et al. Nihonban "Sosharu Sapoto Shakudo" no shinraisei narabini datosei--Chukonensha o taisho to shita kento. Journal of Health and Welfare Statistics 2007;54(6):26-33 [FREE Full text]
38. Zimet GD, Powell SS, Farley GK, Werkman S, Berkoff KA. Psychometric characteristics of the Multidimensional Scale of Perceived Social Support. J Pers Assess 1990;55(3-4):610-617. [doi: 10.1080/00223891.1990.9674095] [Medline: 2280326]
39. Nishi D, Uehara R, Yoshikawa E, Sato G, Ito M, Matsuoka Y. Culturally sensitive and universal measure of resilience for Japanese populations: Tachikawa Resilience Scale in comparison with Resilience Scale 14-item version. Psychiatry Clin Neurosci 2013 Apr;67(3):174-181. [doi: 10.1111/pcn.12028] [Medline: 23581869]

40. Flick U. The SAGE Handbook of Qualitative Data Analysis: SAGE Publications; 2013. [doi: 10.4135/9781446282243]
41. Hungerbuehler I, Vollrath ME, Landolt MA. Posttraumatic growth in mothers and fathers of children with severe illnesses. J Health Psychol 2011 Nov;16(8):1259-1267. [doi: 10.1177/1359105311405872] [Medline: 21708866]
42. Güçlü O, Enüstün Hürmeydan C. Being the mother of a special child: resilience and marital adjustment in mothers of children with autism spectrum disorder. Psychiatry Clin Psychopharmacol 2024 Mar;34(1):64-73. [doi: 10.5152/pcp.2023.22592] [Medline: 38883886]
43. Jose P, Sundaram S, Varma RP. Buffering effect of spousal support on stress levels in mothers of children with a diagnosis of autism spectrum disorder in Kerala, India. J Neurosci Rural Pract 2021 Jul;12(3):535-542. [doi: 10.1055/s-0041-1727559] [Medline: 34295109]
44. Long LJ. A cross-cultural comparison of the relationship between optimism and subjective well-being in Japan and the United States.: University of Houston; 2018. URL: https://www.proquest.com/dissertations-theses/cross-cultural-comparison-relationship-between/docview/2470294310/se-2?accountid=16714 [accessed 2025-01-29]
45. Brown RA. American and Japanese beliefs about self ‐ esteem. Asian J of Social Psycho 2008 Dec;11(4):293-299 [FREE Full text] [doi: 10.1111/j.1467-839X.2008.00270.x]
46. Chen C, Lee SY, Stevenson HW. Response style and cross-cultural comparisons of rating scales among East Asian and North American students. Psychol Sci 1995 May;6(3):170-175. [doi: 10.1111/j.1467-9280.1995.tb00327.x]
47. Molinaro ML, Rollo LE, Fletcher PC, Schneider MA. Having a sibling with ASD: perspectives of siblings and their parents. Compr Child Adolesc Nurs 2020 Mar;43(1):35-47. [doi: 10.1080/24694193.2018.1559256] [Medline: 30576229]
48. Bayat M. Evidence of resilience in families of children with autism. J Intellect Disabil Res 2007 Sep;51(Pt 9):702-714. [doi: 10.1111/j.1365-2788.2007.00960.x] [Medline: 17845239]
49. Friedman D, Holmbeck GN, Jandasek B, Zukerman J, Abad M. Parent functioning in families of preadolescents with spina bifida: longitudinal implications for child adjustment. J Fam Psychol 2004 Dec;18(4):609-619. [doi: 10.1037/0893-3200.18.4.609] [Medline: 15598166]
50. Fagan J, Schor D. Mothers of children with spina bifida: factors related to maternal psychosocial functioning. Am J Orthopsychiatry 1993 Jan;63(1):146-152. [doi: 10.1037/h0079400] [Medline: 8427306]

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

Edited by S Badawy; submitted 21.Mar.2025; peer-reviewed by MQM Sabri, PA Okooboh; revised version received 11.Jan.2026; accepted 07.Feb.2026; published 17.Mar.2026.

Please cite as:
Cui X, Kawahara T, Yamazaki A
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
JMIR Pediatr Parent 2026;9:e74069
URL: https://pediatrics.jmir.org/2026/1/e74069
doi:10.2196/74069

Motives of Children for Digital Gaming and Physical Activity and Their Parents’ Perceptions: Cross-Sectional Matched-Pair Study

Felix Wachholz*, PhD; Nicole Gamper*, MSc; Sarah Kruse*, BSc; Ruben Maria Anderlan*, MSc; Martin Schnitzer*, Prof Dr

Department of Sport Science, Faculty for Psychology and Sport Science, Universität Innsbruck, Fürstenweg 185, Innsbruck, Austria

*all authors contributed equally

Corresponding Author:
Felix Wachholz, PhD
Department of Sport Science, Faculty for Psychology and Sport Science, Universität Innsbruck, Fürstenweg 185, Innsbruck, Austria

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.

(JMIR Pediatr Parent 2026;9:e80129) doi:10.2196/80129

KEYWORDS

video gaming; digital gaming; physical exercise; parental; leisure time activities; adolescence

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 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 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

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.

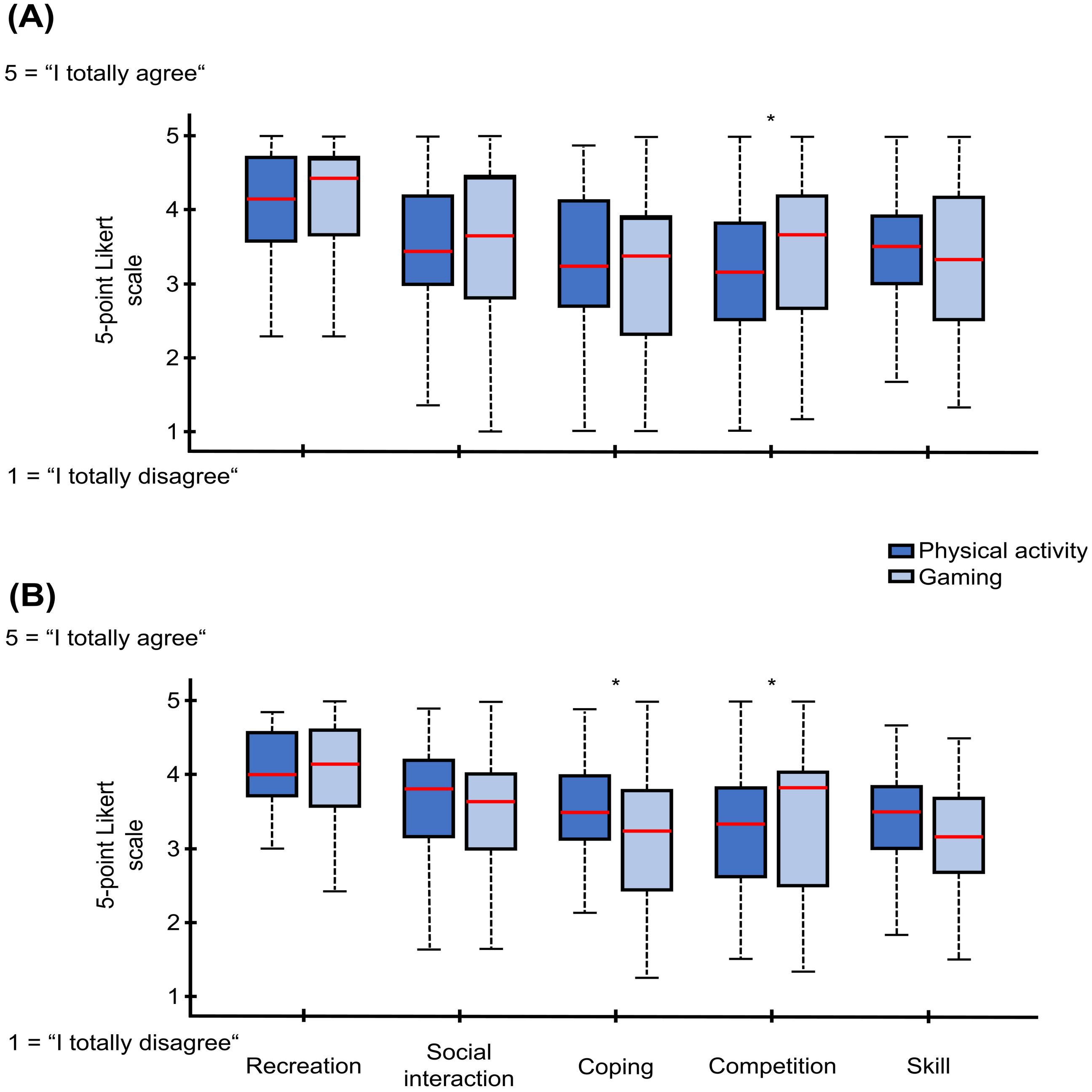
To examine the robustness of the findings across recruitment sites (Frühjahrsmesse and Gamers Heaven), separate 2 (group: child vs adult) × 2 (activity: PA vs DG) × 5 (motive) mixed ANOVAs were conducted for each location [45]. The analyses revealed highly consistent patterns, with significant main effects 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 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

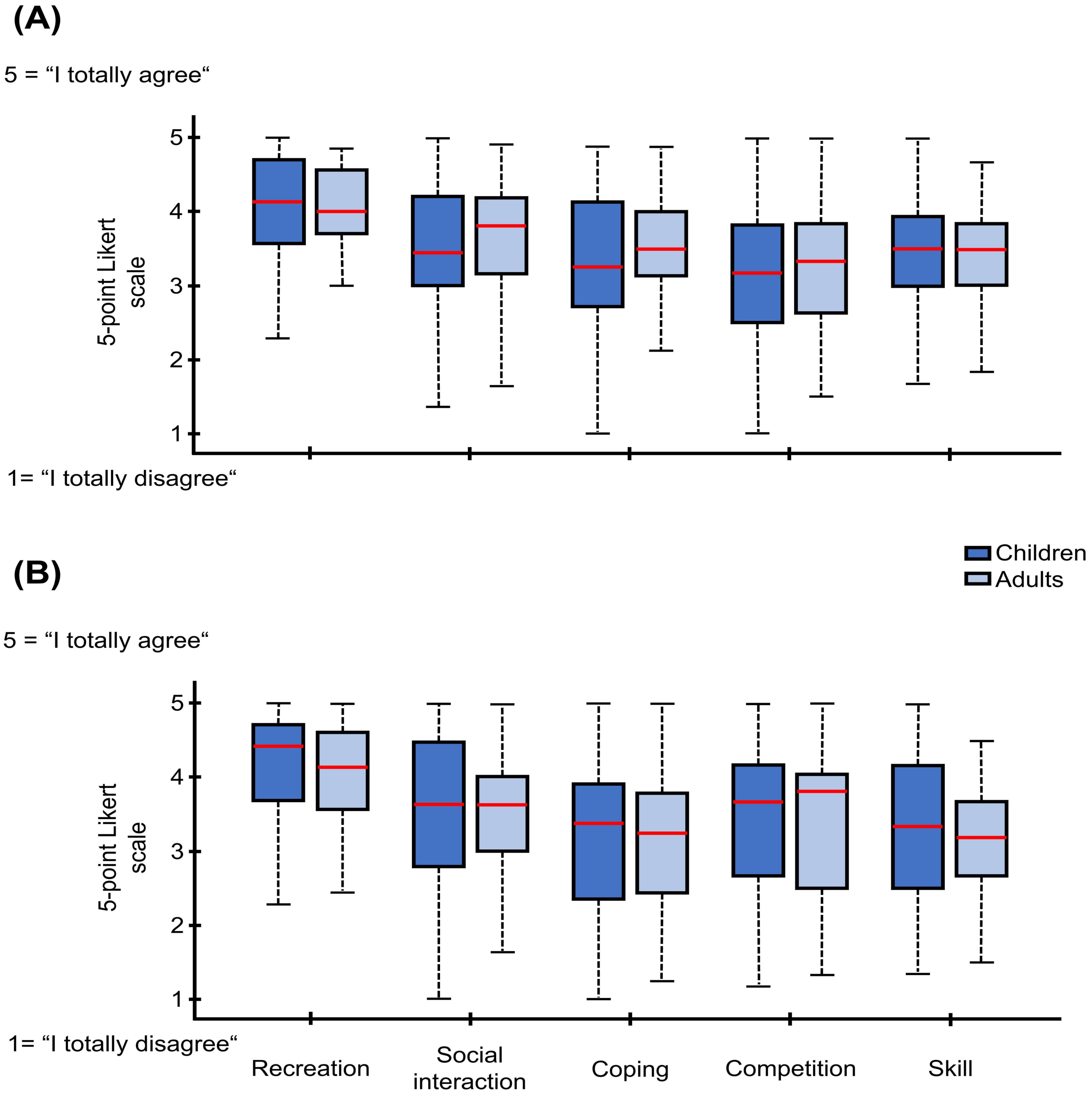
For adults, multivariate tests revealed a significant main effect of motives, $F_{4,45}$=20.68, P<.001, partial η^2=.648, indicating substantial differences across motivational dimensions. The main effect of activity was not significant, $F_{1,48}$=1.40, P=.24, partial η^2=.028. Importantly, the interaction 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,

$F_{3.06,146.71}$=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.



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 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.

Acknowledgments

We would like to thank the organizers of events Frühjahrsmesse and Gamers Heaven for allowing us to collect data without requiring entrance fees. We are also grateful to Dr Martin Niedermeier for providing statistical support. Furthermore, we used the generative AI tool ChatGPT from OpenAI [55] to assist with language corrections in the manuscript. All generated content was carefully reviewed by the authors, who take full responsibility for the final version.

Funding

This project was partially funded by the Sports Research Lab Tirol and Open Access Publishing Fund of the University of Innsbruck; however, the funder had no influence on the analyses or the interpretation of the results.

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]

References

1. Clark H, Coll-Seck AM, Banerjee A, et al. A future for the world’s children? A WHO–UNICEF–Lancet Commission. The Lancet 2020 Feb;395(10224):605-658. [doi: 10.1016/S0140-6736(19)32540-1]
2. Janssen I, Leblanc AG. Systematic review of the health benefits of physical activity and fitness in school-aged children and youth. Int J Behav Nutr Phys Act 2010 May 11;7(1):40. [doi: 10.1186/1479-5868-7-40] [Medline: 20459784]
3. WHO guidelines on physical activity and sedentary behaviour. World Health Organization. URL: https://www.who.int/publications/i/item/9789240015128 [accessed 2025-06-16]
4. Lubans DR, Plotnikoff RC, Lubans NJ. Review: a systematic review of the impact of physical activity programmes on social and emotional well-being in at-risk youth. Child Adolesc Ment Health 2012 Feb;17(1):2-13. [doi: 10.1111/j.1475-3588.2011.00623.x] [Medline: 32847310]
5. Bouzouraa MM, Dhahbi W, Ghouili H, et al. Enhancing problem-solving skills and creative thinking abilities in U-13 soccer players: the impact of rondo possession games’ training. Biol Sport 2025;42(3):227-238. [doi: 10.5114/biolsport.2025.146782]
6. Westerbeek H, Eime R. The physical activity and sport participation framework—a policy model toward being physically active across the lifespan. Front Sports Act Living 2021;3:608593. [doi: 10.3389/fspor.2021.608593] [Medline: 34027402]
7. Visier-Alfonso ME, Sánchez-López M, Rodríguez-Martín B, et al. Parents' perceptions of children's and adolescents' use of electronic devices to promote physical activity: systematic review of qualitative evidence. JMIR Mhealth Uhealth 2023 Jul 20;11(1):e44753. [doi: 10.2196/44753] [Medline: 37471127]

8. Carson V, Hunter S, Kuzik N, et al. Systematic review of sedentary behaviour and health indicators in school-aged children and youth: an update. Appl Physiol Nutr Metab 2016 Jun;41(6 Suppl 3):S240-S265. [doi: 10.1139/apnm-2015-0630] [Medline: 27306432]
9. McMichael L, Farič N, Newby K, et al. Parents of adolescents perspectives of physical activity, gaming and virtual reality: qualitative study. JMIR Serious Games 2020 Aug 25;8(3):e14920. [doi: 10.2196/14920] [Medline: 32840487]
10. Strong WB, Malina RM, Blimkie CJR, et al. Evidence based physical activity for school-age youth. J Pediatr 2005 Jun;146(6):732-737. [doi: 10.1016/j.jpeds.2005.01.055] [Medline: 15973308]
11. Warburton DER, Bredin SSD. Health benefits of physical activity: a systematic review of current systematic reviews. Curr Opin Cardiol 2017 Sep;32(5):541-556. [doi: 10.1097/HCO.0000000000000437] [Medline: 28708630]
12. Bouzouraa E, Dhahbi W, Ferchichi A, et al. Single-night sleep extension enhances morning physical and cognitive performance across time of day in physically active university students: a randomized crossover study. Life (Basel) 2025 Jul 24;15(8):1178. [doi: 10.3390/life15081178] [Medline: 40868825]
13. Puolitaival T, Sieppi M, Pyky R, Enwald H, Korpelainen R, Nurkkala M. Health behaviours associated with video gaming in adolescent men: a cross-sectional population-based MOPO study. BMC Public Health 2020 Mar 30;20(1):415. [doi: 10.1186/s12889-020-08522-x] [Medline: 32228539]
14. Granic I, Lobel A, Engels R. The benefits of playing video games. Am Psychol 2014 Jan;69(1):66-78. [doi: 10.1037/a0034857] [Medline: 24295515]
15. Martucci A, Gursesli MC, Duradoni M, Guazzini A. Overviewing gaming motivation and its associated psychological and sociodemographic variables: a PRISMA systematic review. Hum Behav Emerg Technol 2023 Mar 14;2023:1-156. [doi: 10.1155/2023/5640258]
16. Sauce B, Liebherr M, Judd N, Klingberg T. The impact of digital media on children’s intelligence while controlling for genetic differences in cognition and socioeconomic background. Sci Rep 2022 May 11;12(1):7720. [doi: 10.1038/s41598-022-11341-2] [Medline: 35545630]
17. Barnett LM, Ridgers ND, Hanna L, Salmon J. Parents’ and children’s views on whether active video games are a substitute for the ‘real thing’. Qual Res Sport Exerc Health 2014 Jul 3;6(3):366-381. [doi: 10.1080/2159676X.2013.809379]
18. Nordlund A, Sekki S, Korvela P, Silvonen J. The changing everyday life of families and young people. In: Toivonen M, Saari E, editors. Human-Centered Digitalization and Services: Springer Nature; 2019:79-100. [doi: 10.1007/978-981-13-7725-9_5]
19. Granic I, Morita H, Scholten H. Beyond screen time: identity development in the digital age. Psychol Inq 2020 Jul 2;31(3):195-223. [doi: 10.1080/1047840X.2020.1820214]
20. Salmensalo M, Ruotsalainen H, Hylkilä K, et al. Associations between digital gaming behavior and physical activity among Finnish vocational students. J Public Health (Berl) 2024 Jan;32(1):53-63. [doi: 10.1007/s10389-022-01788-y]
21. Pedersen MRL, Hansen AF, Elmose-Østerlund K. Motives and barriers related to physical activity and sport across social backgrounds: implications for health promotion. Int J Environ Res Public Health 2021 May 28;18(11):5810. [doi: 10.3390/ijerph18115810] [Medline: 34071630]
22. Wachholz F, Gamper N, Schnitzer M. An 8-week physical exercise intervention for e’athletes improves physical performance rather than short-term esports performance parameters - a randomized controlled trial. Front Sports Act Living 2024;6:1504205. [doi: 10.3389/fspor.2024.1504205] [Medline: 39906318]
23. Elmose-Østerlund K, Dalgas BW, Bredahl TVG, Lenze L, Høyer-Kruse J, Ibsen B. Motives for leisure-time physical activity participation: an analysis of their prevalence, consistency and associations with activity type and social background. BMC Public Health 2023 Dec 2;23(1):2399. [doi: 10.1186/s12889-023-17304-0] [Medline: 38042783]
24. Lewis BA, Williams DM, Frayeh A, Marcus BH. Self-efficacy versus perceived enjoyment as predictors of physical activity behaviour. Psychol Health 2016 Apr 2;31(4):456-469. [doi: 10.1080/08870446.2015.1111372]
25. Frederick-Recascino CM, Schuster-Smith H. Competition and intrinsic motivation in physical activity: a comparison of two groups. J Sport Behav 2003;26(3):240-254 [FREE Full text]
26. de Maio Nascimento M, Gouveia É, Gouveia BR, et al. Differential patterns in motivations for practicing sport and their effects on physical activity engagement across the lifespan. Healthcare (Basel) 2023 Jan 16;11(2):274. [doi: 10.3390/healthcare11020274] [Medline: 36673642]
27. Frömel K, Groffik D, Šafář M, Mitáš J. Differences and associations between physical activity motives and types of physical activity among adolescent boys and girls. Biomed Res Int 2022;2022(1):6305204. [doi: 10.1155/2022/6305204] [Medline: 35686232]
28. Barnett J, Coulson M. Virtually real: a psychological perspective on massively multiplayer online games. Rev Gen Psychol 2010 Jun;14(2):167-179. [doi: 10.1037/a0019442]
29. López-Fernández FJ, Mezquita L, Griffiths MD, Ortet G, Ibáñez MI. The development and validation of the Videogaming Motives Questionnaire (VMQ). PLoS One 2020;15(10):e0240726. [doi: 10.1371/journal.pone.0240726] [Medline: 33095762]
30. Souissi MA, Gouasmia C, Dergaa I, et al. Impact of evening blue light exposure timing on sleep, motor, and cognitive performance in young athletes with intermediate chronotype. Biol Sport 2025;42(3):61-68. [doi: 10.5114/biolsport.2025.146787]

31. Ferguson CJ, Olson CK. Friends, fun, frustration and fantasy: child motivations for video game play. Motiv Emot 2013 Mar;37(1):154-164. [doi: 10.1007/s11031-012-9284-7]
32. Wachholz F, Gamper N, Anderlan RM, Kruse S, Schnitzer M. Motivational differences for physical activity and gaming: do the perceived motives of parents differ from those of their children? Curr Issues Sport Sci 2024 Oct 15;9(4):067. [doi: 10.36950/2024.4ciss067]
33. Johannes N, Vuorre M, Przybylski AK. Video game play is positively correlated with well-being. R Soc Open Sci 2021 Feb 17;8(2):202049. [doi: 10.1098/rsos.202049] [Medline: 33972879]
34. Pallavicini F, Pepe A, Mantovani F. The effects of playing video games on stress, anxiety, depression, loneliness, and gaming disorder during the early stages of the COVID-19 pandemic: PRISMA systematic review. Cyberpsychol Behav Soc Netw 2022 Jun;25(6):334-354. [doi: 10.1089/cyber.2021.0252] [Medline: 35639118]
35. Valls-Serrano C, De Francisco C, Vélez-Coto M, Caracuel A. Visuospatial working memory and attention control make the difference between experts, regulars and non-players of the videogame League of Legends. Front Hum Neurosci 2022;16:933331. [doi: 10.3389/fnhum.2022.933331] [Medline: 35937676]
36. Rhodes RE, Nwachukwu N, Quinlan A. Family exergaming: correlates and preferences. Games Health J 2018 Jun;7(3):188-196. [doi: 10.1089/g4h.2017.0177] [Medline: 29688819]
37. Ng K, Kaskinen AP, Katila R, Koski P, Karhulahti VM. Associations between sports videogames and physical activity in children. Phys Cult Sport Stud Res 2022 Jun 1;95(1):68-75. [doi: 10.2478/pcssr-2022-0012]
38. Markovits AS, Green AI. FIFA, the video game: a major vehicle for soccer's popularization in the United States. In: Bandyopadhyay K, Naha S, Mitra S, editors. FIFA World Cup and Beyond: Sport, Culture, Media and Governance, 1st edition: Routledge; 2018:170-188 URL: https://www.taylorfrancis.com/chapters/edit/10.4324/9781351181921-13/fifa-video-game-major-vehicle-soccer-popularization-united-states-andrei-markovits-adam-green [accessed 2026-02-10] [doi: 10.4324/9781351181921-13]
39. Franzò M, Olivieri GM, Salerni A, Iosa M. Perceptions of parents and children about videogame use. Multimodal Technol Interact 2025 Mar;9(3):21. [doi: 10.3390/mti9030021]
40. Kutner LA, Olson CK, Warner DE, Hertzog SM. Parents' and sons' perspectives on video game play. J Adolesc Res 2008 Jan;23(1):76-96. [doi: 10.1177/0743558407310721]
41. Tay GWN, Chan MJ, Kembhavi G, et al. Children's perceptions of factors influencing their physical activity: a focus group study on primary school children. Int J Qual Stud Health Well-being 2021 Dec;16(1):1980279. [doi: 10.1080/17482631.2021.1980279] [Medline: 34661503]
42. Ostermeier E, Tucker P, Tobin D, Clark A, Gilliland J. Parents' perceptions of their children's physical activity during the COVID-19 pandemic. BMC Public Health 2022 Aug 1;22(1):1459. [doi: 10.1186/s12889-022-13829-y] [Medline: 35915418]
43. Ikonen J, Ryhänen P, Parkkila J, Knutas A. Linking physical activities and video games. Presented at: CompSysTech '15: Proceedings of the 16th International Conference on Computer Systems and Technologies; Jun 25-26, 2015; Dublin, Ireland p. 120-127. [doi: 10.1145/2812428.2812457]
44. Faul F, Erdfelder E, Lang AG, Buchner A. G*Power 3: a flexible statistical power analysis program for the social, behavioral, and biomedical sciences. Behav Res Methods 2007 May;39(2):175-191. [doi: 10.3758/bf03193146] [Medline: 17695343]
45. Thabane L, Mbuagbaw L, Zhang S, et al. A tutorial on sensitivity analyses in clinical trials: the what, why, when and how. BMC Med Res Methodol 2013 Jul 16;13(1):92. [doi: 10.1186/1471-2288-13-92] [Medline: 23855337]
46. Podsakoff PM, MacKenzie SB, Lee JY, Podsakoff NP. Common method biases in behavioral research: a critical review of the literature and recommended remedies. J Appl Psychol 2003 Oct;88(5):879-903. [doi: 10.1037/0021-9010.88.5.879] [Medline: 14516251]
47. Ohno S. The link between battle royale games and aggressive feelings, addiction, and sense of underachievement: exploring eSports-related genres. Int J Ment Health Addiction 2022 Jun;20(3):1873-1881. [doi: 10.1007/s11469-021-00488-0]
48. Lemmens JS. Play or pay to win: loot boxes and gaming disorder in FIFA ultimate team. Telemat Inform Rep 2022 Dec;8:100023. [doi: 10.1016/j.teler.2022.100023]
49. Griffiths MD, Kuss DJ, King DL. Video game addiction: past, present and future. Curr Psychiatry Rev 2012;8:308-318. [doi: 10.2174/157340012803520414]
50. Mohammad S, Jan RA, Alsaedi SL. Symptoms, mechanisms, and treatments of video game addiction. Cureus 2023 Mar;15(3):e36957. [doi: 10.7759/cureus.36957] [Medline: 37009362]
51. Anto A, Basu A, Selim R, Foscht T, Eisingerich AB. Open-world games' affordance of cognitive escapism, relaxation, and mental well-being among postgraduate students: mixed methods study. J Med Internet Res 2024 Dec 17;26(1):e63760. [doi: 10.2196/63760] [Medline: 39689301]
52. Bowditch L, Naweed A, Signal T, Chapman J. More than just a game: understanding how internet games are used in times of stress. Entertain Comput 2024 Mar;49:100617. [doi: 10.1016/j.entcom.2023.100617]
53. Jokovic A, Locker D, Guyatt G. How well do parents know their children? Implications for proxy reporting of child health-related quality of life. Qual Life Res 2004 Sep;13(7):1297-1307. [doi: 10.1023/B:QURE.0000037480.65972.eb] [Medline: 15473508]

54. Cremeens J, Eiser C, Blades M. Factors influencing agreement between child self-report and parent proxy-reports on the Pediatric Quality of Life Inventory 4.0 (PedsQL) generic core scales. Health Qual Life Outcomes 2006 Aug 30;4(1):58. [doi: 10.1186/1477-7525-4-58] [Medline: 16942613]
55. OpenAI. 2024. URL: https://chat.openai.com/chat [accessed 2026-02-10]

Abbreviations

AVG: active video games
DG: digital gaming
PA: physical activity
VMQ: Videogaming Motives Questionnaire

Edited by S Badawy; submitted 04.Jul.2025; peer-reviewed by T Baranowski, W Dhahbi; accepted 24.Dec.2025; published 02.Mar.2026.

Please cite as:
Wachholz F, Gamper N, Kruse S, Anderlan RM, Schnitzer M
Motives of Children for Digital Gaming and Physical Activity and Their Parents' Perceptions: Cross-Sectional Matched-Pair Study
JMIR Pediatr Parent 2026;9:e80129
URL: https://pediatrics.jmir.org/2026/1/e80129
doi:10.2196/80129

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

Lisa Blom[1], PhD; Jenny Rickardsson[2], PhD; Fredrik Livheim[2], PhD; Lene Lindberg[1], PhD

[1]Department of Global Public Health, Karolinska Institutet, Stockholm, Sweden

[2]Department of Clinical Neuroscience, Karolinska Institutet, Stockholm, Sweden

Corresponding Author:
Lisa Blom, PhD
Department of Global Public Health
Karolinska Institutet
Solnav. 1E
Stockholm, 11365
Sweden
Phone: 46 8 524 832 93
Email: lisa.blom@ki.se

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

(JMIR Pediatr Parent 2026;9:e71367) doi:10.2196/71367

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].

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.

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 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.

Figure 1. Flowchart of the recruitment and the participants. PHQ-9: Patient Health Questionnaire-9.

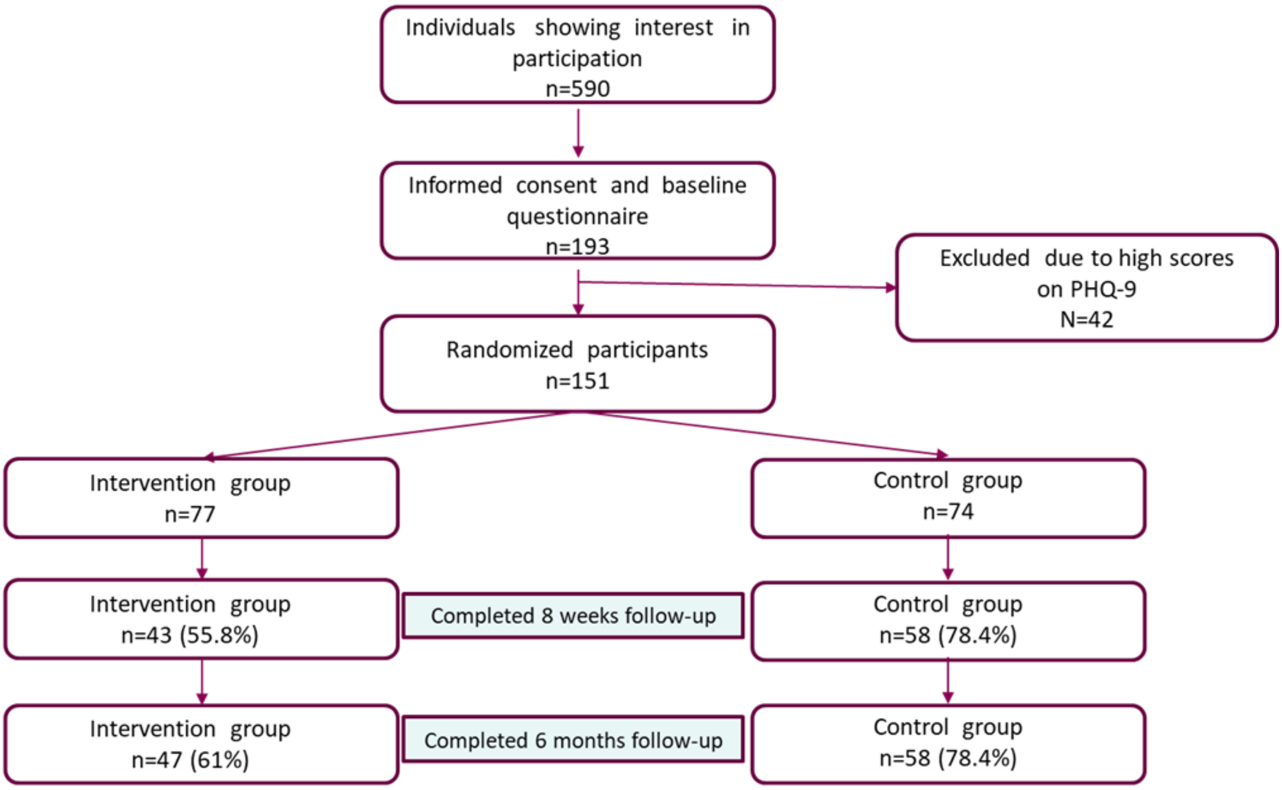


Table 1. Background characteristics of the participants at baseline assessment for the intervention and control groups, and for participants with disabilities and no disability.

	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)	

	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.

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 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).

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).

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.

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.

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.

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

[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 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], 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.

Acknowledgments

We would like to express our sincere gratitude to the participants of the study. We would also like to thank the people working in municipalities or organizations meeting young NEET individuals who supported the outreach to potential participants.

Funding

We would like to thank the Swedish Research Council for Health, Working Life and Welfare (Forte) who funded the study (2015-01136). The funders had no role in the design of the study or the reporting of the results.

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.

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]

References

1. Transforming our world: the 2030 agenda for sustainable development. United Nations. URL: https://sdgs.un.org/2030agenda [accessed 2025-01-13]
2. Brandt M, Hank K. Scars that will not disappear: long-term associations between early and later life unemployment under different welfare regimes. J Soc Pol 2014;43(4):727-743. [doi: 10.1017/s0047279414000397]
3. Exploring the diversity of NEETs. Eurofound. Luxembourg: Publications Office of the European Union; 2016. URL: https://www.eurofound.europa.eu/en/publications/all/exploring-diversity-neets](https://www.eurofound.europa.eu/en/publications/all/exploring-diversity-neets) [accessed 2026-01-10]
4. Strandh M, Winefield A, Nilsson K, Hammarström A. Unemployment and mental health scarring during the life course. Eur J Public Health 2014;24(3):440-445. [doi: 10.1093/eurpub/cku005] [Medline: 24567295]
5. Döring N, Lundberg M, Dalman C, Hemmingsson T, Rasmussen F, Wallin AS, et al. Labour market position of young people and premature mortality in adult life: A 26-year follow-up of 569 528 Swedish 18 year-olds. Lancet Reg Health Eur 2021 Apr;3:100048 [FREE Full text] [doi: 10.1016/j.lanepe.2021.100048] [Medline: 34557798]
6. Exploring the diversity of NEETs: country profiles. Eurofound. URL: https://www.eurofound.europa.eu/sites/default/files/ef1602en2.pdf; [accessed 2026-01-10]
7. Labour market inclusion of people with disability: where are we now? Disability, work and inclusion: mainstreaming in all policies and practices.: OECD; 2022. URL: https://www.oecd.org/content/dam/oecd/en/publications/reports/2022/10/disability-work-and-inclusion_db6df91a/1eaa5e9c-en.pdf [accessed 2026-01-10]
8. OECD. Supporting all young people in education and into employment. Disability, work and inclusion: mainstreaming in all policies and practices. 2022. URL: https://www.oecd.org/en/publications/disability-work-and-inclusion_1eaa5e9c-en.html [accessed 2026-01-10]
9. Supporting young people's mental health through the Covid-19 crisis. OECD. 2021. URL: https://www.oecd.org/en/publications/supporting-young-people-s-mental-health-through-the-covid-19-crisis_84e143e5-en.html [accessed 2026-01-10]
10. Guidelines on mental health at work. World Health Organization. Geneva; 2022. URL: https://www.who.int/publications/i/item/9789240053052 [accessed 2025-01-13]
11. Mawn L, Oliver EJ, Akhter N, Bambra CL, Torgerson C, Bridle C, et al. Are we failing young people not in employment, education or training (NEETs)? A systematic review and meta-analysis of re-engagement interventions. Syst Rev 2017 Jan 25;6(1):16 [FREE Full text] [doi: 10.1186/s13643-016-0394-2] [Medline: 28122584]
12. Gariépy G, Danna SM, Hawke L, Henderson J, Iyer SN. The mental health of young people who are not in education, employment, or training: a systematic review and meta-analysis. Soc Psychiatry Psychiatr Epidemiol 2022;57(6):1107-1121 [FREE Full text] [doi: 10.1007/s00127-021-02212-8] [Medline: 34931257]
13. Robertson PJ. Developing career capabilities in “NEET” young people: experiences of participants in the prince’s trust team programme. Brit J Guid Couns 2018;46(6):752-764. [doi: 10.1080/03069885.2018.1434130]
14. Buckman JEJ, Stott J, Main N, Antoine DM, Singh S, Naqvi S. Understanding the psychological therapy treatment outcomes for young adults who are not in education, employment, or training (NEET), moderators of outcomes, and what might be done to improve them. Psychol Med 2023:2808-2819. [doi: 10.1017/s0033291721004773]
15. Bennett CB, Ruggero CJ, Sever AC, Yanouri L. eHealth to redress psychotherapy access barriers both new and old: a review of reviews and meta-analyses. J Psychother Integr 2020;30(2):188-207. [doi: 10.1037/int0000217]
16. Klimczak KS, San Miguel GG, Mukasa MN, Twohig MP, Levin ME. A systematic review and meta-analysis of self-guided online acceptance and commitment therapy as a transdiagnostic self-help intervention. Cogn Behav Ther 2023;52(3):269-294 [FREE Full text] [doi: 10.1080/16506073.2023.2178498] [Medline: 36847182]

17. Brown M, Glendenning A, Hoon AE, John A. Effectiveness of web-delivered acceptance and commitment therapy in relation to mental health and well-being: a systematic review and meta-analysis. J Med Internet Res 2016;18(8):e221 [FREE Full text] [doi: 10.2196/jmir.6200] [Medline: 27558740]
18. Linardon J. Can acceptance, mindfulness, and self-compassion be learned by smartphone apps? A systematic and meta-analytic review of randomized controlled trials. Behav Ther 2020;51(4):646-658. [doi: 10.1016/j.beth.2019.10.002] [Medline: 32586436]
19. Puolakanaho A, Lappalainen R, Lappalainen P, Muotka JS, Hirvonen R, Eklund KM, et al. Reducing Stress and Enhancing Academic Buoyancy among Adolescents Using a Brief Web-based Program Based on Acceptance and Commitment Therapy: A Randomized Controlled Trial. J Youth Adolesc 2019 Feb;48(2):287-305 [FREE Full text] [doi: 10.1007/s10964-018-0973-8] [Medline: 30560515]
20. Räsänen P, Lappalainen P, Muotka J, Tolvanen A, Lappalainen R. An online guided ACT intervention for enhancing the psychological wellbeing of university students: a randomized controlled clinical trial. Behav Res Ther 2016;78:30-42. [doi: 10.1016/j.brat.2016.01.001] [Medline: 26848517]
21. Firth J, Torous J, Nicholas J, Carney R, Pratap A, Rosenbaum S, et al. The efficacy of smartphone-based mental health interventions for depressive symptoms: a meta-analysis of randomized controlled trials. World Psychiatry 2017 Oct;16(3):287-298 [FREE Full text] [doi: 10.1002/wps.20472] [Medline: 28941113]
22. Effective outreach to NEETs experience from the ground. European Commission. 2018. URL: https://www.cedefop.europa.eu/en/tools/neets/resources/european-commission-effective-outreach-neets-experience-ground [accessed 2026-01-10]
23. Statsbidrag till samverkansinsatser för unga som varken arbetar eller studerar. Bidragets användning, deltagarnas erfarenheter och effekter av beviljade projekt 2016-2018. MUCF. 2019. URL: https://www.mucf.se/publikationer/statsbidrag-till-samverkansinsatser-unga-som-varken-arbetar-eller-studerar [accessed 2025-01-13]
24. Darko EM, Kleib M, Olson J. Social media use for research participant recruitment: integrative literature review. J Med Internet Res 2022;24(8):e38015 [FREE Full text] [doi: 10.2196/38015] [Medline: 35925655]
25. Topolovec-Vranic J, Natarajan K. The use of social media in recruitment for medical research studies: a scoping review. J Med Internet Res 2016;18(11):e286 [FREE Full text] [doi: 10.2196/jmir.5698] [Medline: 27821383]
26. Apunyo R, White H, Otike C, Katairo T, Puerto S, Gardiner D, et al. Interventions to increase youth employment: An evidence and gap map. Campbell Syst Rev 2022 Mar;18(1):e1216 [FREE Full text] [doi: 10.1002/cl2.1216] [Medline: 36913191]
27. Selenko E, Pils K. The after-effects of youth unemployment: more vulnerable persons are less likely to succeed in youth guarantee programmes. Economic and Industrial Democracy 2016;40(2):282-300. [doi: 10.1177/0143831x16653186]
28. Eysenbach G, CONSORT-EHEALTH Group. CONSORT-EHEALTH: improving and standardizing evaluation reports of web-based and mobile health interventions. J Med Internet Res 2011;13(4):e126 [FREE Full text] [doi: 10.2196/jmir.1923] [Medline: 22209829]
29. 29k Foundation. 2024. URL: https://29k.org/ [accessed 2026-01-10]
30. Rosenberg M. Society and Adolescent Child. Princeton, NJ: Princeton University Press; 1965.
31. WHO (Fem) Välbefinnandeindex (2010 version). Frederiksborg General Hospital. URL: https://www.psykiatri-regionh.dk/who-5/Documents/WHO5_Swedish.pdf [accessed 2025-01-13]
32. Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. J Health Soc Behav 1983;24(4):385. [doi: 10.2307/2136404]
33. Nordin M, Nordin S. Psychometric evaluation and normative data of the Swedish version of the 10-item perceived stress scale. Scand J Psychol 2013;54(6):502-507. [doi: 10.1111/sjop.12071] [Medline: 24118069]
34. Spitzer RL, Kroenke K, Williams JBW, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med 2006;166(10):1092-1097. [doi: 10.1001/archinte.166.10.1092] [Medline: 16717171]
35. Kroenke K, Spitzer RL, Williams JBW. The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med 2001;16(9):606-613 [FREE Full text] [doi: 10.1046/j.1525-1497.2001.016009606.x] [Medline: 11556941]
36. Maggiori C, Rossier J, Savickas ML. Career adapt-abilities scale–short form (CAAS-SF). J Career Assess 2015;25(2):312-325. [doi: 10.1177/1069072714565856]
37. Cohen J. A power primer. Psychol Bull 1992;112(1):155-159. [doi: 10.1037//0033-2909.112.1.155] [Medline: 19565683]
38. Marques MJ, Alves RF, Dias S, Torri E, Paza A, Dantas C, et al. A realist synthesis of interventions for youth not in education, employment or training (NEET): building programme theories for effective support. International Journal of Adolescence and Youth 2025 Mar 04;30(1):2472022. [doi: 10.1080/02673843.2025.2472022]
39. Gunnes M, Thaulow K, Kaspersen SL, Jensen C, Ose SO. Young adults not in education, employment, or training (NEET): a global scoping review. BMC Public Health 2025;25(1):3394 [FREE Full text] [doi: 10.1186/s12889-025-24781-y] [Medline: 41063079]
40. Rickwood D, Kennedy V, Miyazaki K, Telford N, Carbone S, Hewitt E, et al. An Online Platform to Provide Work and Study Support for Young People With Mental Health Challenges: Observational and Survey Study. JMIR Ment Health 2021 Feb 09;8(2):e21872 [FREE Full text] [doi: 10.2196/21872] [Medline: 33560238]

41. Felicia OT, Talabi FO, Adelabu O, Okpara CV, Gever VC. Effect of a social media-based intervention on perception, knowledge, and intention toward painting, fashion and design among unemployed young graduates in nigeria. Child & Youth Services 2021;43(4):346-365. [doi: 10.1080/0145935x.2021.1894921]
42. Straand IJ, Følstad A, Bjørnestad JR. Exploring a gaming-based intervention for unemployed young adults: thematic analysis. JMIR Hum Factors 2024;11:e44423 [FREE Full text] [doi: 10.2196/44423] [Medline: 38236624]
43. Cheng C, Ebrahimi OV. A meta-analytic review of gamified interventions in mental health enhancement. Comput Human Behav 2023;141:107621. [doi: 10.1016/j.chb.2022.107621]
44. Kõiv K, Saks K, Azzopardi A, Todoroska V, Şen E. Empowering NEET youth: assessing the impact of self-directed learning skills intervention. Int J Educ Res 2025;129:102497. [doi: 10.1016/j.ijer.2024.102497]
45. Berry C, Fountain J, Forbes L, Bogen-Johnston L, Thomson A, Zylko Y, et al. Developing a hope-focused intervention to prevent mental health problems and improve social outcomes for young women who are not in education, employment, or training (NEET): A qualitative co-design study in deprived coastal communities in South-East England. PLoS One 2024;19(5):e0304470 [FREE Full text] [doi: 10.1371/journal.pone.0304470] [Medline: 38820387]
46. Effektutvärdering av insatser för unga med aktivitetsersättning [in Swedish]. Försäkringskassan [Swedish Social Insurance Agency]. 2017. URL: https://www.sfse.se/wp-content/uploads/2018/09/Effektutvardering.pdf [accessed 2026-01-10]
47. Lin MH, Lim PK, Azalea A, Lee MCC. Factors affecting career motivation of recent graduates: career adaptability as a mediator. Career Dev Q 2024;72(4):276-294. [doi: 10.1002/cdq.12361]
48. Bond GR, Drake RE, Campbell K. Effectiveness of individual placement and support supported employment for young adults. Early Interv Psychiatry 2016;10(4):300-307 [FREE Full text] [doi: 10.1111/eip.12175] [Medline: 25138195]
49. Sveinsdottir V, Lie SA, Bond GR, Eriksen HR, Tveito TH, Grasdal AL, et al. Individual placement and support for young adults at risk of early work disability (the SEED trial). A randomized controlled trial. Scand J Work Environ Health 2020 Jan 01;46(1):50-59 [FREE Full text] [doi: 10.5271/sjweh.3837] [Medline: 31170299]
50. Stea TH, Bertelsen TB, Fegran L, Sejersted E, Kleppang AL, Fyhn T. Interventions targeting young people not in employment, education or training (NEET) for increased likelihood of return to school or employment-A systematic review. PLoS One 2024;19(6):e0306285. [doi: 10.1371/journal.pone.0306285] [Medline: 38935788]
51. Unga som varken arbetar eller studerar - en kartläggning och kunskapsöversikt [Young people not in employment, education or training - a mapping and knowledge overview]. Forte - Forskningsrådet för hälsa, arbetsliv och välfärd. 2020. URL: https://forte.se/upptack-forskning/publikationer/unga-som-varken-arbetar-eller-studerar---en-kartlaggning-och-kunskapsoversikt [accessed 2026-01-10]
52. Distribution of Snapchat users in Nordic countries in 2022, by gender 2023. Statista. 2023. URL: https://www.statista.com/statistics/1277055/snapchat-profiles-nordics-by-gender/ [accessed 2026-01-10]
53. Garrido S, Millington C, Cheers D, Boydell K, Schubert E, Meade T, et al. What Works and What Doesn't Work? A Systematic Review of Digital Mental Health Interventions for Depression and Anxiety in Young People. Front Psychiatry 2019;10:759 [FREE Full text] [doi: 10.3389/fpsyt.2019.00759] [Medline: 31798468]
54. Johansson B. Dropping out of school – a systematic and integrative research review on risk factors and interventions. Örebro University. 2019. URL: https://www.oru.se/contentassets/e468d751588a415bba870ae8580bfd03/johansson-nr-16_1311_2019_us-002.pdf [accessed 2025-01-13]
55. Steijn B, Need A, Gesthuizen M. Well begun, half done?: long-term effects of labour market entry in the Netherlands, 1950-2000. Work, Employment and Society 2006;20(3):453-472. [doi: 10.1177/0950017006066996]
56. Linardon J, Fuller-Tyszkiewicz M. Attrition and adherence in smartphone-delivered interventions for mental health problems: a systematic and meta-analytic review. J Consult Clin Psychol 2020;88(1):1-13. [doi: 10.1037/ccp0000459] [Medline: 31697093]
57. Swedish and foreign-born population by region, age and sex. Statistics Sweden. 2024. URL: https://www.statistikdatabasen.scb.se/pxweb/en/ssd/START__BE__BE0101__BE0101E/InrUtrFoddaRegAlKon/ [accessed 2024-06-10]

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

RCT: randomized controlled trial
REDCap: Research Electronic Data Capture
WHO-5: World Health Organization-Five Well-Being Index

Edited by S Badawy; submitted 16.Jan.2025; peer-reviewed by C Chikwe, S Lau; comments to author 10.Sep.2025; revised version received 17.Dec.2025; accepted 06.Jan.2026; published 12.Feb.2026.

Please cite as:
Blom L, Rickardsson J, Livheim F, Lindberg L
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
JMIR Pediatr Parent 2026;9:e71367
URL: https://pediatrics.jmir.org/2026/1/e71367
doi:10.2196/71367
PMID:

Original Paper

Febrile Seizures in an App-Based Children's Fever Registry: Mixed Methods Study

David Martin[1,2], Prof Dr Med; Ricarda Möhler[1], BSc, MA; Christopher B Germann[1], MSc, PhD; Moritz Gwiasda[1], BSc, MSc; Silke Schwarz[1], Dr Med; Ekkehart Jenetzky[1,3], Prof Dr Med

[1]School of Medicine, Faculty of Health, Witten/Herdecke University, Witten, Germany

[2]Department of Pediatrics, University of Tübingen, Tübingen, Germany

[3]Department of Child and Adolescent Psychiatry and Psychotherapy, University Medical Center of the Johannes Gutenberg University Mainz, Mainz, Germany

Corresponding Author:
David Martin, Prof Dr Med
School of Medicine
Faculty of Health
Witten/Herdecke University
Alfred-Herrhausen-Straße 50
Witten, 58455
Germany
Phone: 49 2330 62 4760
Email: david.martin@uni-wh.de

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.

(JMIR Pediatr Parent 2026;9:e74933) doi:10.2196/74933

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 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].

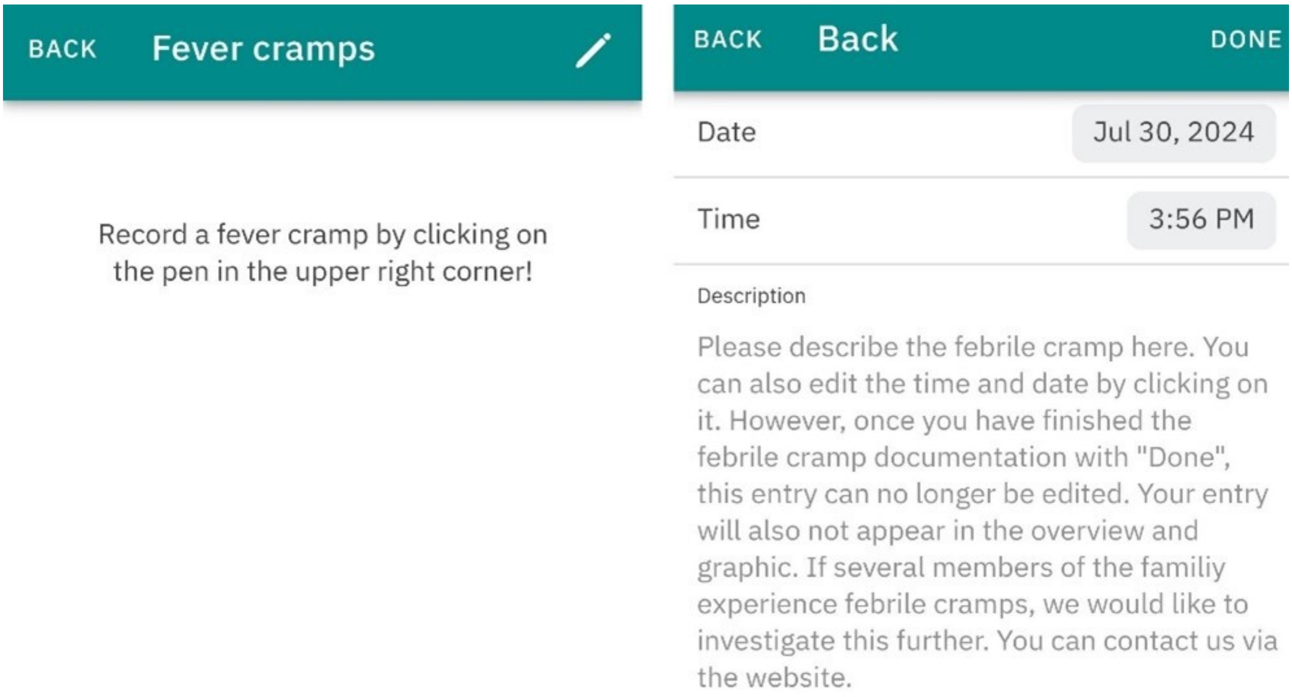
The primary objective of this study is to investigate the FeverApp as an EMA-based registry for febrile illnesses, with a particular focus on differentiating specific conditions such as febrile seizures. Additionally, the study aims to examine febrile seizure records for their conformity with current 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).

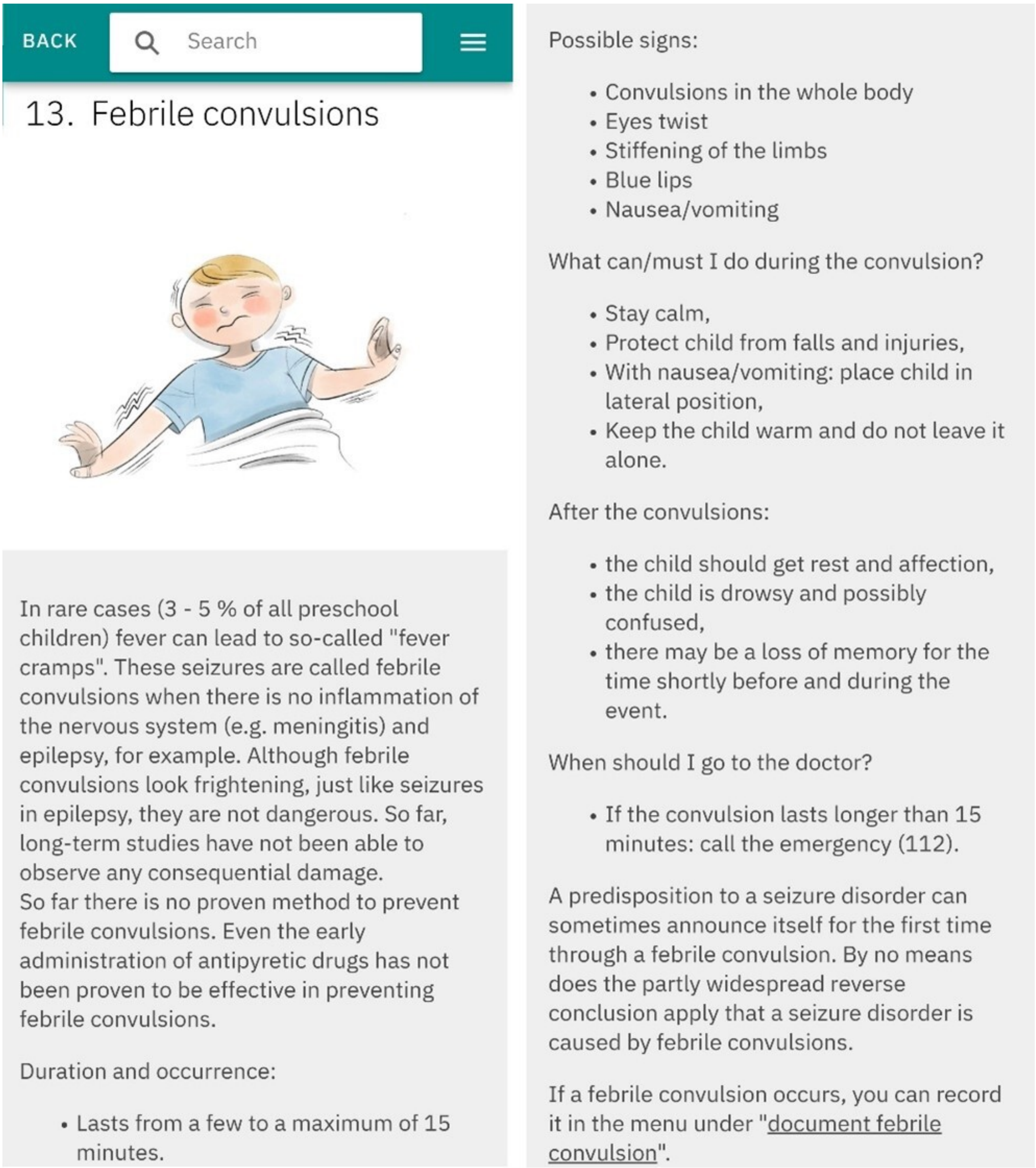
Figure 1. Febrile seizure module within the FeverApp.



Record a fever cramp by clicking on the pen in the upper right corner!

Please describe the febrile cramp here. You can also edit the time and date by clicking on it. However, once you have finished the febrile cramp documentation with "Done", this entry can no longer be edited. Your entry will also not appear in the overview and graphic. If several members of the familiy experience febrile cramps, we would like to investigate this further. You can contact us via the website.

Figure 2. Chapter about febrile seizures in the Info Library of the FeverApp.



13. Febrile convulsions

In rare cases (3 - 5 % of all preschool children) fever can lead to so-called "fever cramps". These seizures are called febrile convulsions when there is no inflammation of the nervous system (e.g. meningitis) and epilepsy, for example. Although febrile convulsions look frightening, just like seizures in epilepsy, they are not dangerous. So far, long-term studies have not been able to observe any consequential damage.
So far there is no proven method to prevent febrile convulsions. Even the early administration of antipyretic drugs has not been proven to be effective in preventing febrile convulsions.

Duration and occurrence:

- Lasts from a few to a maximum of 15 minutes.

Possible signs:

- Convulsions in the whole body
- Eyes twist
- Stiffening of the limbs
- Blue lips
- Nausea/vomiting

What can/must I do during the convulsion?

- Stay calm,
- Protect child from falls and injuries,
- With nausea/vomiting: place child in lateral position,
- Keep the child warm and do not leave it alone.

After the convulsions:

- the child should get rest and affection,
- the child is drowsy and possibly confused,
- there may be a loss of memory for the time shortly before and during the event.

When should I go to the doctor?

- If the convulsion lasts longer than 15 minutes: call the emergency (112).

A predisposition to a seizure disorder can sometimes announce itself for the first time through a febrile convulsion. By no means does the partly widespread reverse conclusion apply that a seizure disorder is caused by febrile convulsions.

If a febrile convulsion occurs, you can record it in the menu under "document febrile convulsion".

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 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.

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)

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).

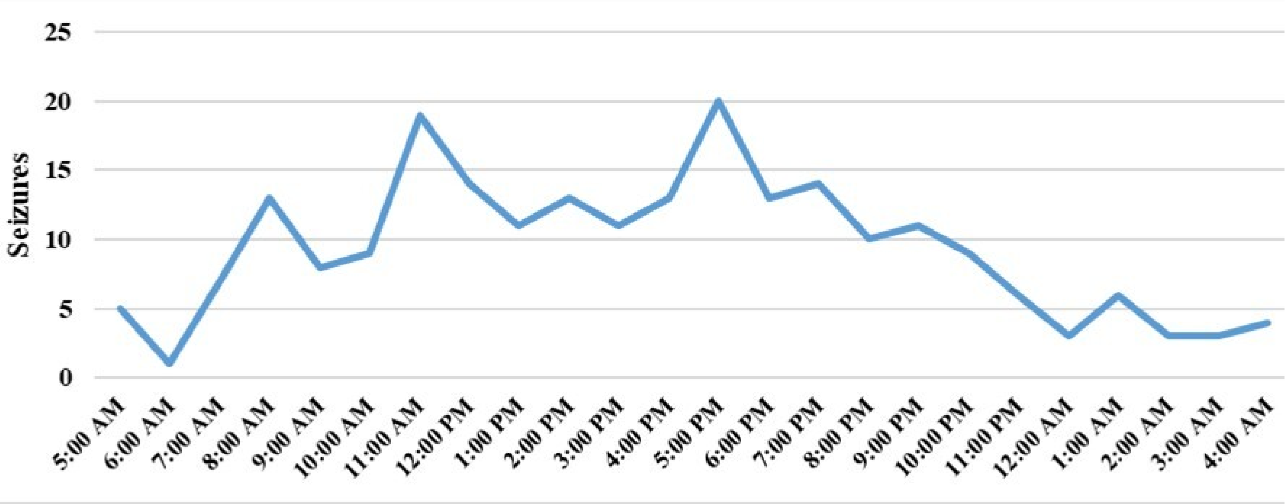
The FeverApp Registry is registered in the German Clinical Trials Register (DRKS-ID: DRKS00016591). The registry follows the Declaration of Helsinki. Informed consent was obtained from all participants involved in the study. After installing the app, users must confirm a data privacy statement where 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 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.

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).

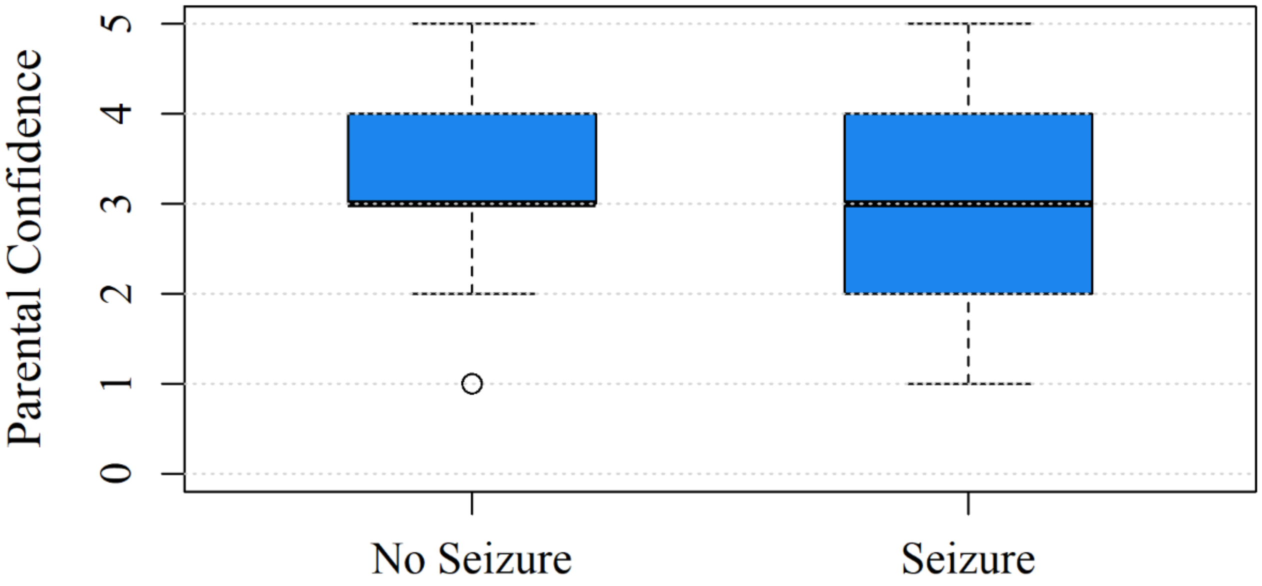
Temperature

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.

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.

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 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

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 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

We thank all parents and pediatricians who helped us in this project.

Funding

The funding for the FeverApp was provided by the Software AG Foundation (20%) and a total of 80% by the German Federal Ministry of Education and Research (grant number: 01GY1905) for the years 2019–2024.

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]

References

1. Kurlemann G, Muhle H, Gesellschaft für Neuropädiatrie (GNP). S1-Leitlinie: Fieberkrämpfe im Kindesalter. AWMF-Leitlinienregister. 2021. URL: https://register.awmf.org/assets/guidelines/022-005l_S1_Fieberkraempfe-im-Kindesalter_2021-09.pdf [accessed 2025-02-13]
2. Byeon JH, Kim GH, Eun BL. Prevalence, incidence, and recurrence of febrile seizures in Korean children based on national registry data. J Clin Neurol 2018;14(1):43-47 [FREE Full text] [doi: 10.3988/jcn.2018.14.1.43] [Medline: 29629539]
3. Delpisheh A, Veisani Y, Sayehmiri K, Fayyazi A. Febrile seizures: etiology, prevalence, and geographical variation. Iran J Child Neurol 2014;8(3):30-37 [FREE Full text] [Medline: 25143771]
4. Sawires R, Buttery J, Fahey M. A review of febrile seizures:recent advances in understanding of febrile seizure pathophysiology and commonly implicated viral triggers. Front Pediatr 2021;9:801321 [FREE Full text] [doi: 10.3389/fped.2021.801321] [Medline: 35096712]
5. Jones T, Jacobsen SJ. Childhood febrile seizures: overview and implications. Int J Med Sci 2007;4(2):110-114 [FREE Full text] [doi: 10.7150/ijms.4.110] [Medline: 17479160]
6. Graves RC, Oehler K, Tingle LE. Febrile seizures: risks, evaluation, and prognosis. Am Fam Physician 2012;85(2):149-153 [FREE Full text] [Medline: 22335215]
7. Leung AK, Hon KL, Leung TN. Febrile seizures: an overview. Drugs Context 2018;7:212536 [FREE Full text] [doi: 10.7573/dic.212536] [Medline: 30038660]
8. ICD-11 for Mortality and Morbidity Statistics. URL: https://icd.who.int/browse/2024-01/mms/en [accessed 2025-01-13]
9. Nguyen L, Whitehall J, Edwards M. Accuracy of clinical coding for febrile seizures and implications for activity-based funding. Intern Med J 2017;47(S3):21-21. [doi: 10.1111/imj.11_13462]
10. Canpolat M, Per H, Gumus H, Elmali F, Kumandas S. Investigating the prevalence of febrile convulsion in Kayseri, Turkey: an assessment of the risk factors for recurrence of febrile convulsion and for development of epilepsy. Seizure 2018;55:36-47 [FREE Full text] [doi: 10.1016/j.seizure.2018.01.007] [Medline: 29353090]
11. Verity CM. Do seizures damage the brain? The epidemiological evidence. Arch Dis Child 1998;78(1):78-84 [FREE Full text] [doi: 10.1136/adc.78.1.78] [Medline: 9534684]
12. Gordon KE, Dooley JM, Camfield PR, Camfield CS, MacSween J. Treatment of febrile seizures: the influence of treatment efficacy and side-effect profile on value to parents. Pediatrics 2001;108(5):1080-1088. [doi: 10.1542/peds.108.5.1080] [Medline: 11694684]
13. Steering Committee on Quality Improvement Management, Subcommittee on Febrile Seizures. Febrile seizures: clinical practice guideline for the long-term management of the child with simple febrile seizures. Pediatrics 2008;121(6):1281-1286. [doi: 10.1542/peds.2008-0939] [Medline: 18519501]
14. Natsume J, Hamano SI, Iyoda K, Kanemura H, Kubota M, Mimaki M. New guidelines for management of febrile seizures in Japan. Brain Dev 2017;39(1):2-9. [doi: 10.1016/j.braindev.2016.06.003] [Medline: 27613077]
15. Saguil A, Servey J. Predicting the likelihood of a recurrent febrile seizure. Am Fam Physician 2020;101(8):497-498 [FREE Full text] [Medline: 32293843]
16. Shen F, Lu L, Wu Y, Suo G, Zheng Y, Zhong X. Risk factors and predictors of recurrence of febrile seizures in children in Nantong, China: a retrospective cohort study. BMC Pediatr 2024;24(1):420 [FREE Full text] [doi: 10.1186/s12887-024-04895-9] [Medline: 38951748]
17. Hashimoto R, Suto M, Tsuji M, Sasaki H, Takehara K, Ishiguro A. Use of antipyretics for preventing febrile seizure recurrence in children: a systematic review and meta-analysis. Eur J Pediatr 2021;180(4):987-997. [doi: 10.1007/s00431-020-03845-8] [Medline: 33125519]
18. Sullivan JE, Farrar HC, Section on Clinical Pharmacology and Therapeutics, Committee on Drugs. Fever and antipyretic use in children. Pediatrics 2011;127(3):580-587. [doi: 10.1542/peds.2010-3852] [Medline: 21357332]
19. Velíšková J, Vezzani A, Nehlig A. Seizure propensity and brain development: a lesson from animal models. In: Janigro D, editor. Mammalian Brain Development. Totowa: Humana Press; 2009:77-104.
20. Smith DK, Sadler KP, Benedum M. Febrile seizures: risks, evaluation, and prognosis. Am Fam Physician 2019;99(7):445-450 [FREE Full text] [Medline: 30932454]
21. Patel N, Ram D, Swiderska N, Mewasingh LD, Newton RW, Offringa M. Febrile seizures. BMJ 2015;351:h4240. [doi: 10.1136/bmj.h4240] [Medline: 26286537]
22. Yi Y, Zhong C, Wei-Wei H. The long-term neurodevelopmental outcomes of febrile seizures and underlying mechanisms. Front Cell Dev Biol 2023;11:1186050 [FREE Full text] [doi: 10.3389/fcell.2023.1186050] [Medline: 37305674]
23. Chung B, Wong V. Relationship between five common viruses and febrile seizure in children. Arch Dis Child 2007;92(7):589-593 [FREE Full text] [doi: 10.1136/adc.2006.110221] [Medline: 17284480]
24. Hviid A. Measles-mumps-rubella-varicella combination vaccine increases risk of febrile seizure. J Pediatr 2011;158(1):170. [doi: 10.1016/j.jpeds.2010.09.075] [Medline: 21146049]
25. Rowhani-Rahbar A, Fireman B, Lewis E, Nordin J, Naleway A, Jacobsen SJ. Effect of age on the risk of fever and seizures following immunization with measles-containing vaccines in children. JAMA Pediatr 2013;167(12):1111-1117. [doi: 10.1001/jamapediatrics.2013.2745] [Medline: 24126936]

26. Vestergaard M, Hviid A, Madsen KM, Wohlfahrt J, Thorsen P, Schendel D. MMR vaccination and febrile seizures: evaluation of susceptible subgroups and long-term prognosis. JAMA 2004;292(3):351-351. [doi: 10.1001/jama.292.3.351] [Medline: 15265850]
27. Deng CT, Zulkifli HI, Azizi BH. Parental reactions to febrile seizures in Malaysian children. Med J Malaysia 1996;51(4):462-468 [FREE Full text] [Medline: 10968035]
28. Parmar RC, Sahu DR, Bavdekar SB. Knowledge, attitude and practices of parents of children with febrile convulsion. J Postgrad Med 2001;47(1):19-23 [FREE Full text] [Medline: 11590285]
29. Kokotos F. The vulnerable child syndrome. Pediatr Rev 2009;30(5):193-194. [doi: 10.1542/pir.30-5-193] [Medline: 19411339]
30. Rice SA, Müller RM, Jeschke S, Herziger B, Bertsche T, Neininger MP. Febrile seizures: perceptions and knowledge of parents of affected and unaffected children. Eur J Pediatr 2022;181(4):1487-1495 [FREE Full text] [doi: 10.1007/s00431-021-04335-1] [Medline: 34873647]
31. Martin D, Wachtmeister J, Ludwigs K, Jenetzky E. The FeverApp registry - ecological momentary assessment (EMA) of fever management in families regarding conformity to up-to-date recommendations. BMC Med Inform Decis Mak 2020;20(1):249 [FREE Full text] [doi: 10.1186/s12911-020-01269-w] [Medline: 33004050]
32. Jenetzky E, Schwarz S, Fingerhut I, Kerdar SH, Gwiasda M, Rathjens L. Das FieberApp Register – ein Weg, um Eltern durch eigene Dokumentation zu einer abgestuften Entscheidung zu führen. Gesundheitswesen 2021;83(S 01):S4-S11. [doi: 10.1055/a-1581-8155] [Medline: 34731887]
33. Rathjens L, Gwiasda M, Schwarz S, Möhler R, Martin DD, Jenetzky E. Reliability of data collected via ecological momentary assessment on the example of FeverApp registry. Children (Basel) 2023;10(2):385 [FREE Full text] [doi: 10.3390/children10020385] [Medline: 36832514]
34. Rathjens L, Fingerhut I, Martin D, Hamideh Kerdar S, Gwiasda M, Schwarz S. Data completeness and concordance in the FeverApp registry: comparative study. JMIR Pediatr Parent 2022;5(4):e35510 [FREE Full text] [doi: 10.2196/35510] [Medline: 36322119]
35. Joosen C, Toelen J, Asscherickx W. Clinical decision support for parents through mobile applications: a systematic assessment of pediatric fever management apps. Belg J Paediatr 2024;26(4):275-281. [doi: 10.1556/650.2025.33325]
36. National Institute for Health and Care Excellence (NICE). Fever in under 5s: Assessment and initial management. NICE Guideline No. 143 (National Institute for Health and Care Excellence, London) 2021. [Medline: 31891472]
37. Deutsche Gesellschaft für Kinder- und Jugendmedizin e. V. (DGKJ). S3-Leitlinie: Fiebermanagement bei Kindern und Jugendlichen. AWMF-Leitlinienregister Nr. 027-074. 2025. URL: https://register.awmf.org/de/leitlinien/detail/027-074 [accessed 2025-11-17]
38. Colombo D, Fernández-Álvarez J, Patané A, Semonella M, Kwiatkowska M, García-Palacios A. Current state and future directions of technology-based ecological momentary assessment and intervention for major depressive disorder: a systematic review. J Clin Med 2019;8(4):465 [FREE Full text] [doi: 10.3390/jcm8040465] [Medline: 30959828]
39. Stone AA, Schneider S, Smyth JM. Evaluation of pressing issues in ecological momentary assessment. Annu Rev Clin Psychol 2023;19:107-131 [FREE Full text] [doi: 10.1146/annurev-clinpsy-080921-083128] [Medline: 36475718]
40. Wrzus C, Neubauer AB. Ecological momentary assessment: a meta-analysis on designs, samples, and compliance across research fields. Assessment 2023;30(3):825-846 [FREE Full text] [doi: 10.1177/10731911211067538] [Medline: 35016567]
41. Braun V, Clarke V. Thematic Analysis: A Practical Guide. London: SAGE; 2021.
42. de Winter JFC, Dodou D. Five-point Likert items: t test versus Mann-Whitney-Wilcoxon. Pract Assess Res Eval 2010;15(1):11. [doi: 10.7275/bj1p-ts64]
43. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med 2014;89(9):1245-1251 [FREE Full text] [doi: 10.1097/ACM.0000000000000388] [Medline: 24979285]
44. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. J Clin Epidemiol 2008;61(4):344-349. [doi: 10.1016/j.jclinepi.2007.11.008] [Medline: 18313558]
45. Liu J, Li H. How state anxiety influences retrospective time perception: the moderated mediation of perceived control and memory bias. J Cogn Psychol 2022;35(1):76-87. [doi: 10.1080/20445911.2022.2123490]
46. Eilbert W, Chan C. Febrile seizures: a review. J Am Coll Emerg Physicians Open 2022;3(4):e12769 [FREE Full text] [doi: 10.1002/emp2.12769] [Medline: 36016968]
47. Trinka E, Cock H, Hesdorffer D, Rossetti AO, Scheffer IE, Shinnar S. A definition and classification of status epilepticus — report of the ILAE Task Force on Classification of Status Epilepticus. Epilepsia 2015;56(10):1515-1523. [doi: 10.1111/epi.13121] [Medline: 26336950]
48. Marrosu F, Marrosu G, Rachel MG, Biggio G. Paradoxical reactions elicited by diazepam in children with classic autism. Funct Neurol 1987;2(3):355-361. [Medline: 2826308]
49. Noguchi KK, Fuhler NA, Wang SH, Capuano S, Brunner KR, Larson S. Brain pathology caused in the neonatal macaque by short and prolonged exposures to anticonvulsant drugs. Neurobiol Dis 2021;149:105245 [FREE Full text] [doi: 10.1016/j.nbd.2020.105245] [Medline: 33385515]

50. Cutler AJ, Mattingly GW, Maletic V. Understanding the mechanism of action and clinical effects of neuroactive steroids and GABAergic compounds in major depressive disorder. Transl Psychiatry 2023;13(1):228 [FREE Full text] [doi: 10.1038/s41398-023-02514-2] [Medline: 37365161]
51. Shi Y, Cui M, Ochs K, Brendel M, Strübing FL, Briel N. Long-term diazepam treatment enhances microglial spine engulfment and impairs cognitive performance via the mitochondrial 18 kDa translocator protein (TSPO). Nat Neurosci 2022;25(3):317-329. [doi: 10.1038/s41593-022-01013-9] [Medline: 35228700]
52. FDA drug safety communication: FDA requiring boxed warning updated to improve safe use of benzodiazepine drug class. U.S. Food and Drug Administration. URL: https://www.fda.gov/media/142368/download?attachment [accessed 2025-02-13]
53. Hasday JD, Singh IS. Fever and the heat shock response: distinct, partially overlapping processes. Cell Stress Chaperones 2000;5(5):471-480 [FREE Full text] [doi: 10.1379/1466-1268(2000)005<0471:fathsr>2.0.co;2] [Medline: 11189454]
54. Martin D. Fieberkrämpfe: hilft Wärme im Fieberanstieg? Z Komplementärmed 2017;09(01):38-41. [doi: 10.1055/s-0043-100123]
55. Lin WY, Muo CH, Ku YC, Sung FC, Kao CH. Risk of subsequent asthma in children with febrile seizures: a nationwide population-based retrospective cohort study. Pediatr Neurol 2014;51(6):795-799. [doi: 10.1016/j.pediatrneurol.2014.06.017] [Medline: 25444093]
56. Sadri H, Madanipour A, Toami N, Bakhtiari M, Montazerlotfelahi H, Zahmatkesh E. A survey on the association of seizure disorders with asthma and allergies in children. Eur Ann Allergy Clin Immunol 2024;56(6):263-270 [FREE Full text] [doi: 10.23822/EurAnnACI.1764-1489.328] [Medline: 38347809]
57. Ateşoğlu M, İnce T, Lüleci D, Ergör A, Aydın A. Sociodemographic risk factors for febrile seizures: a school-based study from Izmir, Turkey. Seizure 2018;61:45-49 [FREE Full text] [doi: 10.1016/j.seizure.2018.07.019] [Medline: 30081300]
58. Möhler R, Jenetzky E, Schwarz S, Gwiasda M, Rathjens L, Martin D. Children's symptoms with a febrile illness and a positive or negative test of SARS-CoV-2 during the Omicron wave. Children (Basel) 2023;10(3):149 [FREE Full text] [doi: 10.3390/children10030419] [Medline: 36979977]

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

Edited by S Badawy; submitted 02.Apr.2025; peer-reviewed by KR Konnaiyan, C Baxter; comments to author 22.Sep.2025; accepted 24.Dec.2025; published 06.Mar.2026.

Please cite as:
Martin D, Möhler R, Germann CB, Gwiasda M, Schwarz S, Jenetzky E
Febrile Seizures in an App-Based Children's Fever Registry: Mixed Methods Study
JMIR Pediatr Parent 2026;9:e74933
URL: https://pediatrics.jmir.org/2026/1/e74933
doi:10.2196/74933
PMID:

Original Paper

Facilitating Communication With Children and Young Adults With Special Health Care Needs Through a Web-Based Application: Qualitative Descriptive Study

Jessica R Hanks[1], MD; Ashley M Hughes[2], MS, PhD; Safura Sultana[3], MBA; Ryan Klute[4], MS; Kyle Formella[4], BSED, MS; Connor Flynn[5], BS; Allison Wallenfang[5], BS; Divya Krishnakumar[6], BS; Masah Mourad[7], BS; Yoonje Cho Morse[5], BS; Matthew J Mischler[8,9], MD

[1]Department of Health Sciences Education and Pathology, College of Medicine Peoria, University of Illinois Chicago, Peoria, IL, United States
[2]Department of Medicine at Metrohealth, School of Medicine, Case Western Reserve University, Cleveland, OH, United States
[3]Healthcare Analytics, OSF, Peoria, IL, United States
[4]Innovation, OSF, Peoria, IL, United States
[5]College of Medicine Peoria, University of Illinois Chicago, Peoria, IL, United States
[6]College of Medicine, University of Illinois Chicago, Chicago, IL, United States
[7]School of Public Health, University of Illinois Chicago, Chicago, IL, United States
[8]Department of Medicine, College of Medicine Peoria, University of Illinois Chicago, Peoria, IL, United States
[9]OSF Saint Francis Medical Center, Peoria, IL, United States

Corresponding Author:
Jessica R Hanks, MD
Department of Health Sciences Education and Pathology
College of Medicine Peoria
University of Illinois Chicago
1 Illini Drive
Peoria, IL, 61603
United States
Phone: 1 309 671 8407
Fax: 1 3096808480
Email: jhanks1@uic.edu

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.

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.

(JMIR Pediatr Parent 2026;9:e76512) doi:10.2196/76512

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 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

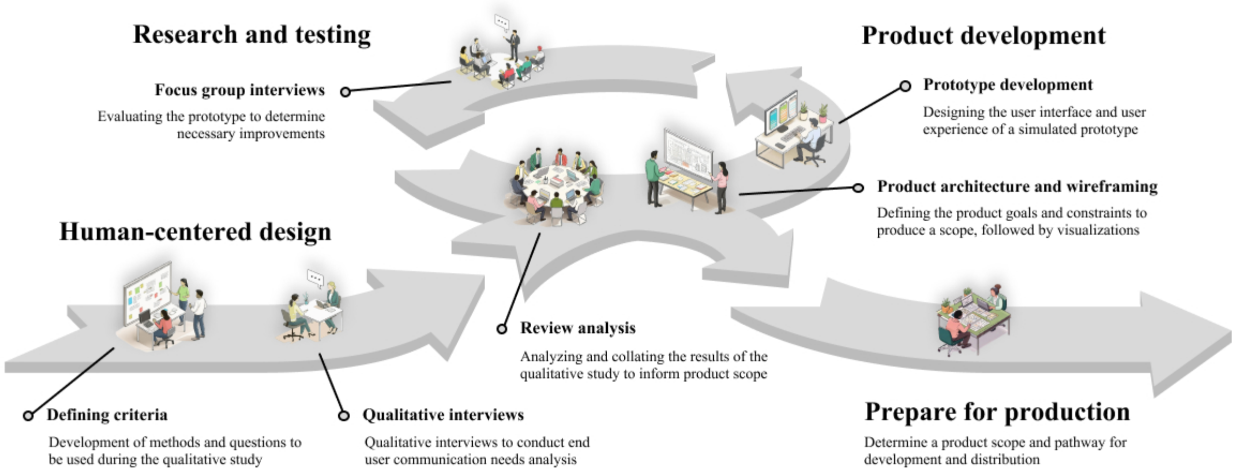
Recruitment for participation in the interviews to aid in the development of the web-based application and for the focus groups to provide feedback on the prototype took place via informational study fliers that were distributed electronically via email and physically within inpatient and outpatient 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

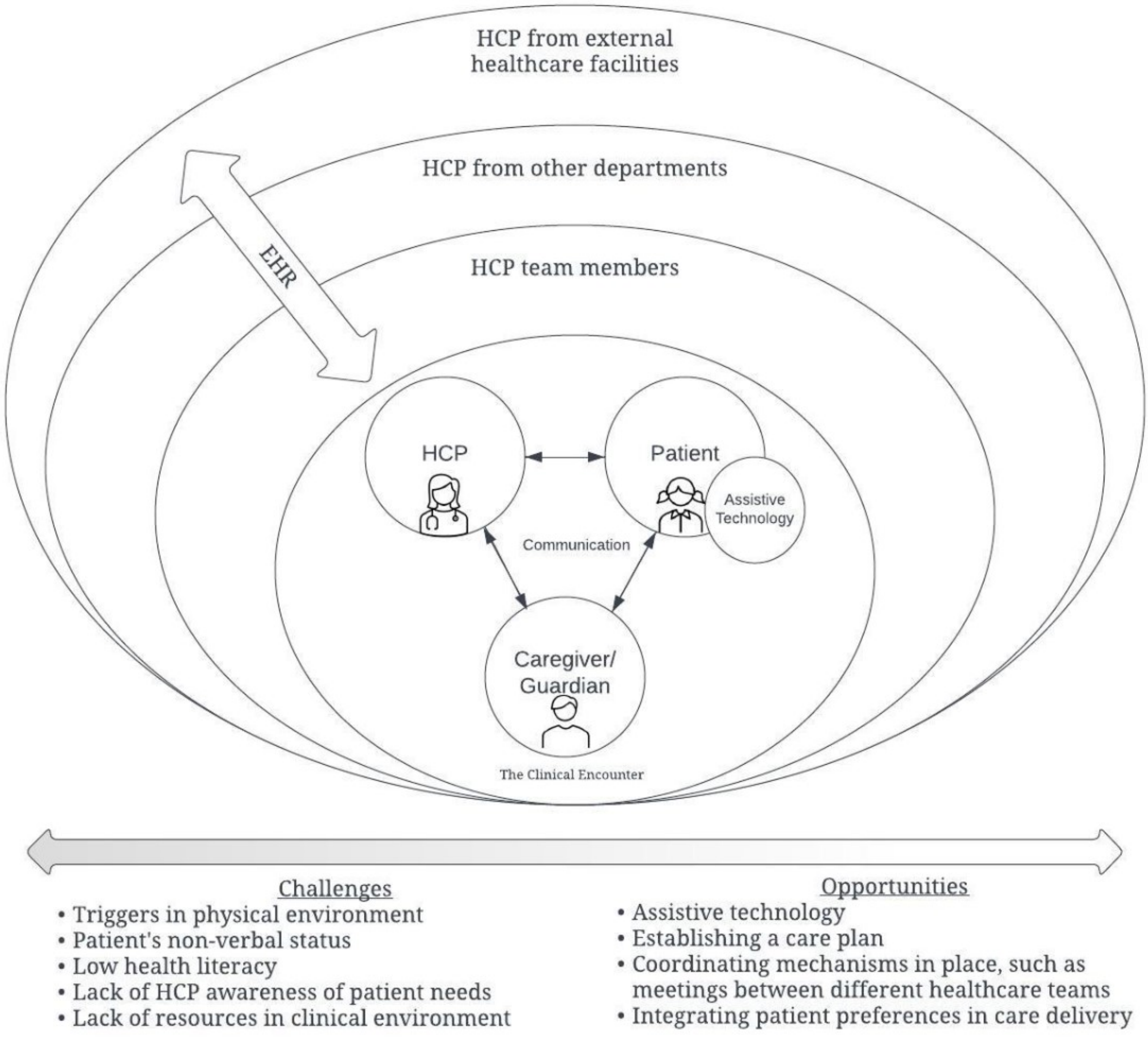
School of Public Health Collaboratory for Health Justice [19]. Training materials were presented, followed by opportunities to practice using the guide. The first 2 to 4 interviews were conducted under the supervision of a faculty member with expertise in qualitative human-centered design methods (AMH). 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.



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, 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:

> *[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.

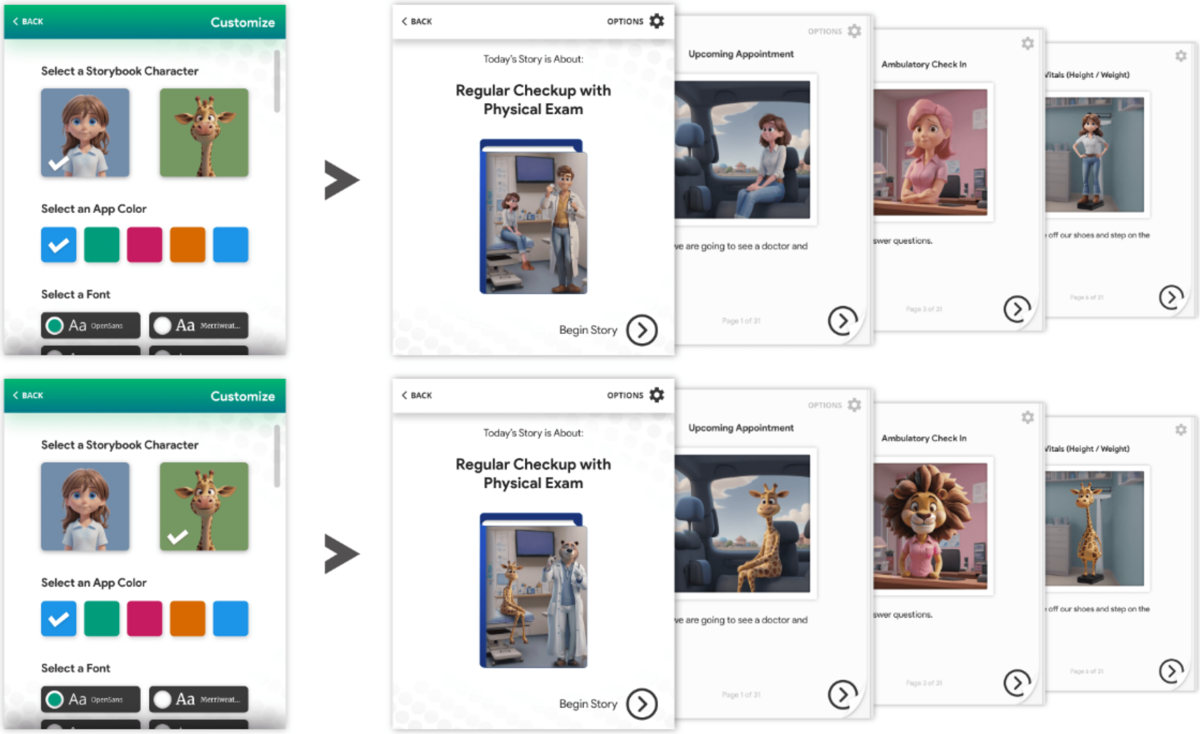
Common procedures patients undergo in both settings are phlebotomy and measurement of vital signs, and a common visit focus in the outpatient setting is a preventative examination or annual physical examination (including obtaining vital signs). An outline of narrative details was created that would 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.

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).

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 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.

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.

Funding

This project was funded by the Community Health Advocacy (CHA) program through the University of Illinois Chicago Office of the Vice Chancellor for Innovation.

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]

References

1. Stevens AC, Carroll DD, Courtney-Long EA, Zhang QC, Sloan ML, Griffin-Blake S, et al. Adults with one or more functional disabilities - United States, 2011-2014. MMWR Morb Mortal Wkly Rep 2016 Sep 30;65(38):1021-1025 [FREE Full text] [doi: 10.15585/mmwr.mm6538a1] [Medline: 27684532]
2. Disability impacts all of us infographic. Centers for Disease Control and Prevention. 2024. URL: https://www.cdc.gov/disability-and-health/articles-documents/disability-impacts-all-of-us-infographic.html [accessed 2025-02-25]
3. Gulley SP, Rasch EK, Chan L. The complex web of health: relationships among chronic conditions, disability, and health services. Public Health Rep 2011 Jul 01;126(4):495-507 [FREE Full text] [doi: 10.1177/003335491112600406] [Medline: 21800744]
4. Kennedy J, Wood EG, Frieden L. Disparities in insurance coverage, health services use, and access following implementation of the Affordable Care Act: a comparison of disabled and nondisabled working-age adults. Inquiry 2017;54:46958017734031 [FREE Full text] [doi: 10.1177/0046958017734031] [Medline: 29166812]
5. Kraus L, Lauer E, Coleman R, Houtenville A. 2017 Disability statistics annual report. University of New Hampshire. 2018. URL: https://files.eric.ed.gov/fulltext/ED583258.pdf [accessed 2025-12-09]
6. Crabb C, Owen R, Stober K, Heller T. Longitudinal appraisals of family caregiving for people with disabilities enrolled in Medicaid managed care. Disabil Rehabil 2020 Aug 29;42(16):2287-2294. [doi: 10.1080/09638288.2018.1557266] [Medline: 30696289]
7. Ghandour RM, Hirai AH, Kenney MK. Children and youth with special health care needs: a profile. Pediatrics 2022 Jun 01;149(Suppl 7):e2021056150D. [doi: 10.1542/peds.2021-056150D] [Medline: 35642877]

8. Mimmo L, Harrison R, Travaglia J, Hu N, Woolfenden S. Inequities in quality and safety outcomes for hospitalized children with intellectual disability. Dev Med Child Neurol 2022 Mar 25;64(3):314-322 [FREE Full text] [doi: 10.1111/dmcn.15066] [Medline: 34562021]
9. Boudreau AA, Perrin JM, Goodman E, Kurowski D, Cooley WC, Kuhlthau K. Care coordination and unmet specialty care among children with special health care needs. Pediatrics 2014 Jun 26;133(6):1046-1053. [doi: 10.1542/peds.2013-2174] [Medline: 24864172]
10. McLellan SE, Mann MY, Scott JA, Brown TW. A blueprint for change: guiding principles for a system of services for children and youth with special health care needs and their families. Pediatrics 2022 Jun 01;149(Suppl 7):e2021056150C. [doi: 10.1542/peds.2021-056150C] [Medline: 35642876]
11. Association of Maternal and Child Health Programs. Models of care for children and youth with special health care needs: promising models for transforming California’s system of care. Lucile Packard Foundation Children's Health. 2009 Nov 1. URL: https://tinyurl.com/2f35n6eh [accessed 2024-07-16]
12. Karam M, Chouinard MC, Poitras ME, Couturier Y, Vedel I, Grgurevic N, et al. Nursing care coordination for patients with complex needs in primary healthcare: a scoping review. Int J Integr Care 2021 Mar 19;21(1):16 [FREE Full text] [doi: 10.5334/ijic.5518] [Medline: 33776605]
13. Wahman CL, Pustejovsky JE, Ostrosky MM, Santos RM. Examining the effects of social stories™ on challenging behavior and prosocial skills in young children: a systematic review and meta-analysis. Top Early Child Spec Educ 2019 Aug 02;41(4):267-279. [doi: 10.1177/0271121419855692]
14. Ivey ML, Heflin LJ, Alberto P. The use of social stories to promote independent behaviors in novel events for children with PDD-NOS. Focus Autism Other Dev Disabl 2004 Aug 01;19(3):164-176. [doi: 10.1177/10883576040190030401]
15. Wright LA, McCathren RB. Utilizing social stories to increase prosocial behavior and reduce problem behavior in young children with autism. Child Dev Res 2012 May 08;2012:1-13. [doi: 10.1155/2012/357291]
16. Cassidy L, Quirke MB, Alexander D, Greene J, Hill K, Connolly M, et al. Integrated care for children living with complex care needs: an evolutionary concept analysis. Eur J Pediatr 2023 Apr 13;182(4):1517-1532 [FREE Full text] [doi: 10.1007/s00431-023-04851-2] [Medline: 36780041]
17. Wilson SA, Peterson CC. Medical care experiences of children with autism and their parents: a scoping review. Child Care Health Dev 2018 Nov 22;44(6):807-817. [doi: 10.1111/cch.12611] [Medline: 30136407]
18. Yates KA, Feldon DF. Advancing the practice of cognitive task analysis: a call for taxonomic research. Theor Issues Ergonomics Sci 2011 Nov;12(6):472-495. [doi: 10.1080/1463922X.2010.505269]
19. Collaboratory for health justice. University of Illinois Chicago. URL: https://publichealth.uic.edu/community-engagement/collaboratory-for-health-justice/ [accessed 2024-06-04]
20. Hwang S. Utilizing qualitative data analysis software: a review of Atlas.ti. Soc Sci Comput Rev 2007;26(4):519-527. [doi: 10.1177/0894439307312485]
21. Hennink MM, Kaiser BN, Marconi VC. Code saturation versus meaning saturation: how many interviews are enough? Qual Health Res 2017 Mar;27(4):591-608 [FREE Full text] [doi: 10.1177/1049732316665344] [Medline: 27670770]
22. Hutchins E. Cognition, distributed. In: Smelser NJ, Baltes PB, editors. International Encyclopedia of the Social & Behavioral Sciences. Oxford, UK: Pergamon Press; 2001:2068-2072.
23. Brooke J. SUS: a 'quick and dirty' usability scale. In: Jordan PW, Thomas B, McClelland IL, Weerdmeester B, editors. Usability Evaluation in Industry. London, UK: CRC Press; 1996.
24. Ko EJ, Nam KA, Kim EJ. Development and psychometric testing of learning immersion scale in clinical simulation: a methodological study. Nurse Educ Today 2022 Jun;113:105363. [doi: 10.1016/j.nedt.2022.105363] [Medline: 35439632]
25. Sauro J, Lewis JR. Quantifying the User Experience: Practical Statistics for User Research. Burlington, MA: Morgan Kaufmann Publishers; 2016.
26. Melnick ER, Dyrbye LN, Sinsky CA, Trockel M, West CP, Nedelec L, et al. The association between perceived electronic health record usability and professional burnout among US physicians. Mayo Clin Proc 2020 Mar;95(3):476-487 [FREE Full text] [doi: 10.1016/j.mayocp.2019.09.024] [Medline: 31735343]
27. Sauro J. Measuring Usability with the System Usability Scale (SUS). MeasuringU. 2011 Feb 3. URL: https://measuringu.com/sus/ [accessed 2024-04-25]
28. Sauro J. 5 ways to interpret a SUS score. MeasuringU. 2018 Sep 19. URL: https://measuringu.com/interpret-sus-score/ [accessed 2024-04-23]
29. Tian Z, Zhang K, Zhang T, Dai X, Lin J. Application of Ausubel cognitive assimilation theory in teaching/learning medical biochemistry and molecular biology. Biochem Mol Biol Educ 2020 May 20;48(3):202-219 [FREE Full text] [doi: 10.1002/bmb.21327] [Medline: 31859445]
30. Hyzy M, Bond R, Mulvenna M, Bai L, Dix A, Leigh S, et al. System usability scale benchmarking for digital health apps: meta-analysis. JMIR Mhealth Uhealth 2022 Aug 18;10(8):e37290 [FREE Full text] [doi: 10.2196/37290] [Medline: 35980732]

Abbreviations

HCP: health care provider
SUS: System Usability Scale

Edited by S Badawy; submitted 03.Jun.2025; peer-reviewed by A Roundtree; comments to author 02.Jul.2025; revised version received 23.Nov.2025; accepted 27.Nov.2025; published 06.Jan.2026.

Please cite as:
Hanks JR, Hughes AM, Sultana S, Klute R, Formella K, Flynn C, Wallenfang A, Krishnakumar D, Mourad M, Morse YC, Mischler MJ
Facilitating Communication With Children and Young Adults With Special Health Care Needs Through a Web-Based Application: Qualitative Descriptive Study
JMIR Pediatr Parent 2026;9:e76512
URL: https://pediatrics.jmir.org/2026/1/e76512
doi:10.2196/76512
PMID:

Relationship Among Internet Use, eHealth Literacy, Internet Addiction, and Physical Activity Among Adolescents: Cross-Sectional Study

Xavier C C Fung, PhD; Joyce S C Cheung, MSocSc; Fay F Wang, MSc; Benson W M Lau, PhD; Shirley P C Ngai, PhD

[1]Department of Rehabilitation Sciences, Faculty of Health and Social Sciences, The Hong Kong Polytechnic University, Hong Kong Special Administrative Region, China

Corresponding Author:
Shirley P C Ngai, PhD
Department of Rehabilitation Sciences, Faculty of Health and Social Sciences, The Hong Kong Polytechnic University, Hong Kong Special Administrative Region, China

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.

(JMIR Pediatr Parent 2026;9:e83936) doi:10.2196/83936

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 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.

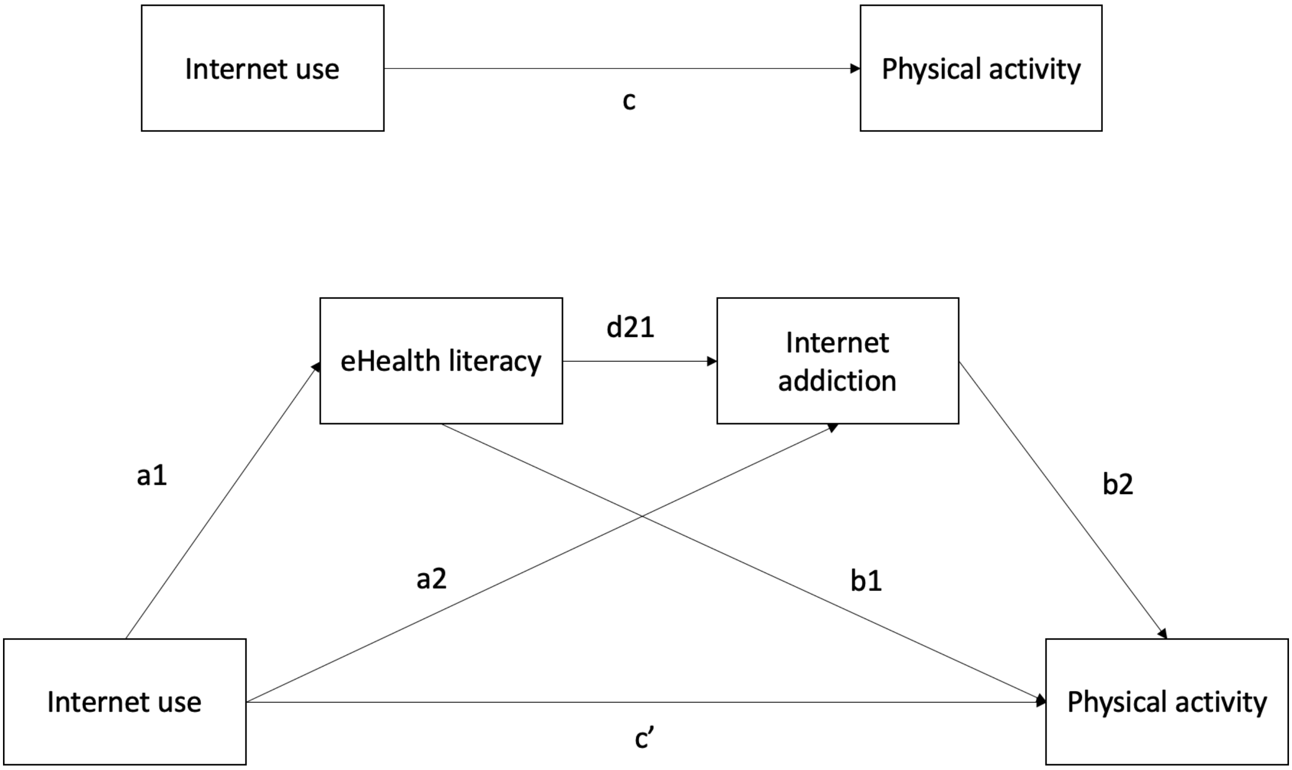
The potential impact of internet addiction on physical activity and cardiovascular health has elicited concern [6-9]. Problematic internet use has been associated with physical inactivity among high school students [10,11]. Physical inactivity and sedentary behavior can lead to adverse health problems, 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.

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.

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.

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).

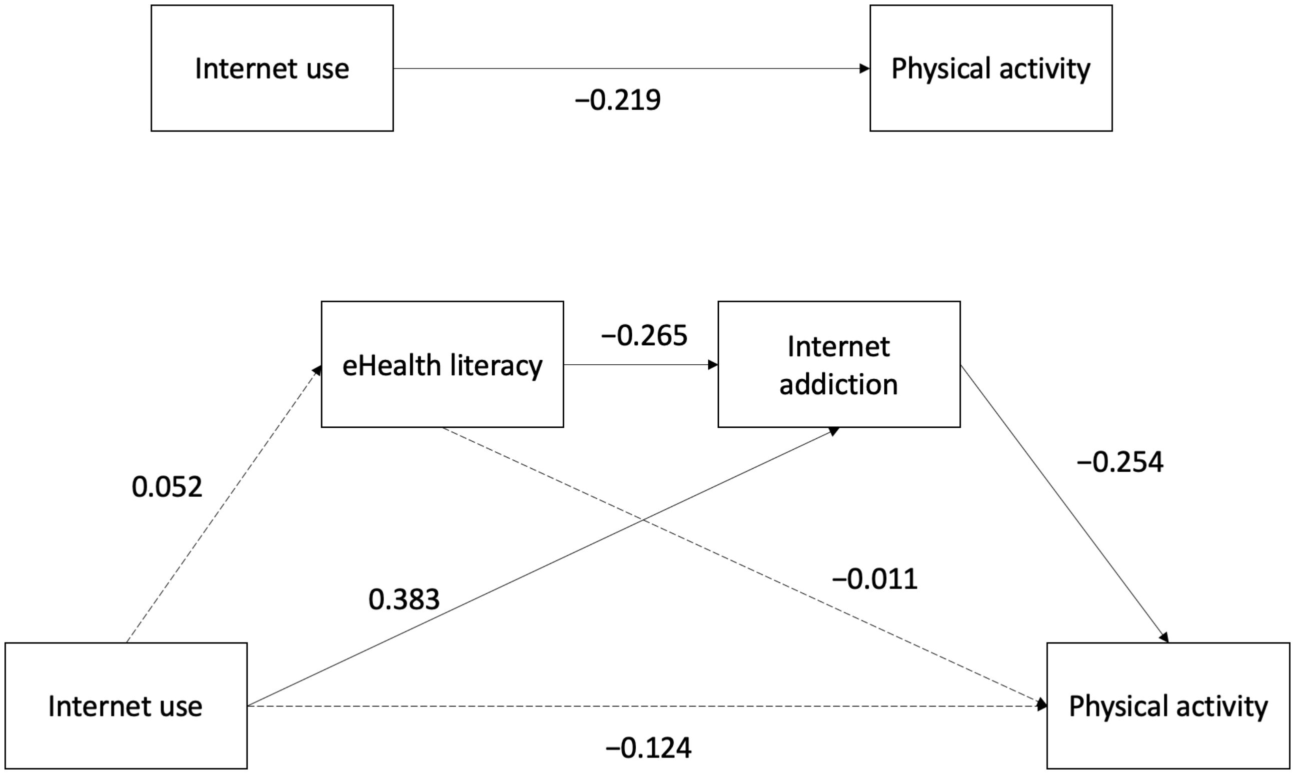
Table . Mediation analysis of the relationship between internet use on physical activity via eHealth literacy and internet addiction[a].

	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.

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 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.

Acknowledgments

Professional English-language editing support was provided by AsiaEdit.

Funding

The study was supported by The Hong Kong Polytechnic University (P0040602 [ZYVT] and P0052607 [ZZUA]).

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.

References

1. Vuorre M, Przybylski AK. A multiverse analysis of the associations between internet use and well-being. Technology, Mind, and Behavior 2024;5(2):65-75. [doi: 10.1037/tmb0000127]
2. Kuss DJ, Griffiths MD, Karila L, Billieux J. Internet addiction: a systematic review of epidemiological research for the last decade. Curr Pharm Des 2014;20(25):4026-4052. [doi: 10.2174/13816128113199990617] [Medline: 24001297]
3. Shek DTL, Yu L. Adolescent internet addiction in Hong Kong: prevalence, change, and correlates. J Pediatr Adolesc Gynecol 2016 Feb;29(1 Suppl):S22-S30. [doi: 10.1016/j.jpag.2015.10.005] [Medline: 26461526]

4. Chung TWH, Sum SMY, Chan MWL. Adolescent internet addiction in Hong Kong: prevalence, psychosocial correlates, and prevention. J Adolesc Health 2019 Jun;64(6S):S34-S43. [doi: 10.1016/j.jadohealth.2018.12.016] [Medline: 31122547]
5. Fung XCC, Siu AMH, Potenza MN, et al. Problematic use of internet-related activities and perceived weight stigma in schoolchildren: a longitudinal study across different epidemic periods of COVID-19 in China. Front Psychiatry 2021;12:675839. [doi: 10.3389/fpsyt.2021.675839] [Medline: 34108898]
6. Kwok C, Leung PY, Poon KY, Fung XCC. The effects of internet gaming and social media use on physical activity, sleep, quality of life, and academic performance among university students in Hong Kong. Asian J Soc Health Behav 2021;4(1):36-44. [doi: 10.4103/shb.shb_81_20]
7. Lin PC, Kuo SY, Lee PH, Sheen TC, Chen SR. Effects of internet addiction on heart rate variability in school-aged children. J Cardiovasc Nurs 2014;29(6):493-498. [doi: 10.1097/JCN.0b013e3182a477d5] [Medline: 24088623]
8. Poskotinova LV, Krivonogova OV, Zaborsky OS. Cardiovascular response to physical exercise and the risk of internet addiction in 15-16-year-old adolescents. J Behav Addict 2021 Jul 15;10(2):347-351. [doi: 10.1556/2006.2021.00021] [Medline: 33909593]
9. Ying Ying C, Awaluddin SM, Kuang Kuay L, et al. Association of internet addiction with adolescents’ lifestyle: a national school-based survey. Int J Environ Res Public Health 2020 Dec 29;18(1):168. [doi: 10.3390/ijerph18010168] [Medline: 33383635]
10. Han G, Zhang J, Ma S, et al. Prevalence of internet addiction and its relationship with combinations of physical activity and screen-based sedentary behavior among adolescents in China. J Phys Act Health 2021 Aug 14;18(10):1245-1252. [doi: 10.1123/jpah.2020-0512] [Medline: 34391206]
11. K C S, Kaphle HP, Neupane N, Baral S. Internet use and its association with physical activity among adolescents in Beni Municipality, Myagdi, Nepal. PLoS ONE 2024;19(5):e0302456. [doi: 10.1371/journal.pone.0302456] [Medline: 38701076]
12. Owen N, Sparling PB, Healy GN, Dunstan DW, Matthews CE. Sedentary behavior: emerging evidence for a new health risk. Mayo Clin Proc 2010 Dec;85(12):1138-1141. [doi: 10.4065/mcp.2010.0444] [Medline: 21123641]
13. Lin YC, Fung XCC, Tsai MC, Strong C, Hsieh YP, Lin CY. Insufficient physical activity and overweight: does caregiver screen-viewing matter? J Child Fam Stud 2019 Jan;28(1):286-297. [doi: 10.1007/s10826-018-1247-5]
14. Kamdem F, Bika Léle EC, Mekoulou Ndongo J, et al. Cardiovascular risk factors among Cameroonian adolescents: comparison between public and private schools and association with physical activity practice-a cross-sectional study. JRSM Cardiovasc Dis 2023;12:20480040231210371. [doi: 10.1177/20480040231210371] [Medline: 37900881]
15. Oshima SM, Tait SD, Thomas SM, et al. Association of smartphone ownership and internet use with markers of health literacy and access: cross-sectional survey study of perspectives from project PLACE (Population Level Approaches to Cancer Elimination). J Med Internet Res 2021 Jun 9;23(6):e24947. [doi: 10.2196/24947] [Medline: 34106076]
16. Norman CD, Skinner HA. eHealth literacy: essential skills for consumer health in a networked world. J Med Internet Res 2006 Jun 16;8(2):e9. [doi: 10.2196/jmir.8.2.e9] [Medline: 16867972]
17. Neter E, Brainin E. eHealth literacy: extending the digital divide to the realm of health information. J Med Internet Res 2012 Jan 27;14(1):e19. [doi: 10.2196/jmir.1619] [Medline: 22357448]
18. Gürkan KP, Ayar D. The impact of e-Health literacy on health promotion behaviors of high school students. J Pediatr Res 2020 Jul 8;7(4):286-292. [doi: 10.4274/jpr.galenos.2019.81488]
19. Korkmaz Aslan G, Kartal A, Turan T, Taşdemir Yiğitoğlu G, Kocakabak C. Association of electronic health literacy with health-promoting behaviours in adolescents. Int J Nurs Pract 2021 Apr;27(2):e12921. [doi: 10.1111/ijn.12921] [Medline: 33615625]
20. Gordon-Larsen P, Adair LS, Nelson MC, Popkin BM. Five-year obesity incidence in the transition period between adolescence and adulthood: the National Longitudinal Study of Adolescent Health. Am J Clin Nutr 2004 Sep;80(3):569-575. [doi: 10.1093/ajcn/80.3.569] [Medline: 15321794]
21. Lawrence EM, Mollborn S, Hummer RA. Health lifestyles across the transition to adulthood: implications for health. Soc Sci Med 2017 Nov;193:23-32. [doi: 10.1016/j.socscimed.2017.09.041] [Medline: 28992538]
22. Liu Y, Wu N, Yan J, Yu J, Liao L, Wang H. The relationship between health literacy and internet addiction among middle school students in Chongqing, China: a cross-sectional survey study. PLOS ONE 2023;18(3):e0283634. [doi: 10.1371/journal.pone.0283634] [Medline: 36961794]
23. Bandura A. Social Foundations of Thought and Action: A Social Cognitive Theory: Prentice-Hall; 1986.
24. Huang WY, Wong SHS, Sit CHP, Wong MCS, Wong SWS, Ho RST. Results from the Hong Kong’s 2022 report card on physical activity for children and adolescents. J Exerc Sci Fit 2023 Jan;21(1):45-51. [doi: 10.1016/j.jesf.2022.10.010] [Medline: 36408208]
25. Mo PKH, Chan VWY, Wang X, Lau JTF. Gender difference in the association between internet addiction, self-esteem and academic aspirations among adolescents: a structural equation modelling. Comput Educ 2020 Oct;155:103921 [FREE Full text] [doi: 10.1016/j.compedu.2020.103921]
26. Student health service annual health report for 2023/24 school year. : Student Health Service, Department of Health, Hong Kong Special Administrative Region; 2025 URL: https://www.studenthealth.gov.hk/english/annual_health/files/student_health_service_annual_health_report_for_2023_24_school_year.pdf [accessed 2026-03-16]

27. Wong DKK, Cheung MK. Online health information seeking and eHealth literacy among patients attending a primary care clinic in Hong Kong: a cross-sectional survey. J Med Internet Res 2019 Mar 27;21(3):e10831. [doi: 10.2196/10831] [Medline: 30916666]
28. Xu RH, Zhou LM, Wong ELY, Wang D. The association between patients' eHealth literacy and satisfaction with shared decision-making and well-being: multicenter cross-sectional study. J Med Internet Res 2021 Sep 24;23(9):e26721. [doi: 10.2196/26721] [Medline: 34559062]
29. Koo M, Norman CD, Chang HM. Psychometric evaluation of a Chinese version of the eHealth Literacy Scale (eHEALS) in school age children. Int Electron J Health Educ 2012;15:29-36 [FREE Full text]
30. Macfarlane DJ, Lee CCY, Ho EYK, Chan KL, Chan DTS. Reliability and validity of the Chinese version of IPAQ (short, last 7 days). J Sci Med Sport 2007 Feb;10(1):45-51. [doi: 10.1016/j.jsams.2006.05.003] [Medline: 16807105]
31. Chen SH, Weng LJ, Su YJ, Wu HM, Yang PF. Development of a Chinese Internet Addiction Scale and its psychometric study. Chin J Psychol 2003;45:279-294 [FREE Full text]
32. Yang X, Huang Y, Li S, Yeung KY, Zhang L. The role of eHealth literacy in psychological distress and health-related quality of life in adolescents in Hong Kong: the potential mediation of screen-based lifestyles. J Affect Disord 2026 Jan 15;393(Pt B):120421. [doi: 10.1016/j.jad.2025.120421] [Medline: 41083071]
33. Ko CH, Yen JY, Yen CF, Chen CC, Yen CN, Chen SH. Screening for Internet addiction: an empirical study on cut-off points for the Chen Internet Addiction Scale. Kaohsiung J Med Sci 2005 Dec;21(12):545-551. [doi: 10.1016/S1607-551X(09)70206-2] [Medline: 16670046]
34. Lau JTF, Gross DL, Wu AMS, Cheng KM, Lau MMC. Incidence and predictive factors of Internet addiction among Chinese secondary school students in Hong Kong: a longitudinal study. Soc Psychiatry Psychiatr Epidemiol 2017 Jun;52(6):657-667. [doi: 10.1007/s00127-017-1356-2] [Medline: 28417158]
35. Hayes AF. Introduction to Mediation, Moderation, and Conditional Process Analysis: A Regression-Based Approach, 3rd edition: The Guilford Press; 2022.
36. Cheng C, Elsworth G, Osborne RH. Validity evidence based on relations to other variables of the eHealth Literacy Questionnaire (eHLQ): Bayesian approach to test for known-groups validity. J Med Internet Res 2021 Oct 14;23(10):e30243. [doi: 10.2196/30243] [Medline: 34647897]
37. Hesse BW, Nelson DE, Kreps GL, et al. Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. Arch Intern Med 2005;165(22):2618-2624. [doi: 10.1001/archinte.165.22.2618] [Medline: 16344419]
38. Zhao BY, Huang L, Cheng X, et al. Digital health literacy and associated factors among internet users from China: a cross-sectional study. BMC Public Health 2024 Mar 27;24(1):908. [doi: 10.1186/s12889-024-18324-0] [Medline: 38539176]
39. Gunlu A. Examining the mediating role of e-health literacy in the relationship between COVID-19 awareness and dispositional hope and the experiences of those who survived the disease. J Community Psychol 2024 Sep;52(7):877-894. [doi: 10.1002/jcop.23134] [Medline: 38995702]
40. Tong W, Meng S. Effects of physical activity on mobile phone addiction among college students: the chain-based mediating role of negative emotion and e-Health literacy. Psychol Res Behav Manag 2023;16:3647-3657. [doi: 10.2147/PRBM.S419799] [Medline: 37700883]
41. He G, Huang WY, Wong SH. Physical activity research in Hong Kong from 1987 to 2012: evidence on children and adolescents. Asia Pac J Public Health 2014 Nov;26(6):560-574. [doi: 10.1177/1010539513499623] [Medline: 24097932]
42. Rosselli M, Ermini E, Tosi B, et al. Gender differences in barriers to physical activity among adolescents. Nutr Metab Cardiovasc Dis 2020 Aug 28;30(9):1582-1589. [doi: 10.1016/j.numecd.2020.05.005] [Medline: 32605880]
43. Faries MD. Why we don't "Just Do It": understanding the intention-behavior gap in lifestyle medicine. Am J Lifestyle Med 2016;10(5):322-329. [doi: 10.1177/1559827616638017] [Medline: 30202289]
44. Bhuyan SS, Lu N, Chandak A, et al. Use of mobile health applications for health-seeking behavior among US adults. J Med Syst 2016 Jun;40(6):153. [doi: 10.1007/s10916-016-0492-7] [Medline: 27147516]
45. Weaver JB 3rd, Mays D, Weaver SS, Hopkins GL, Eroglu D, Bernhardt JM. Health information-seeking behaviors, health indicators, and health risks. Am J Public Health 2010 Aug;100(8):1520-1525. [doi: 10.2105/AJPH.2009.180521] [Medline: 20558794]
46. Zhu Y, Wang X, You X, et al. Cut-off value of the eHEALS score as a measure of eHealth skills among rural residents in Gansu, China. Digit Health 2023;9:20552076231205269. [doi: 10.1177/20552076231205269] [Medline: 37808241]
47. Kharsynniang H. An adolescents health seeking information: a systematic review. : 11th International Scholars Conference; 2024 URL: https://jurnal.unai.edu/isc/article/view/3436 [accessed 2026-03-20]

Abbreviations

CIAS : Chen Internet Addiction Scale
eHEALS : eHealth Literacy Scale
IPAQ : International Physical Activity Questionnaire
MET: metabolic equivalent of task

Edited by J Hagström; submitted 11.Sep.2025; peer-reviewed by SA Kristina, YS Zhang; revised version received 28.Feb.2026; accepted 02.Mar.2026; published 30.Mar.2026.

Please cite as:
Fung XCC, Cheung JSC, Wang FF, Lau BWM, Ngai SPC
Relationship Among Internet Use, eHealth Literacy, Internet Addiction, and Physical Activity Among Adolescents: Cross-Sectional Study
JMIR Pediatr Parent 2026;9:e83936
URL: https://pediatrics.jmir.org/2026/1/e83936
doi:10.2196/83936

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)

Dèsirée Vidaña-Perez[1], MSc, PhD; Inti Barrientos-Gutierrez[2], MBA; Rosibel Rodríguez-Bolaños[3], PhD; Evangelina Díaz-Andrade[4,5], PhD; Diego F Leal[6], PhD; Minji Kim[1], PhD; Jennifer B Unger[7], PhD; Thomas W Valente[7], PhD; Jessica L Barrington-Trimis[7], PhD; James F Thrasher[1], PhD

[1]Department of Health Promotion, Education, and Behavior, Arnold School of Public Health, University of South Carolina, Columbia, SC, United States

[2]Evaluation and Surveys Research Center, National Institute of Public Health, Cuernavaca, Morelos, Mexico

[3]Department of Reproductive Health, Population Health Research Center, National Institute of Public Health, Cuernavaca, Morelos, Mexico

[4]Health Region VI, Ciudad Guzman, Jalisco, Health Services, Cd. Guzman, Mexico

[5]University Center of the South, Universidad de Guadalajara, Guadalajara, Mexico

[6]School of Sociology, University of Arizona, Tucson, AZ, United States

[7]Department of Population and Public Health Sciences, University of Southern California, Los Angeles, CA, United States

Corresponding Author:
James F Thrasher, PhD
Department of Health Promotion, Education, and Behavior
Arnold School of Public Health
University of South Carolina
915 Greene St. Discovery 534 D
Columbia, SC, 29201
United States
Phone: 1 803 777 4862
Email: thrasher@mailbox.sc.edu

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.

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.

(JMIR Pediatr Parent 2026;9:e85376) doi:10.2196/85376

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 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 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.

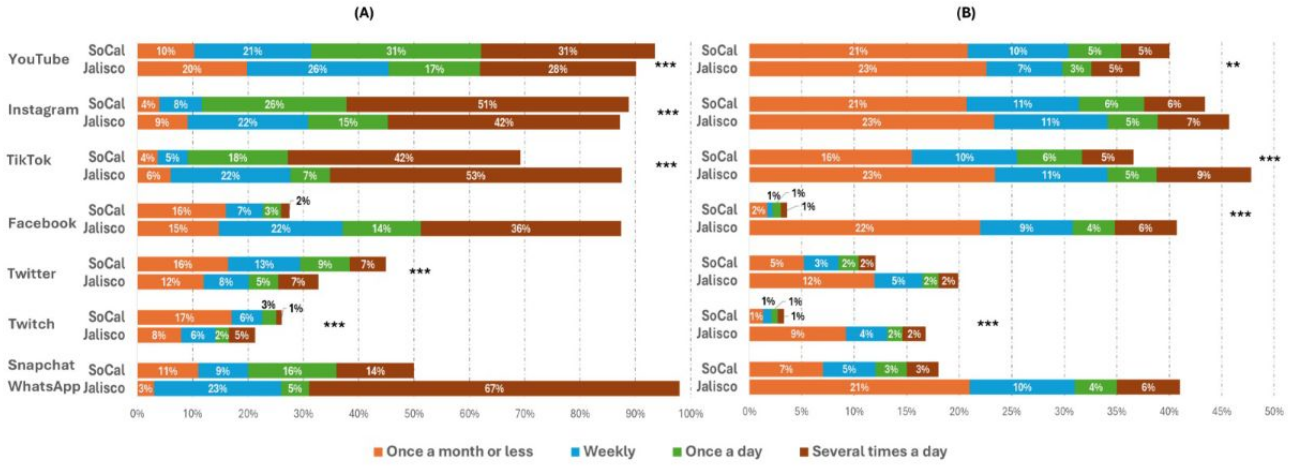
Table 1. Sample characteristics of high-school students in Jalisco (Mexico) and Southern California (United States).

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, 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).

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).

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 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 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.

Funding

Research reported in this study was supported by the Fogarty International Center (R01TW010652), the National Cancer Institute (R01CA229617) of the National Institutes of Health, and the US Food and Drug Administration (U54CA180905). The content is solely the responsibility of the authors and does not represent the official views of the National Institutes of Health or the Food and Drug Administration.

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]

References

1. Freeman B, Watts C, Astuti PAS. Global tobacco advertising, promotion and sponsorship regulation: What's old, what's new and where to next? Tob Control 2022;31(2):216-221. [doi: 10.1136/tobaccocontrol-2021-056551] [Medline: 35241591]

2. Miech RA, Johnson LD, Patrick ME, O'Malley PM, Bachman JG, Schulenberg JE. Monitoring the Future National Survey Results on Drug Use, 1975-2022: Secondary School Students. Michigan: University of Michigan Institute for Social Research; 2023. URL: https://monitoringthefuture.org/wp-content/uploads/2022/12/mtf2022.pdf [accessed 2025-02-08]
3. Gentzke AS, Wang TW, Cornelius M, Park-Lee E, Ren C, Sawdey MD, et al. Tobacco Product Use and Associated Factors Among Middle and High School Students - National Youth Tobacco Survey, United States, 2021. MMWR Surveill Summ 2022 Mar 11;71(5):1-29 [FREE Full text] [doi: 10.15585/mmwr.ss7105a1] [Medline: 35271557]
4. Dewhirst T. Co-optation of harm reduction by Big Tobacco. Tob Control 2021 Nov;30(e1):e1-e3. [doi: 10.1136/tobaccocontrol-2020-056059] [Medline: 32796080]
5. Tobacco 21 | FDA. U.S. Food and Drug Administration. 2019 Dec 20. URL: https://www.fda.gov/tobacco-products/retail-sales-tobacco-products/tobacco-21 [accessed 2024-11-10]
6. How FDA regulates vapes. Food and Drug Administration. URL: https://www.fda.gov/media/159412/download [accessed 2026-02-19]
7. Birdsey J, Cornelius M, Jamal A, Park-Lee E, Cooper MR, Wang J, et al. Tobacco Product Use Among U.S. Middle and High School Students - National Youth Tobacco Survey, 2023. MMWR Morb Mortal Wkly Rep 2023 Nov 03;72(44):1173-1182 [FREE Full text] [doi: 10.15585/mmwr.mm7244a1] [Medline: 37917558]
8. Gentzke AS, Creamer M, Cullen KA, Ambrose BK, Willis G, Jamal A, et al. Vital Signs: Tobacco Product Use Among Middle and High School Students - United States, 2011-2018. MMWR Morb Mortal Wkly Rep 2019 Feb 15;68(6):157-164 [FREE Full text] [doi: 10.15585/mmwr.mm6806e1] [Medline: 30763302]
9. Tobacco use in California 2023. Truth Initiative. URL: https://truthinitiative.org/research-resources/smoking-region/tobacco-use-california-2023 [accessed 2025-05-12]
10. Cámara de Diputados del Congreso de la Nación [Chamber of Deputies National Congress]. Ley general para el control del tabaco [General Tobacco Control Law]. Cámara de Diputados del Congreso de la Nación. 2008. URL: https://www.diputados.gob.mx/LeyesBiblio/pdf/LGCT.pdf; [accessed 2026-02-19]
11. Cámara de diputados del Congreso de la Nación [Chamber of Deputies National Congress]. Decreto por el que se expide la ley general para el control del tabaco; y deroga y reforma diversas disposiciones de la Ley general de salud. Diario Oficial de la Federación. 2008. URL: https://www.dof.gob.mx/nota_detalle.php?codigo=5037388&fecha=30/05/2008#gsc.tab=0 [accessed 2022-09-27]
12. Zavala-Arciniega, Luis. Use of tobacco and new products during the COVID-19 pandemic in Mexico: A social determinants perspective. Congreso de Investigacion en Salud Publica Public Health Research Congress, Cuernavaca: Instituto Nacional de Salud Publica National Institute of Public Health; 2023 Mar 15 Presented at: Congreso de Investigacion en Salud Publica [Public Health Research Congress]; 03/15/2023; Cuernavaca, Morelos, Mexico.
13. Barrientos-Gutierrez I, Lozano P, Arillo-Santillan E, Morello P, Mejia R, Thrasher JF. "Technophilia": A new risk factor for electronic cigarette use among early adolescents? Addict Behav 2019 Apr;91:193-200 [FREE Full text] [doi: 10.1016/j.addbeh.2018.09.004] [Medline: 30224154]
14. Vidaña-Pérez D, Gallegos-Carrillo K, Barrientos-Gutierrez I, Cruz-Jiménez L, Rodríguez-Bolaños R, Arillo-Santillán E, et al. Prevalence and correlates of e-cigarette source and use of e-cigarettes with nicotine: A case study of Mexico, where e-cigarettes are banned. Int J Drug Policy 2024 Nov;133:104609. [doi: 10.1016/j.drugpo.2024.104609] [Medline: 39369574]
15. Zavala-Arciniega L, Reynales-Shigematsu LM, Lozano P, Rodríguez-Andrade MA, Arillo-Santillán E, Thrasher JF. Patterns of awareness and use of electronic cigarettes in Mexico, a middle-income country that bans them: Results from a 2016 national survey. Prev Med 2018 Nov;116:211-218 [FREE Full text] [doi: 10.1016/j.ypmed.2018.09.018] [Medline: 30261244]
16. Digital 2024: Global overview report. We are Social, Meltwater. 2024. URL: https://datareportal.com/reports/digital-2024-global-overview-report [accessed 2024-12-14]
17. Instituto Nacional de Estadística y Geografia (INEGI). Encuesta Nacional sobre Disponibilidad y Uso de Tecnologías de la Información en los Hogares (ENDUTIH). National Survey on Availability and Use of Information Technologies in Households Press Release. Mexico City. Instituto Nacional de Estadística y Geografia (INEGI); Instituto Federal de Telecomunicaciones. 2021 Jul 04. URL: https://ift.org.mx/comunicacion-y-medios/comunicados-ift/es/encuesta-nacional-sobre-disponibilidad-y-uso-de-tecnologias-de-la-informacion-en-los-hogares-endutih [accessed 2022-11-10]
18. Teens, social media and technology. Pew Research Center. 2022. URL: https://www.pewresearch.org/internet/2022/08/10/teens-social-media-and-technology-2022/ [accessed 2023-04-19]
19. Centers for Disease Control and Prevention. 2024. URL: https://www.cdc.gov/yrbs/dstr/index.html [accessed 2026-02-19]
20. Cho YJ, Thrasher JF, Driezen P, Hitchman SC, Reid JL, Hammond D. Trends in exposure to and perceptions of e-cigarette marketing among youth in England, Canada and the United States between 2017 and 2019. Health Educ Res 2022 Jan 29;36(6):657-668 [FREE Full text] [doi: 10.1093/her/cyab039] [Medline: 34849859]
21. Results from the annual national youth tobacco survey. Food and Drug Administration (FDA). 2023. URL: https://www.fda.gov/tobacco-products/youth-and-tobacco/results-annual-national-youth-tobacco-survey [accessed 2024-05-14]
22. Lee J, Suttiratana SC, Sen I, Kong G. E-Cigarette Marketing on Social Media: A Scoping Review. Curr Addict Rep 2023 Mar;10(1):29-37. [doi: 10.1007/s40429-022-00463-2] [Medline: 41001189]

23. Zheng X, Li W, Li R, Yang M, Lin HC. Exposure to user-generated e-cigarette content on social media associated with greater vulnerability to e-cigarette use among youth non-users. Addict Behav 2024;156:108061. [doi: 10.1016/j.addbeh.2024.108061] [Medline: 38744213]
24. Duke JC, Allen JA, Eggers ME, Nonnemaker J, Farrelly MC. Exploring Differences in Youth Perceptions of the Effectiveness of Electronic Cigarette Television Advertisements. Nicotine Tob Res 2016 May;18(5):1382-1386. [doi: 10.1093/ntr/ntv264] [Medline: 26706908]
25. Mantey DS, Cooper MR, Clendennen SL, Pasch KE, Perry CL. E-Cigarette Marketing Exposure Is Associated With E-Cigarette Use Among US Youth. J Adolesc Health 2016 Jun;58(6):686-690 [FREE Full text] [doi: 10.1016/j.jadohealth.2016.03.003] [Medline: 27080732]
26. Vassey J, Valente T, Barker J, Stanton C, Li D, Laestadius L, et al. E-cigarette brands and social media influencers on Instagram: a social network analysis. Tob Control 2023 Aug;32(e2):e184-e191 [FREE Full text] [doi: 10.1136/tobaccocontrol-2021-057053] [Medline: 35131947]
27. Leventhal AM, Strong DR, Kirkpatrick MG, Unger JB, Sussman S, Riggs NR, et al. Association of electronic cigarette use with initiation of combustible tobacco product smoking in early adolescence. JAMA 2015;314(7):700-707 [FREE Full text] [doi: 10.1001/jama.2015.8950] [Medline: 26284721]
28. Pierce JP, Farkas AJ, Evans N, Gilpin E. An improved surveillance measure for adolescent smoking? Tob Control 1995;4(Suppl 1):S47-S56 [FREE Full text] [doi: 10.1136/tc.4.suppl1.s47]
29. Kehoe S, O'Hare L. The reliability and validity of the family affluence scale. Effective Education 2010;2(2):155-164 [FREE Full text] [doi: 10.1080/19415532.2010.524758]
30. Torsheim T, Currie C, Boyce W, Kalnins I, Overpeck M, Haugland S. Material deprivation and self-rated health: A multilevel study of adolescents from 22 European and North American countries. Soc Sci Med 2004;59(1):1-12. [doi: 10.1016/j.socscimed.2003.09.032] [Medline: 15087138]
31. Pérez A, Thrasher J, Monzón JC, Arillo-Santillán E, Barnoya J, Mejía R. La escala de afluencia familiar en la investigación sobre inequidades sociales en salud en adolescentes latinoamericanos. Salud Publica Mex 2021;63(2, Mar-Abr):201-210 [FREE Full text] [doi: 10.21149/11793] [Medline: 33989488]
32. Campaign for Tobacco Free Kids. 2023 Jan 23. URL: https://www.tobaccocontrollaws.org/legislation/mexico/advertising-promotion-sponsorship/regulated-forms-of-advertising-promotion-and-sponsorships [accessed 2025-05-12]
33. California Legislative Information. California Code, BPC 22963. California Code. 2021. URL: https://leginfo.legislature.ca.gov/faces/codes_displaySection.xhtml?sectionNum=22963.&lawCode=BPC [accessed 2024-12-15]
34. Game over: Ending internet sales of commercial tobacco. Public Health Law Center. URL: https://www.publichealthlawcenter.org/commentary/211206/12/6/21-game-over-ending-internet-sales-commercial-tobacco [accessed 2024-12-14]
35. Youth tobacco prevention plan. Food and Drug Administration (FDA). URL: https://www.fda.gov/tobacco-products/youth-and-tobacco/fdas-youth-tobacco-prevention-plan [accessed 2026-02-09]
36. Shamah-Levy T, Romero-Martinez M, Barrientos-Gutierrez T, Cuevas-Nasu L, Bautista-Arredondo S, Colchero MA, et al. Encuesta Nacional de Salud y Nutrición 2021 sobre COVID-19. Resultados nacionales. In: Instituto Nacional de Salud Publica. Cuernavaca, México: Instituto Nacional de Salud Publica [National Institute of Public Health]; 2022.
37. Vannucci A, Simpson EG, Gagnon S, Ohannessian CM. Social media use and risky behaviors in adolescents: A meta-analysis. J Adolesc 2020 Feb;79:258-274. [doi: 10.1016/j.adolescence.2020.01.014] [Medline: 32018149]
38. Facebook is changing how advertisers can reach young people. Meta for Business. 2021. URL: https://www.facebook.com/business/news/facebook-is-changing-how-advertisers-can-reach-young-people [accessed 2024-12-14]
39. Majmundar A, Chu M, Perez C, Hoang Y, Yuan J, Unger JB, et al. Tobacco and cannabis use advertisements targeting adolescents and young adults on Snapchat in 2019. Prev Med Rep 2022 Apr;26:101758 [FREE Full text] [doi: 10.1016/j.pmedr.2022.101758] [Medline: 35295669]
40. Rutherford BN, Lim CCW, Cheng B, Sun T, Vu GT, Johnson B, Daniel Paul Ashley, et al. Viral Vaping: A systematic review and meta analysis of e-cigarette and Tobacco-Related social media content and its influence on youth behaviours and attitudes. Addict Behav 2023 Dec;147:107828. [doi: 10.1016/j.addbeh.2023.107828] [Medline: 37591107]
41. Lee J, Krishnan-Sarin S, Kong G. Social Media Use and Subsequent E-Cigarette Susceptibility, Initiation, and Continued Use Among US Adolescents. Prev Chronic Dis 2023 Sep 07;20:E78 [FREE Full text] [doi: 10.5888/pcd20.220415] [Medline: 37676857]
42. Pérez A, Spells CE, Bluestein MA, Harrell MB, Hébert ET. The longitudinal impact of seeing and posting tobacco-related social media on tobacco use behaviors among Youth (Aged 12-17): Findings from the 2014-2016 population assessment of tobacco and health (PATH) study. Tob Use Insights 2022;15:1179173X221087554 [FREE Full text] [doi: 10.1177/1179173X221087554] [Medline: 35634272]
43. Huang GC, Unger JB, Soto D, Fujimoto K, Pentz MA, Jordan-Marsh M, et al. Peer influences: The impact of online and offline friendship networks on adolescent smoking and alcohol use. J Adolesc Health 2014;54(5):508-514 [FREE Full text] [doi: 10.1016/j.jadohealth.2013.07.001] [Medline: 24012065]
44. What is cross-border TAPS? | WHO FCTC. World Health Organization. URL: https://portal-uat.who.int/fctcapps/fctcapps/fctc/infohubs/crossborder-taps [accessed 2024-12-15]

45. Guidelines for implementation article 13 and specific guidelines to address crossborder tobacco advertising, promotion and sponsorship and the depiction of tobacco in entertainment media for implementation of article 13 of the WHO FCTC. In: World Health Organization. Geneva: World Health Organization; 2024.
46. Tobacco: Industry tactics to attract younger generations 2020. World Health Organization. 2020 Mar 25. URL: https://www.who.int/news-room/questions-and-answers/item/tobacco-industry-tactics-to-attract-younger-generations [accessed 2024-12-15]
47. Smith MJ, Buckton C, Patterson C, Hilton S. User-generated content and influencer marketing involving e-cigarettes on social media: A scoping review and content analysis of youTube and instagram. BMC Public Health 2023;23(1):530 [FREE Full text] [doi: 10.1186/s12889-023-15389-1] [Medline: 36941553]
48. Groom AL, Vu TT, Landry RL, Kesh A, Hart JL, Walker KL, et al. The influence of friends on teen vaping: A mixed-methods approach. Int J Environ Res Public Health 2021;18(13):6784 [FREE Full text] [doi: 10.3390/ijerph18136784] [Medline: 34202600]
49. Henneberger A, Mushonga DR, Preston AM. Peer influence and adolescent substance use: A systematic review of dynamic social network research. Adolescent Res Rev 2020;6(1):57-73 [FREE Full text] [doi: 10.1007/s40894-019-00130-0]
50. Valente TW, Piombo SE, Edwards KM, Waterman EA, Banyard VL. Social network influences on adolescent E-cigarette use. Subst Use Misuse 2023;58(6):780-786 [FREE Full text] [doi: 10.1080/10826084.2023.2188429] [Medline: 36924165]
51. Kitts JA, Leal DF. What is(n't) a friend? Dimensions of the friendship concept among adolescents. Soc Networks 2021;66:161-170 [FREE Full text] [doi: 10.1016/j.socnet.2021.01.004] [Medline: 34012218]
52. Vidaña-Pérez D, Mus S, Monzón J, Dávila G, Fahsen N, Barnoya J, et al. Factors associated with the changes in smoking and electronic cigarette use in adolescents during the COVID-19 pandemic: A longitudinal analysis. J Adolesc Health 2024;74(5):925-932. [doi: 10.1016/j.jadohealth.2023.11.399] [Medline: 38206227]
53. Lozano P, Arillo-Santillán E, Barrientos-Gutíerrez I, Reynales Shigematsu LM, Thrasher JF. E-cigarette social norms and risk perceptions among susceptible adolescents in a country that bans E-cigarettes. Health Educ Behav 2019;46(2):275-285 [FREE Full text] [doi: 10.1177/1090198118818239] [Medline: 30606077]
54. Valente TW. Network models and methods for studying the diffusion of innovations. In: Carrington PJ, Sctt J, Wasserman S, editors. Models and Methods in Social Network Analysis. United Kingdom: Cambridge University Press; 2005:98-116.
55. Hammond D, Reid JL, Burkhalter R, East K. Use of disposable e-cigarettes among youth who vape in Canada, England and the United States: Repeat cross-sectional surveys, 2017-2023. Addiction 2025;120(3):405-413. [doi: 10.1111/add.16596] [Medline: 38946542]
56. The role of the media in promoting and reducing tobacco use. National Cancer Institute. 2008. URL: https://cancercontrol.cancer.gov/brp/tcrb/monographs/monograph-19 [accessed 2026-02-19]
57. Digital 2022: Global overview report. We are Social, Hootsuite. 2023. URL: https://datareportal.com/reports/digital-2022-global-overview-report [accessed 2026-01-31]

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

Edited by S Badawy; submitted 06.Oct.2025; peer-reviewed by K Cummins, V Pravosud; comments to author 24.Dec.2025; accepted 16.Feb.2026; published 13.Mar.2026.

Please cite as:
Vidaña-Perez D, Barrientos-Gutierrez I, Rodríguez-Bolaños R, Díaz-Andrade E, Leal DF, Kim M, Unger JB, Valente TW, Barrington-Trimis JL, Thrasher JF
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)
JMIR Pediatr Parent 2026;9:e85376
URL: https://pediatrics.jmir.org/2026/1/e85376
doi:10.2196/85376
PMID:

The Feasibility of Supporting Caregivers of Young Children With Disruptive Behaviors Through Nurse-Delivered Phone Coaching: Quality Improvement Study

Hannah Mulholland[1], MSW, LICSW; Jasmine Berry[2], PhD; Tammy Schmit[3], RN; Barbara McIlrath[3], RN; Jocelyn Lebow[2], PhD

[1]Department of Social Work, Mayo Clinic, Rochester, MN, United States
[2]Department of Psychiatry and Psychology, Mayo Clinic, 200 First Street SW, Rochester, MN, United States
[3]Department of Nursing, Mayo Clinic, Rochester, MN, United States

Corresponding Author:
Jocelyn Lebow, PhD
Department of Psychiatry and Psychology, Mayo Clinic, 200 First Street SW, Rochester, MN, United States

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.

(JMIR Pediatr Parent 2026;9:e65244) doi:10.2196/65244

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 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.

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.

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).

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 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.

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.

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 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.

Acknowledgments

The Scientific Publications staff at Mayo Clinic provided copyediting support. The authors wish to acknowledge the patients and families who contributed to this work through their participation in the SAPPHIRE program.

Funding

No external financial support or grants were received from any public, commercial, or not-for-profit entities for the research, authorship, or publication of this article.

Data Availability

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

Conflicts of Interest

None declared.

References

1. Sheldrick RC, Marakovitz S, Garfinkel D, Perrin EC, Carter AS. Prevalence and co-occurrence of developmental and emotional-behavioral problems in young children. Acad Pediatr 2023 Apr;23(3):623-630. [doi: 10.1016/j.acap.2022.11.008] [Medline: 36417968]
2. Vasileva M, Graf RK, Reinelt T, Petermann U, Petermann F. Research review: a meta-analysis of the international prevalence and comorbidity of mental disorders in children between 1 and 7 years. J Child Psychol Psychiatry 2021 Apr;62(4):372-381. [doi: 10.1111/jcpp.13261] [Medline: 32433792]

3. Jeung J, Nguyen A, Martinez J, Zhang L. A primary care group resilience intervention promotes child and caregiver behavioral health. JMIR Pediatr Parent 2025 Feb 10;8(1):e67638. [doi: 10.2196/67638] [Medline: 39931025]
4. van As NMC, Janssens J. Relationships between child behavior problems and family functioning: a literature review. Int J Child Fam Welf 2002;5(1-2):40-51 [FREE Full text]
5. Bultas MW, McMillin SE, Zand DH. Reducing barriers to care in the office-based health care setting for children with autism. J Pediatr Health Care 2016;30(1):5-14. [doi: 10.1016/j.pedhc.2015.08.007] [Medline: 26455786]
6. O'Farrelly C, Watt H, Babalis D, et al. A brief home-based parenting intervention to reduce behavior problems in young children: a pragmatic randomized clinical trial. JAMA Pediatr 2021 Jun 1;175(6):567-576. [doi: 10.1001/jamapediatrics.2020.6834] [Medline: 33720329]
7. Zisser A, Eyberg SM. Parent-child interaction therapy and the treatment of disruptive behavior disorders. In: Weisz JR, Kazdin AE, editors. Evidence-Based Psychotherapies for Children and Adolescents, 2nd edition: Guilford Press; 2010:179-193 URL: https://books.google.co.in/books?id=QLzBv53CU2UC&pg=PR17&lr=&source=gbs_selected_pages&cad=1#v=onepage&q&f=false [accessed 2026-03-09]
8. Dishion TJ, Brennan LM, Shaw DS, McEachern AD, Wilson MN, Jo B. Prevention of problem behavior through annual family check-ups in early childhood: intervention effects from home to early elementary school. J Abnorm Child Psychol 2014;42(3):343-354. [doi: 10.1007/s10802-013-9768-2] [Medline: 24022677]
9. Florean IS, Dobrean A, Păsărelu CR, Georgescu RD, Milea I. The efficacy of internet-based parenting programs for children and adolescents with behavior problems: a meta-analysis of randomized clinical trials. Clin Child Fam Psychol Rev 2020 Dec;23(4):510-528. [doi: 10.1007/s10567-020-00326-0] [Medline: 32897527]
10. Young KT, Davis K, Schoen C, Parker S. Listening to parents. a national survey of parents with young children. Arch Pediatr Adolesc Med 1998 Mar;152(3):255-262. [doi: 10.1001/archpedi.152.3.255] [Medline: 9529463]
11. Chacko A, Jensen SA, Lowry LS, et al. Engagement in behavioral parent training: review of the literature and implications for practice. Clin Child Fam Psychol Rev 2016 Sep;19(3):204-215. [doi: 10.1007/s10567-016-0205-2] [Medline: 27311693]
12. DuPaul GJ, Kern L, Belk G, et al. Face-to-face versus online behavioral parent training for young children at risk for ADHD: treatment engagement and outcomes. J Clin Child Adolesc Psychol 2018;47(sup1):S369-S383. [doi: 10.1080/15374416.2017.1342544] [Medline: 28715272]
13. Weisenmuller C, Hilton D. Barriers to access, implementation, and utilization of parenting interventions: considerations for research and clinical applications. Am Psychol 2021 Jan;76(1):104-115. [doi: 10.1037/amp0000613] [Medline: 32134281]
14. Kazdin AE. Parent management training: evidence, outcomes, and issues. J Am Acad Child Adolesc Psychiatry 1997 Oct;36(10):1349-1356. [doi: 10.1097/00004583-199710000-00016] [Medline: 9334547]
15. Grindle CF, Kovshoff H, Hastings RP, Remington B. Parents' experiences of home-based applied behavior analysis programs for young children with autism. J Autism Dev Disord 2009 Jan;39(1):42-56. [doi: 10.1007/s10803-008-0597-z] [Medline: 18535893]
16. Thornton S, Calam R. Predicting intention to attend and actual attendance at a universal parent-training programme: a comparison of social cognition models. Clin Child Psychol Psychiatry 2011 Jul;16(3):365-383. [doi: 10.1177/1359104510366278] [Medline: 20876286]
17. Briggs RD, German M, Schrag Hershberg R, Cirilli C, Crawford DE, Racine AD. Integrated pediatric behavioral health: implications for training and intervention models. Prof Psychol Res Prac 2016;47(4):312-319. [doi: 10.1037/pro0000093]
18. Wissow LS, van Ginneken N, Chandna J, Rahman A. Integrating children's mental health into primary care. Pediatr Clin North Am 2016 Feb;63(1):97-113. [doi: 10.1016/j.pcl.2015.08.005] [Medline: 26613691]
19. Fanton JH, MacDonald B, Harvey EA. Preschool parent-pediatrician consultations and predictive referral patterns for problematic behaviors. J Dev Behav Pediatr 2008 Dec;29(6):475-482. [doi: 10.1097/DBP.0b013e31818d4345] [Medline: 18941427]
20. Asarnow JR, Rozenman M, Wiblin J, Zeltzer L. Integrated medical-behavioral care compared with usual primary care for child and adolescent behavioral health: a meta-analysis. JAMA Pediatr 2015 Oct;169(10):929-937. [doi: 10.1001/jamapediatrics.2015.1141] [Medline: 26259143]
21. Breitenstein SM, Fogg L, Ocampo EV, Acosta DI, Gross D. Parent use and efficacy of a self-administered, tablet-based parent training intervention: a randomized controlled trial. JMIR Mhealth Uhealth 2016 Apr 20;4(2):e36. [doi: 10.2196/mhealth.5202] [Medline: 27098111]
22. Wakida EK, Talib ZM, Akena D, et al. Barriers and facilitators to the integration of mental health services into primary health care: a systematic review. Syst Rev 2018 Nov 28;7(1):211. [doi: 10.1186/s13643-018-0882-7] [Medline: 30486900]
23. Brady KJS, Durham MP, Francoeur A, et al. Barriers and facilitators to integrating behavioral health services and pediatric primary care. Clin Pract Pediatr Psychol 2021 Dec;9(4):359-371. [doi: 10.1037/cpp0000356]
24. Kolko DJ, Pardini DA. ODD dimensions, ADHD, and callous-unemotional traits as predictors of treatment response in children with disruptive behavior disorders. J Abnorm Psychol 2010 Nov;119(4):713-725. [doi: 10.1037/a0020910] [Medline: 21090875]

25. Ristkari T, Kurki M, Suominen A, et al. Web-based parent training intervention with telephone coaching for disruptive behavior in 4-year-old children in real-world practice: implementation study. J Med Internet Res 2019 Apr 11;21(4):e11446. [doi: 10.2196/11446] [Medline: 30973337]
26. Sourander A, McGrath PJ, Ristkari T, et al. Internet-assisted parent training intervention for disruptive behavior in 4-year-old children: a randomized clinical trial. JAMA Psychiatry 2016 Apr;73(4):378-387. [doi: 10.1001/jamapsychiatry.2015.3411] [Medline: 26913614]
27. Sourander A, McGrath PJ, Ristkari T, et al. Two-year follow-up of internet and telephone assisted parent training for disruptive behavior at age 4. J Am Acad Child Adolesc Psychiatry 2018 Sep;57(9):658-668. [doi: 10.1016/j.jaac.2018.07.001] [Medline: 30196869]
28. Jones TL, Prinz RJ. Potential roles of parental self-efficacy in parent and child adjustment: a review. Clin Psychol Rev 2005 May;25(3):341-363. [doi: 10.1016/j.cpr.2004.12.004] [Medline: 15792853]
29. Lieneman CC, Brabson LA, Highlander A, Wallace NM, McNeil CB. Parent-child interaction therapy: current perspectives. Psychol Res Behav Manag 2017;10:239-256. [doi: 10.2147/PRBM.S91200] [Medline: 28790873]
30. Jellinek MS, Murphy JM, Robinson J, Feins A, Lamb S, Fenton T. Pediatric Symptom Checklist: screening school-age children for psychosocial dysfunction. J Pediatr 1988 Feb;112(2):201-209. [doi: 10.1016/s0022-3476(88)80056-8] [Medline: 3339501]
31. Murphy JM, Bergmann P, Chiang C, et al. The PSC-17: subscale scores, reliability, and factor structure in a new national sample. Pediatrics 2016 Sep;138(3):e20160038. [doi: 10.1542/peds.2016-0038] [Medline: 27519444]
32. Sheldrick RC, Henson BS, Merchant S, Neger EN, Murphy JM, Perrin EC. The Preschool Pediatric Symptom Checklist (PPSC): development and initial validation of a new social/emotional screening instrument. Acad Pediatr 2012;12(5):456-467. [doi: 10.1016/j.acap.2012.06.008] [Medline: 22921494]
33. Gilmore L, Cuskelly M. Factor structure of the Parenting Sense of Competence scale using a normative sample. Child Care Health Dev 2009 Jan;35(1):48-55. [doi: 10.1111/j.1365-2214.2008.00867.x] [Medline: 18991983]
34. Cohen J. Statistical Power Analysis for the Behavioral Sciences, 2nd edition: Lawrence Erlbaum Associates; 1988. URL: https://utstat.toronto.edu/~brunner/oldclass/378f16/readings/CohenPower.pdf [accessed 2026-03-09]
35. Granpeesheh D, Dixon DR, Tarbox J, Kaplan AM, Wilke AE. The effects of age and treatment intensity on behavioral intervention outcomes for children with autism spectrum disorders. Res Autism Spectr Disord 2009 Oct;3(4):1014-1022. [doi: 10.1016/j.rasd.2009.06.007]

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

Edited by J Zhang, M Balcarras; submitted 09.Aug.2024; peer-reviewed by T Pummanee, M Jordan; revised version received 08.Dec.2025; accepted 23.Feb.2026; published 27.Mar.2026.

Please cite as:
Mulholland H, Berry J, Schmit T, McIlrath B, Lebow J
The Feasibility of Supporting Caregivers of Young Children With Disruptive Behaviors Through Nurse-Delivered Phone Coaching: Quality Improvement Study
JMIR Pediatr Parent 2026;9:e65244
URL: https://pediatrics.jmir.org/2026/1/e65244
doi:10.2196/65244

Feasibility, Diagnostic Accuracy, and Satisfaction of an Acute Pediatric Video Interconsultation Model in Rural Primary Care in Catalonia: Prospective Observational Study

Marta Castillo-Rodenas[1,2], MD; Núria Solanas Bacardit[1], RNC; Clotilde Farràs Company[1], MD; Queralt Miró Catalina[2,3], MSc, PhD; Laia Solà Reguant[3,4], MSc; Aïna Fuster-Casanovas[5,6,7], RPh, PhD; Francesc López Seguí[8,9], PhD; Josep Vidal-Alaball[2,3,10], MD, MPH, PhD

[1]Centre d'Atenció Primària Cardona, Gerència d'Atenció Primària i a la Comunitat de la Catalunya Central, Institut Català de la Salut (ICS), Cardona, Barcelona, Spain

[10]Department of Medicine, Faculty of Medicine, University of Vic - Central University of Catalonia (UVIC-UCC), Vic, Catalonia, Spain

[2]Intelligence for Primary Care Research Group (I4PC), Fundació Institut Universitari per a la Recerca a l'Atenció Primària de Salut Jordi Gol i Gurina, Manresa, Catalonia, Spain

[3]Unitat de Recerca i Innovació Gerència d'Atenció Primària i a la Comunitat de la Catalunya Central, Institut Català de la Salut (ICS), Carrer de Soler i March, 6, CAP Bages, Manresa, Catalonia, Spain

[4]Health Promotion in Rural Areas Research Group, Fundació Institut Universitari per a la Recerca a l'Atenció Primària de Salut Jordi Gol i Gurina, Manresa, Catalonia, Spain

[5]Unitat d'Innovació, Direcció de Qualitat, Processos i Innovació, Hospital Universitari Vall d'Hebron, Barcelona, Catalonia, Spain

[6]Grup de recerca en Serveis Sanitaris, Vall d'Hebron Research Institute, Barcelona, Catalonia, Spain

[7]eHealth Lab Research Group School of Health Sciences and eHealth Centre, Universitat Oberta de Catalunya (UOC), Barcelona, Catalonia, Spain

[8]Chair in ICT and Health Centre for Health and Social Care Research, University of Vic - Central University of Catalonia (UVIC-UCC), Vic, Catalonia, Spain

[9]Centre de Recerca en Economia i Salut (CRES), Universitat Pompeu Fabra (UPF), Barcelona, Catalonia, Spain

Corresponding Author:
Josep Vidal-Alaball, MD, MPH, PhD
Intelligence for Primary Care Research Group (I4PC), Fundació Institut Universitari per a la Recerca a l'Atenció Primària de Salut Jordi Gol i Gurina, Manresa, Catalonia, Spain

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 rural areas and help reduce health care disparities. Further research is needed to support scalability and implementation in routine clinical practice.

International Registered Report Identifier (IRRID): RR2-10.2196/52946

(JMIR Pediatr Parent 2026;9:e82133) doi:10.2196/82133

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.

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

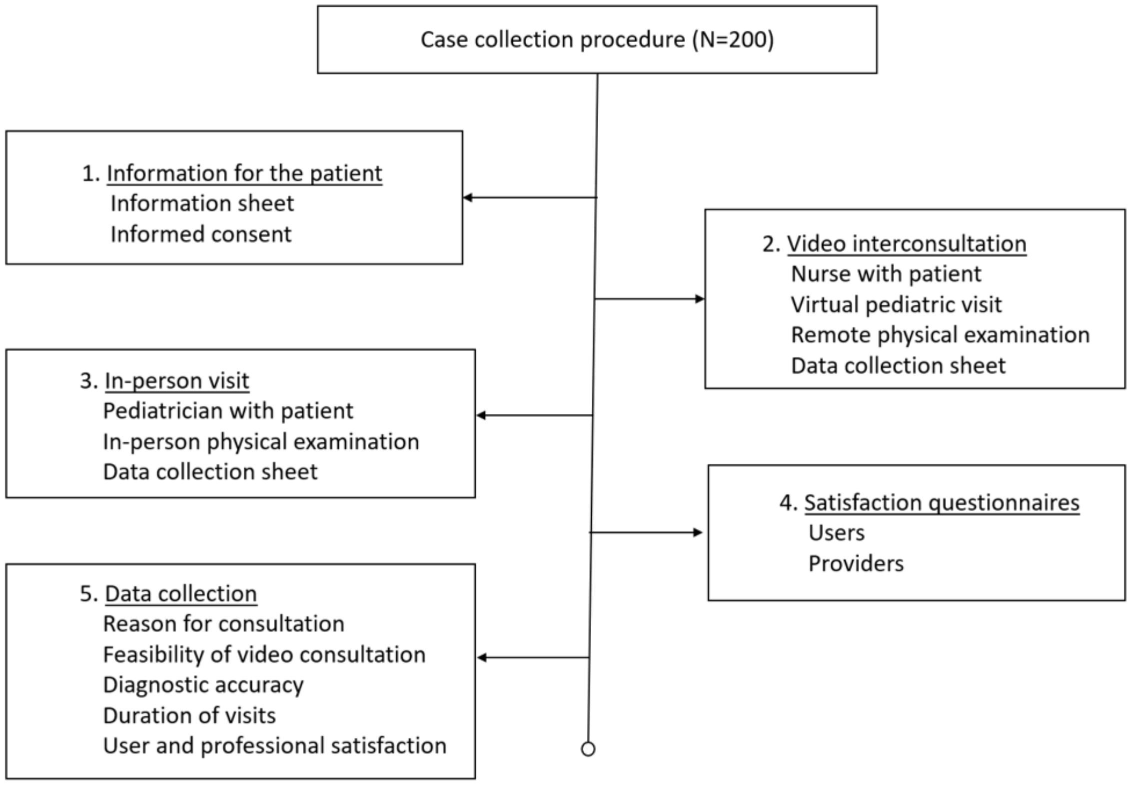
Eligibility criteria included children aged 0 to 14 years presenting with acute conditions requiring care within 48 hours. Acute illness was defined as a condition requiring medical attention within 48 hours. Parental informed consent was mandatory.

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.

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

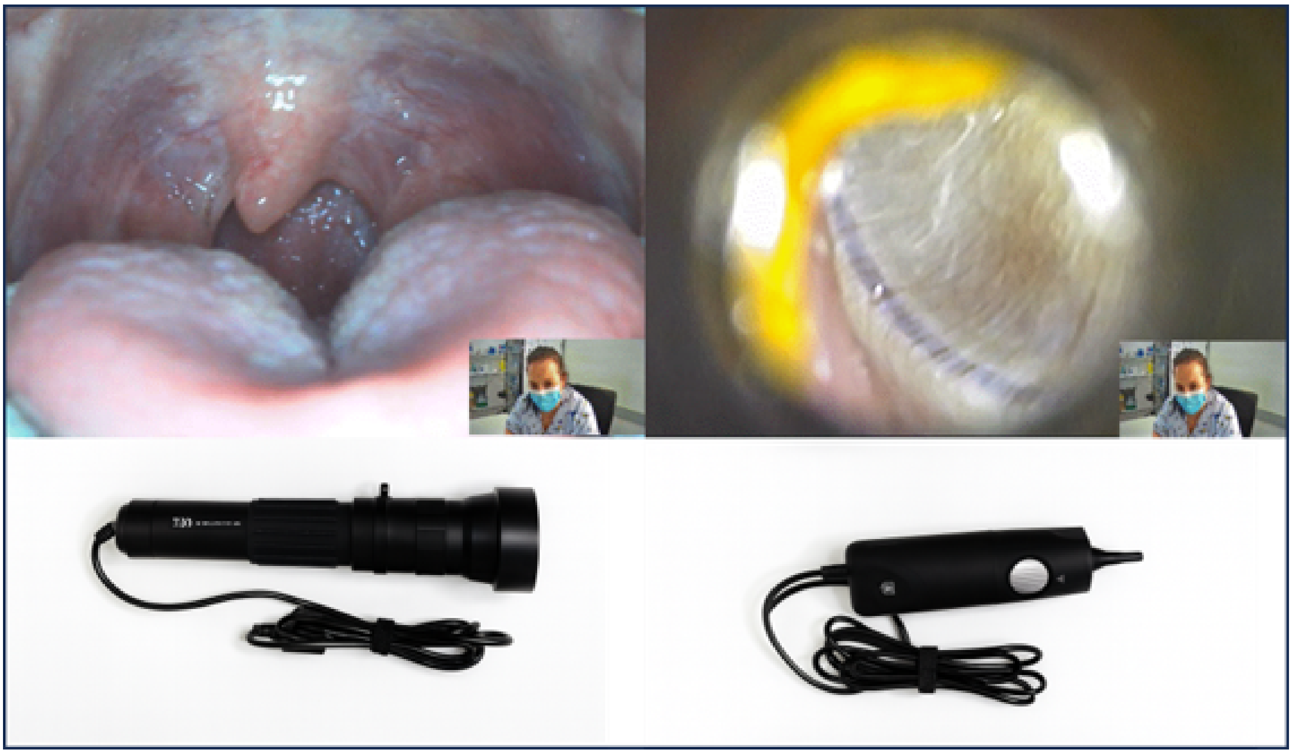
Information and Consent

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.

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

- 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.

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).

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.

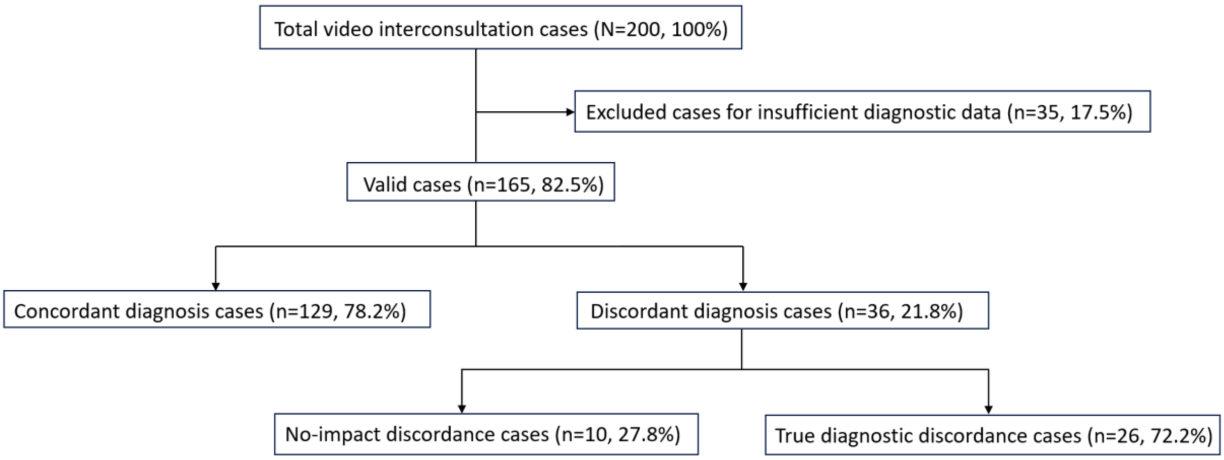
Accuracy

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).

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.

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).

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)

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 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.

Acknowledgments

This study was conducted within the PhD Program in Medicine and Biomedical Sciences at the University of Vic – Central University of Catalonia. The study also received support through a research release fellowship granted by Institut Català de la

Salut - IDIAP Jordi Gol. The authors would like to express their sincere gratitude to the patients and their families for their altruistic participation.

Funding

This study was supported by a financial grant from Consultori Bayés (Vic), which was used to fund the acquisition of the digital devices used in the project. The authors would also like to express their gratitude to Institut Català de la Salut, who kindly covered the publication fees for this article.

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]

References

1. Proposta sobre el model d'atenció pediàtrica a l'atenció primària a Catalunya. Societat Catalana de Pediatria Secció d'Atenció Primària. 2022. URL: http://www.scpediatria.cat/adjunts_mails/prop-model-At-pediatrica-AP_01-06-2022.pdf [accessed 2025-05-01]
2. Rodrigo MA, Sanz AC, Pina CS, et al. The role of pediatricians in providing greater-quality care for children: an ongoing debate. J Pediatr 2021;231:303-304. [doi: 10.1016/j.jpeds.2020.12.072] [Medline: 33373669]
3. Aparicio Rodrigo M, Ruiz Canela J, Buñuel Álvarez JC, et al. Paediatricians provide higher quality care to children and adolescents in primary care: a systematic review. Acta Paediatr 2020 Oct;109(10):1989-2007. [doi: 10.1111/apa.15324] [Medline: 32311805]
4. Dall'Oglio I, Rosati GV, Biagioli V, et al. Pediatric nurses in pediatricians' offices: a survey for primary care pediatricians. BMC Fam Pract 2021 Jun 29;22(1):136. [doi: 10.1186/s12875-021-01457-1] [Medline: 34187392]
5. Societat Catalana de Pediatria. Secció d'Atenció Primària. Pediatria d'Atenció primària en fallida. PediatresAP.cat. 2020. URL: https://pediatresap.cat/wp-content/uploads/bsk-pdf-manager/2020/10/Pediatria-dAtencio-Primaria-en-fallida.pdf [accessed 2025-05-01]
6. van Esso D, del Torso S, Hadjipanayis A, Primary-Secondary Working Group (PSWG) of European Academy of Paediatrics (EAP), et al. Paediatric primary care in Europe: variation between countries. Arch Dis Child 2010 Oct;95(10):791-795. [doi: 10.1136/adc.2009.178459] [Medline: 20403821]
7. Neumeier S. Pediatric care proximity in Germany: a comparative study of regional accessibility. KN J Cartogr Geogr Inf 2024 Dec;74(3-4):185-204. [doi: 10.1007/s42489-024-00175-9]
8. Bettenhausen JL, Winterer CM, Colvin JD. Health and poverty of rural children: an under-researched and under-resourced vulnerable population. Acad Pediatr 2021;21(8S):S126-S133. [doi: 10.1016/j.acap.2021.08.001] [Medline: 34740419]
9. Saigí-Rubió F, Vidal-Alaball J, Torrent-Sellens J, et al. Determinants of Catalan public primary care professionals' intention to use digital clinical consultations (eConsulta) in the post-COVID-19 context: optical illusion or permanent transformation? J Med Internet Res 2021 May 31;23(6):e28944. [doi: 10.2196/28944] [Medline: 34097638]
10. Jiménez-Rodríguez D, Santillán García A, Montoro Robles J, Rodríguez Salvador MDM, Muñoz Ronda FJ, Arrogante O. Increase in video consultations during the COVID-19 pandemic: healthcare professionals' perceptions about their implementation and adequate management. Int J Environ Res Public Health 2020 Jul 15;17(14):5112. [doi: 10.3390/ijerph17145112] [Medline: 32679848]
11. Firefly telemedicine. Firefly Global. 2025. URL: https://fireflyglobal.com/ [accessed 2025-12-24]

12. TytoCare for professionals: advanced telemedicine solutions. TytoCare. 2025. URL: https://www.tytocare.com/ [accessed 2025-12-24]
13. Higo: a small medical device and telemedical solution. Higo sense. 2025. URL: https://higosense.com/ [accessed 2025-12-24]
14. Vidal-Alaball J, Descals Singla E. Abordaje de la telemedicina entre proveedores: ejemplos de uso. Atenc Prim Práct 2021 Dec;3(1):100112. [doi: 10.1016/j.appr.2021.100112]
15. Castillo-Rodenas M, Vidal-Alaball J, Solanas-Bacardit N, et al. Feasibility of a pediatric acute video consultation process among health care professionals in primary care in a rural setting: protocol for a prospective validation study. JMIR Res Protoc 2024 Feb 1;13:e52946. [doi: 10.2196/52946] [Medline: 38300693]
16. von Elm E, Altman DG, Egger M, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. J Clin Epidemiol 2008 Apr;61(4):344-349. [doi: 10.1016/j.jclinepi.2007.11.008] [Medline: 18313558]
17. Bossuyt PM, Reitsma JB, Bruns DE, et al. STARD 2015: an updated list of essential items for reporting diagnostic accuracy studies. BMJ 2015 Oct 28;351:h5527. [doi: 10.1136/bmj.h5527] [Medline: 26511519]
18. Eysenbach G, CONSORT-EHEALTH Group. CONSORT-EHEALTH: improving and standardizing evaluation reports of web-based and mobile health interventions. J Med Internet Res 2011 Dec 31;13(4):e126. [doi: 10.2196/jmir.1923] [Medline: 22209829]
19. Marrugat J. Calculadora de grandària mostral GRANMO. DATARUS – Applications for Biomedical Research. 2022. URL: https://www.datarus.eu/aplicaciones/granmo/ [accessed 2025-07-29]
20. Vidal-Alaball J, Flores Mateo G, Garcia Domingo JL, et al. Validation of a short questionnaire to assess healthcare professionals' perceptions of asynchronous telemedicine services: the Catalan version of the health optimum telemedicine acceptance qestionnaire. Int J Environ Res Public Health 2020 Mar 25;17(7):2202. [doi: 10.3390/ijerph17072202] [Medline: 32218310]
21. Telehealth satisfaction questionnaire (TSQ). Agency for Healthcare Research and Quality. URL: https://digital.ahrq.gov/sites/default/files/docs/survey/telehealthsatisfactionquestionnaire_comp.pdf [accessed 2025-07-28]
22. Casey SD, Huang J, Parry DD, Lieu TA, Reed ME. Health care utilization with telemedicine and in-person visits in pediatric primary care. JAMA Health Forum 2024 Nov 1;5(11):e244156. [doi: 10.1001/jamahealthforum.2024.4156] [Medline: 39576615]
23. Southgate G, Yassaee AA, Harmer MJ, Livesey H, Pryde K, Roland D. Use of telemedicine in pediatric services for 4 representative clinical conditions: scoping review. J Med Internet Res 2022 Oct 26;24(10):e38267. [doi: 10.2196/38267] [Medline: 36287609]
24. Pathak PR, Stockwell MS, Lane MM, et al. Access to primary care telemedicine and visit characterization in a pediatric, low-income, primarily Latino population: retrospective study. JMIR Pediatr Parent 2024 Dec 17;7:e57702. [doi: 10.2196/57702] [Medline: 39689903]
25. Wagner R, Lima TC, Silva MD, et al. Assessment of pediatric telemedicine using remote physical examinations with a mobile medical device: a nonrandomized controlled trial. JAMA Netw Open 2023 Feb 1;6(2):e2252570. [doi: 10.1001/jamanetworkopen.2022.52570] [Medline: 36729459]
26. Gao Y, Magin P, Tapley A, et al. Prevalence of antibiotic prescribing for aute respiratory tract infection in telehealth versus face-to-face consultations: cross-sectional analysis of general practice registrars' clinical practice. J Med Internet Res 2025 Mar 13;27:e60831. [doi: 10.2196/60831] [Medline: 40080812]
27. Bittmann S, Moschüring-Alieva E, Bittmann L, Luchter E, Villalon G. Preliminary results of a telemedicine questionnaire in pediatrics as an innovative new tool to diagnose and treat children virtually in an ambulatory setting: analysis of 400 pediatric consultations. J Regen Biol Med 2021;3(6):1-3. [doi: 10.37191/Mapsci-2582-385X-3(6)-098]
28. García Ron A, Arias Vivas E, Martínez del Río C, et al. Usefulness of telemedicine in urgent pediatric care during the COVID-19 pandemic [article in Spanish]. Rev Pediatr Aten Primaria 2022;24(93):23-29 [FREE Full text]
29. Mukusheva Z, Assylbekova M, Poddighe D. Management of pediatric rheumatic patients in Kazakhstan during the coronavirus disease 2019 (COVID-19) pandemic. Rheumatol Int 2020 Aug;40(8):1351-1352. [doi: 10.1007/s00296-020-04613-5] [Medline: 32514608]
30. Moltó-Puigmartí C, Segur-Ferrer J, Berdún Peñato J, et al. Evaluación de la seguridad, eficacia/efectividad y eficiencia de la teleconsulta en atención primaria, y de los aspectos organizativos, éticos, sociales y legales ligados a su uso. Scientia. 2022. URL: https://scientiasalut.gencat.cat/handle/11351/7977?show=full [accessed 2025-02-12]
31. Kodjebacheva GD, Culinski T, Kawser B, Coffer K. Satisfaction with telehealth services compared with nontelehealth services among pediatric patients and their caregivers: systematic review of the literature. JMIR Pediatr Parent 2023 Apr 27;6:e41554 [FREE Full text] [doi: 10.2196/41554] [Medline: 37000504]
32. Carta de drets i deures de la ciutadania en relació amb la salut i l'atenció sanitària. Departament de salut. 2015. URL: https://scientiasalut.gencat.cat/handle/11351/1840 [accessed 2025-05-28]
33. Martín-Masot R, Diaz-Martin JJ, Santamaría-Orleans A, Navas-López VM. Impact of the COVID-19 pandemic on the digitization of routine pediatric practice in Spain: a nationwide survey study. Front Pediatr 2023;11:1106488. [doi: 10.3389/fped.2023.1106488] [Medline: 36865698]

34. Navarro-Martínez O, Martinez-Millana A, Traver V. Use of tele-nursing in primary care: a qualitative study on its negative and positive aspects. Aten Primaria 2024 May;56(5):102843. [doi: 10.1016/j.aprim.2023.102843] [Medline: 38215687]
35. Vidal-Alaball J, López Seguí F, Garcia Domingo JL, et al. Primary care professionals' acceptance of medical record-based, store and forward provider-to-provider telemedicine in Catalonia: results of a web-based survey. Int J Environ Res Public Health 2020 Jun 8;17(11):4092. [doi: 10.3390/ijerph17114092] [Medline: 32521740]
36. Inoue Y, Kishi T, Sato T, et al. Telemedicine for paediatric rheumatic diseases in Japan: a national survey of physicians' perspectives. Mod Rheumatol 2025 Dec 22;36(1):83-89. [doi: 10.1093/mr/roaf075] [Medline: 40794858]
37. Finkelstein JB, Tremblay ES, Van Cain M, et al. Pediatric clinicians' use of telemedicine: qualitative interview study. JMIR Hum Factors 2021 Dec 2;8(4):e29941. [doi: 10.2196/29941] [Medline: 34860669]
38. Zafra RP, Parramon NA, Albiol-Perarnau M, Torres OY. Análisis de retos y dilemas que deberá afrontar la bioética del siglo XXI, en la era de la salud digital. Atención Primaria 2024 Jul;56(7):102901. [doi: 10.1016/j.aprim.2024.102901]
39. Telemedicina: com i quan utilitzar-la en la pràctica assistencial quaderns de la bona praxi. Issuu.: Col·legi de Metges de Barcelona URL: https://issuu.com/comb/docs/bona_praxi_37_telemedicina [accessed 2025-05-14]

Abbreviations

CONSORT: Consolidated Standards of Reporting Trials
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

Edited by S Badawy; submitted 09.Aug.2025; peer-reviewed by D Poddighe, M Lemonde; revised version received 22.Nov.2025; accepted 27.Nov.2025; published 26.Jan.2026.

Please cite as:
Castillo-Rodenas M, Solanas Bacardit N, Farràs Company C, Miró Catalina Q, Solà Reguant L, Fuster-Casanovas A, López Seguí F, Vidal-Alaball J
Feasibility, Diagnostic Accuracy, and Satisfaction of an Acute Pediatric Video Interconsultation Model in Rural Primary Care in Catalonia: Prospective Observational Study
JMIR Pediatr Parent 2026;9:e82133
URL: https://pediatrics.jmir.org/2026/1/e82133
doi:10.2196/82133

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

Anna Joy Russ[1], MS; Anna Bullo[1], PhD; Peter J Schulz[1,2,3], PhD

[1]Faculty of Communication, Culture and Society, Università della Svizzera Italiana, Lugano, Switzerland
[2]Wee Kim Wee School of Communication and Information, Nanyang Technological University, Singapore, Singapore
[3]Department of Communication & Media, Ewha Womans University, Seoul, Republic of Korea

Corresponding Author:
Peter J Schulz, PhD
Faculty of Communication, Culture and Society
Università della Svizzera Italiana
Via Buffi, 13
Lugano, 6900
Switzerland
Phone: 41 58 666 40 00
Email: peter.schulz@usi.ch

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.

(JMIR Pediatr Parent 2026;9:e81959) doi:10.2196/81959

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 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 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.

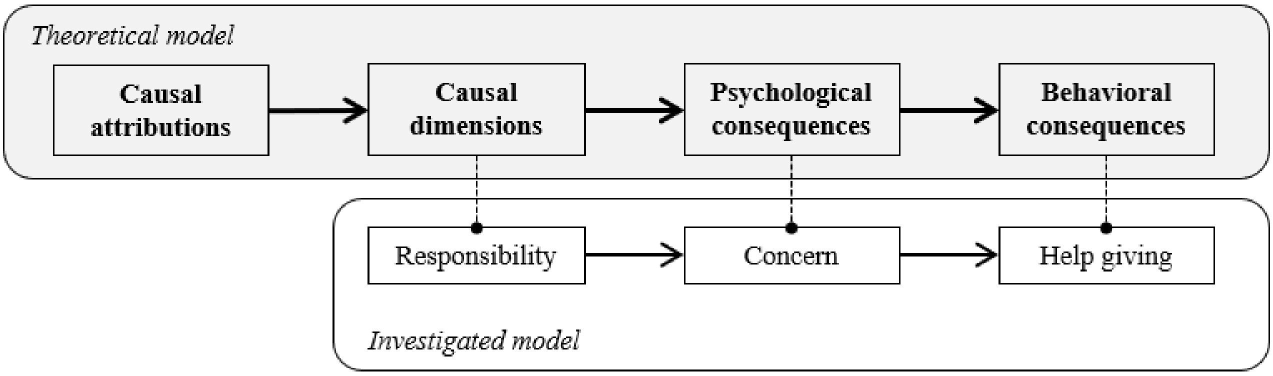
Attribution Theory

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 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.

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.

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.

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.

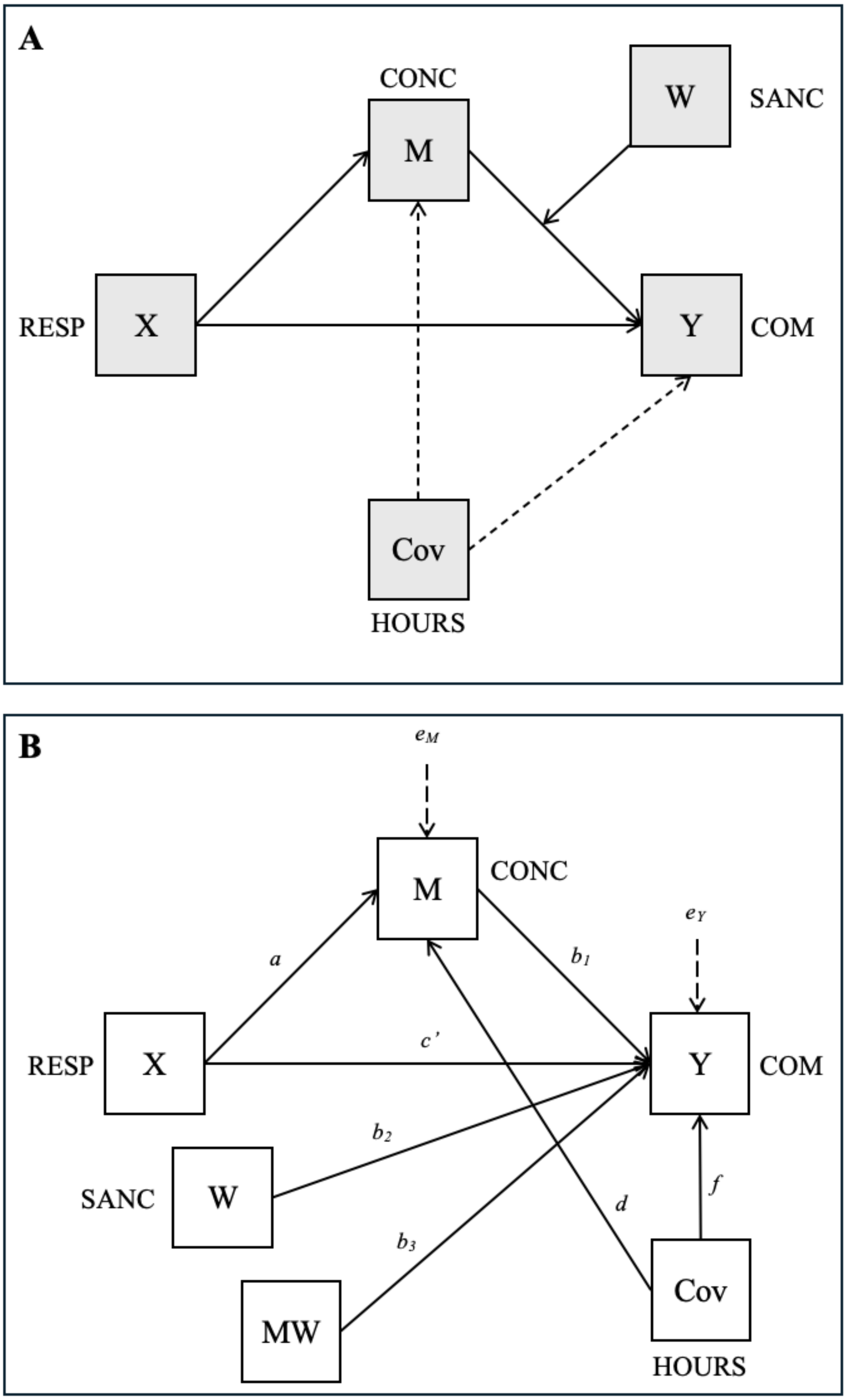


Table 2. Model coefficients for the moderated mediation model.

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.

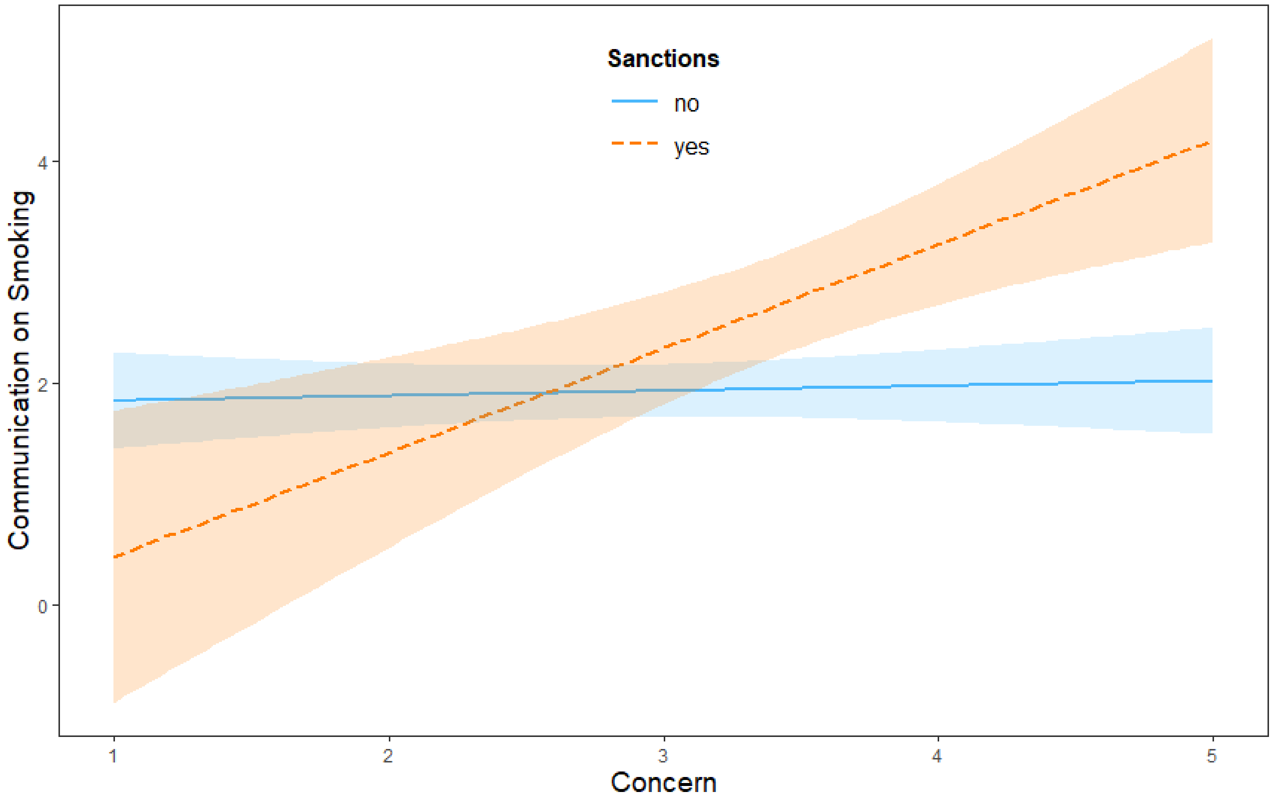
[l] M × W: interaction effect.

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).

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 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 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.

Funding

The work of PJS was supported by the Ministry of Education of the Republic of Korea and the National Research Foundation of Korea under grand number NRF-2020S1A3A2A02095619.

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]

References

1. Heider F. The Psychology of Interpersonal Relations. New York, NY: Psychology Press; 1958.
2. Turner L, Mermelstein R, Flay B. Individual and contextual influences on adolescent smoking. Ann N Y Acad Sci 2004;1021(1):175-197. [doi: 10.1196/annals.1308.023] [Medline: 15251888]
3. Carrión-Valero F, Ribera-Osca JA, Martín-Moreno JM. Adolescent health and parents' and teachers' beliefs about smoking: a cross-sectional study. Children (Basel) 2024 Sep 19;11(9):1135 [FREE Full text] [doi: 10.3390/children11091135] [Medline: 39334667]
4. Huang HW, Lu CC, Yang YH, Huang CL. Smoking behaviours of adolescents, influenced by smoking of teachers, family and friends. Int Nurs Rev 2014;61(2):220-227. [doi: 10.1111/inr.12084] [Medline: 24571366]
5. Nurmansyah MI, Umniyatun Y, Jannah M, Syiroj ATR, Purnama TB, Koire II. Peer, family and teachers' role on smoking behaviour among islamic high school students in depok, indonesia. Vulnerable Children and Youth Studies 2021;16(2):189-194. [doi: 10.1080/17450128.2020.1861398]
6. Lakon CM, Hipp JR, Timberlake DS. The social context of adolescent smoking: A systems perspective. Am J Public Health 2010;100(7):1218-1228. [doi: 10.2105/ajph.2009.167973]
7. Thomas RE, McLellan J, Perera R. School‐based programmes for preventing smoking. Evid Based Child Health 2013;8(5):1616-2040. [doi: 10.1002/ebch.1937]
8. Clarke JH, MacPherson B, Holmes DR, Jones R. Reducing adolescent smoking: A comparison of peer-led, teacher-led, and expert interventions. J Sch Health 1986;56(3):102-106. [doi: 10.1111/j.1746-1561.1986.tb05707.x] [Medline: 3634129]
9. Graham S. A review of attribution theory in achievement contexts. Educ Psychol Rev 1991;3(1):5-39. [doi: 10.1007/bf01323661]

10. Graham S. An attributional theory of motivation. Contemp Educ Psychol 2020;61:101861. [doi: 10.1016/j.cedpsych.2020.101861]
11. Waldeck J, Labelle S. Theoretical and methodological approaches to instructional communication. In: Communication and Learning. Vol 16. Handbook of Communication Science. Berlin, Germany: de Gruyter Mouton; 2016.
12. Duncan LR, Pearson ES, Maddison R. Smoking prevention in children and adolescents: a systematic review of individualized interventions. Patient Educ Couns 2018 Mar;101(3):375-388. [doi: 10.1016/j.pec.2017.09.011] [Medline: 28987451]
13. Thomas RE, McLellan J, Perera R. Effectiveness of school-based smoking prevention curricula: systematic review and meta-analysis. BMJ Open 2015 Mar 10;5(3):e006976 [FREE Full text] [doi: 10.1136/bmjopen-2014-006976] [Medline: 25757946]
14. Titsworth S, Mazer J. Teacher clarity: An analysis of current research and future directions. In: Communication and Learning. Vol 16. Handbook of Communication Science. Berlin, Germany: de Gruyter Mouton; 2016.
15. Yeo SC, Tan J, Lo JC, Chee MWL, Gooley JJ. Associations of time spent on homework or studying with nocturnal sleep behavior and depression symptoms in adolescents from Singapore. Sleep Health 2020 Dec;6(6):758-766 [FREE Full text] [doi: 10.1016/j.sleh.2020.04.011] [Medline: 32536472]
16. Kim SM, Lee SK, Chang J, Son JS, Kim KH, Park SM. Family structure, adolescent mental health, and the role of advisors in the cultural and social context of South Korea. Sci Rep 2026 Jan 02;16(1):1613 [FREE Full text] [doi: 10.1038/s41598-025-30983-6] [Medline: 41484148]
17. Voisin DR, Salazar LF, Crosby R, Diclemente RJ, Yarber WL, Staples-Horne M. Teacher connectedness and health-related outcomes among detained adolescents. J Adolesc Health 2005 Oct;37(4):337. [doi: 10.1016/j.jadohealth.2004.11.137] [Medline: 16182147]
18. Frymier A. Students' motivation to learn. In: Communication and Learning. Vol 16. Handbook of Communication Science. Berlin, Germany: de Gruyter Mouton; 2016.
19. Mesman M, Hendriks H, Onrust S, Van den Putte B. The effects of teacher communication during a health intervention on older adolescents' predictors of health behaviour. EJHC 2022;3(3):143-163. [doi: 10.47368/ejhc.2022.307]
20. Arafa A, Yasui Y, Kokubo Y, Kato Y, Matsumoto C, Teramoto M, et al. Lifestyle behaviors of childhood and adolescence: contributing factors, health consequences, and potential interventions. Am J Lifestyle Med 2024 Apr 12:15598276241245941. [doi: 10.1177/15598276241245941] [Medline: 39554934]
21. Froeliger B, Modlin LA, Kozink RV, Wang L, Garland EL, Addicott MA, et al. Frontoparietal attentional network activation differs between smokers and nonsmokers during affective cognition. Psychiatry Res 2013 Jan 30;211(1):57-63 [FREE Full text] [doi: 10.1016/j.pscychresns.2012.05.002] [Medline: 23154092]
22. Goriounova NA, Mansvelder HD. Short- and long-term consequences of nicotine exposure during adolescence for prefrontal cortex neuronal network function. Cold Spring Harb Perspect Med 2012 Dec 01;2(12):a012120-a012120 [FREE Full text] [doi: 10.1101/cshperspect.a012120] [Medline: 22983224]
23. Swan GE, Lessov-Schlaggar CN. The effects of tobacco smoke and nicotine on cognition and the brain. Neuropsychol Rev 2007 Sep;17(3):259-273. [doi: 10.1007/s11065-007-9035-9] [Medline: 17690985]
24. Beutel MW, Harmon TC, Novotny TE, Mock J, Gilmore ME, Hart SC, et al. A review of environmental pollution from the use and disposal of cigarettes and electronic cigarettes: contaminants, sources, and impacts. Sustainability 2021 Nov 24;13(23):12994. [doi: 10.3390/su132312994]
25. Liu M, Liu X, Song Y, Hu Y, Yang C, Li J, et al. Tobacco production under global climate change: combined effects of heat and drought stress and coping strategies. Front Plant Sci 2024;15:1489993 [FREE Full text] [doi: 10.3389/fpls.2024.1489993] [Medline: 39670262]
26. Valiente R, Escobar F, Urtasun M, Franco M, Shortt NK, Sureda X. Tobacco retail environment and smoking: a systematic review of geographic exposure measures and implications for future studies. Nicotine Tob Res 2021 Aug 04;23(8):1263-1273 [FREE Full text] [doi: 10.1093/ntr/ntaa223] [Medline: 33155040]
27. Mayhew KP, Flay BR, Mott JA. Stages in the development of adolescent smoking. Drug Alcohol Depend 2000 May 01;59 Suppl 1(1):S61-S81. [doi: 10.1016/s0376-8716(99)00165-9] [Medline: 10773438]
28. Charrier L, van DS, Canale N. A Focus on Adolescent Substance Use in Europe, Central Asia and Canada. Health Behaviour in School-Aged Children International Report from the 2021/2022 Survey: Volume 3. Copenhagen, Denmark: World Health Organization Regional Office for Europe; 2024.
29. Finkelstein DM, Kubzansky LD, Goodman E. Social status, stress, and adolescent smoking. J Adolesc Health 2006 Nov;39(5):678-685. [doi: 10.1016/j.jadohealth.2006.04.011] [Medline: 17046504]
30. Gunther AC, Bolt D, Borzekowski DLG, Liebhart JL, Dillard JP. Presumed influence on peer norms: How mass media indirectly affect adolescent smoking. J Commun 2006;56(1):52-68. [doi: 10.1111/j.1460-2466.2006.00002.x]
31. Hertel AW, Mermelstein RJ. Smoker identity development among adolescents who smoke. Psychol Addict Behav 2016 Jun;30(4):475-483 [FREE Full text] [doi: 10.1037/adb0000171] [Medline: 27136374]
32. Joffer J, Burell G, Bergström E, Stenlund H, Sjörs L, Jerdén L. Predictors of smoking among Swedish adolescents. BMC Public Health 2014 Dec 17;14:1296 [FREE Full text] [doi: 10.1186/1471-2458-14-1296] [Medline: 25518992]
33. Jaworska N, MacQueen G. Adolescence as a unique developmental period. J Psychiatry Neurosci 2015 Sep;40(5):291-293 [FREE Full text] [doi: 10.1503/jpn.150268] [Medline: 26290063]

34. Weiner B. Reflections on the history of attribution theory and research. Social Psychology 2008 Jan;39(3):151-156. [doi: 10.1027/1864-9335.39.3.151]
35. Weiner B. Intrapersonal and interpersonal theories of motivation from an attributional perspective. Educational Psychology Review 2000 Mar;12(1):1-14. [doi: 10.1023/a:1009017532121]
36. Gaier SE. Understanding why students do what they do: Using attribution theory to help students succeed academically. Research and Teaching in Developmental Education. 2015. URL: http://www.jstor.org/stable/45373106 [accessed 2026-03-10]
37. Stoycheva V, Weinberger J, Singer E. The place of the normative unconscious in psychoanalytic theory and practice. Psychoanalytic Psychology 2014 Jan;31(1):100-118. [doi: 10.1037/a0035372]
38. Wang H, Hall NC. A systematic review of teachers' causal attributions: prevalence, correlates, and consequences. Front Psychol 2018;9:2305 [FREE Full text] [doi: 10.3389/fpsyg.2018.02305] [Medline: 30618897]
39. Weiner B. An Attributional Theory of Motivation and Emotion. New York, NY: Springer US; 1986.
40. Mora Pinzon M, Hills O, Levy G, James TT, Benitez A, Lawrence S, et al. Implementation of a social media strategy for public health promotion in Black, American Indian or Alaska Native, and Hispanic or Latino communities during the COVID-19 pandemic: cross-sectional study. J Med Internet Res 2024 Dec 10;26:e58581 [FREE Full text] [doi: 10.2196/58581] [Medline: 39657164]
41. Niederdeppe J, Shapiro MA, Porticella N. Attributions of responsibility for obesity: Narrative communication reduces reactive counterarguing among liberals. Human Communication Research 2011;37(3):295-323. [doi: 10.1111/j.1468-2958.2011.01409.x]
42. Fiske ST. Social Cognition: Selected Works of Susan Fiske. London, UK: Routledge; 2018.
43. Miller A. Teachers' attributions of causality, control and responsibility in respect of difficult pupil behaviour and its successful management. Educational Psychology 1995 Jan;15(4):457-471. [doi: 10.1080/0144341950150408]
44. Kelley HH. The processes of causal attribution. American Psychologist 1973 Feb;28(2):107-128. [doi: 10.1037/h0034225]
45. Kearney P, Plax TG, Burroughs NF. An attributional analysis of college students' resistance decisions. Communication Education 1991 Oct;40(4):325-342. [doi: 10.1080/03634529109378858]
46. Kelsey DM, Kearney P, Plax TG, Allen TH, Ritter KJ. College students' attributions of teacher misbehaviors. Communication Education 2004 Jan;53(1):40-55. [doi: 10.1080/0363452032000135760]
47. Wiley AL, Tankersley M, Simms A. Teachers' causal attributions for student problem behavior: implications for school-based behavioral interventions and research. In: Cook BG, Tankersley M, Landrum TJ, editors. Classroom Behavior, Contexts, and Interventions. England: Emerald Group Publishing Limited; 2012:279-300.
48. Burnett S, Bird G, Moll J, Frith C, Blakemore SJ. Development during adolescence of the neural processing of social emotion. J Cogn Neurosci 2009 Sep;21(9):1736-1750 [FREE Full text] [doi: 10.1162/jocn.2009.21121] [Medline: 18823226]
49. Gilam G, Hendler T. With love, from me to you: Embedding social interactions in affective neuroscience. Neurosci Biobehav Rev 2016 Sep;68:590-601. [doi: 10.1016/j.neubiorev.2016.06.027] [Medline: 27339690]
50. Jeng A, Bosch N, Perry M. Sense of belonging predicts perceived helpfulness in online peer help-giving interactions. The Internet and Higher Education 2023 Apr;57:100901. [doi: 10.1016/j.iheduc.2022.100901]
51. Roberts LJ, Salem D, Rappaport J, Toro PA, Luke DA, Seidman E. Giving and receiving help: interpersonal transactions in mutual-help meetings and psychosocial adjustment of members. Am J Community Psychol 1999 Dec;27(6):841-868. [doi: 10.1023/a:1022214710054] [Medline: 10723537]
52. Zwingmann J, Baile WF, Schmier JW, Bernhard J, Keller M. Effects of patient-centered communication on anxiety, negative affect, and trust in the physician in delivering a cancer diagnosis: a randomized, experimental study. Cancer 2017 Aug 15;123(16):3167-3175 [FREE Full text] [doi: 10.1002/cncr.30694] [Medline: 28378366]
53. Khan A, Khan S, Zia-Ul-Islam S, Khan M. Communication skills of a teacher and its role in the development of the students. JEP. URL: https://www.iiste.org/Journals/index.php/JEP/article/view/35059/36057 [accessed 2026-03-10]
54. Blind MT, Starkey N, Bird A, McMillan H. xploring the acceptability, appropriateness, and utility of a digital single-session intervention (Project SOLVE-NZ) for adolescent mental health in New Zealand: interview study among students and teachers. JMIR Form Res 2026 Jan 13;10:e81259 [FREE Full text] [doi: 10.2196/81259] [Medline: 41528797]
55. Hunt S, Simonds C, Cooper P. Communication and teacher education: exploring a communication course for all teachers. Communication Education 2002 Jan;51(1):81-94. [doi: 10.1080/03634520216497]
56. Repubblica e Cantone Ticino. Annuario Statistico Ticinese. 2024. URL: https://www3.ti.ch/DFE/DR/USTAT/allegati/volume/ast_2024.pdf [accessed 2025-06-20]
57. Crespi BM. Scuola media: Idee e lavori in corso: 5: Docente di classe: Riflessioni e approfondimenti proposti dagli istituti scolastici. edudoc. 2011. URL: https://edudoc.ch/record/93540 [accessed 2025-06-05]
58. Faul F, Erdfelder E, Buchner A, Lang AG. Statistical power analyses using G*Power 3.1: tests for correlation and regression analyses. Behav Res Methods 2009 Nov;41(4):1149-1160. [doi: 10.3758/BRM.41.4.1149] [Medline: 19897823]
59. Hayes AF. Introduction to Mediation, Moderation, and Conditional Process Analysis: A Regression‐Based Approach. New York, NY: Guilford Press; Aug 28, 2014:335-337.
60. Long JA. Interactions: comprehensive, user-friendly toolkit for probing interactions. CRAN.R-Project. URL: https://cran.r-project.org/web/packages/interactions/index.html [accessed 2026-03-25]

61. VanderWeele TJ. Mediation Analysis: A Practitioner's Guide. Annu Rev Public Health 2016;37:17-32. [doi: 10.1146/annurev-publhealth-032315-021402] [Medline: 26653405]
62. Woltran F. Insights into teachers’ perceptions of parental involvement as a predictor of educational inequity. Education 3-13 2023 Oct 02;53(8):1285-1298. [doi: 10.1080/03004279.2023.2265392]
63. Repubblica e Cantone Ticino. Programma D'azione Cantonale? Prevenzione Alcol, Tabacco e Prodotti Affini. 2020. URL: https://www4.ti.ch/fileadmin/DSS/DSP/SPVS/SPVS_PAC_Alcol_tabacco_2021-2024.pdf [accessed 2025-05-24]
64. Bullo-Carrara A, Cafaro T, Filipponi C. Adolescenti, Regole e Salute: Studio Longitudinale Sulle Norme e i Comportamenti a Rischio Tra Gli Allievi in Ticino. Lugano, Switzerland: Università della Svizzera Italiana; 2017.
65. Ufficio Federale Della Sanità Pubblica. Educazione Sessuale. 2024. URL: https://www.sbfi.admin.ch/it/educazione-sessuale [accessed 2025-08-06]
66. Krendl AC, Heatherton TF. Social emotions: imaging social emotions. In: Reference Module in Neuroscience and Biobehavioral Psychology. Amsterdam, Netherlands: Elsevier; 2017:35-39.
67. Pfau M, Bockern SV, Kang JG. Use of inoculation to promote resistance to smoking initiation among adolescents. Communication Monographs 2009 Jun 02;59(3):213-230. [doi: 10.1080/03637759209376266]
68. The influence of environment. The Science of Adolescent Risk-Taking: Workshop Report. Washington, DC: National Academies Press; 2011. URL: https://www.ncbi.nlm.nih.gov/books/NBK53409/ [accessed 2025-06-05]
69. Wang. Social perspectives on student learning. In: Communication and Learning. Vol 16. Handbook of Communication Science. Berlin, Germany: de Gruyter Mouton; 2016.
70. Wanous JP, Reichers AE, Hudy MJ. Overall job satisfaction: how good are single-item measures? J Appl Psychol 1997 Apr;82(2):247-252. [doi: 10.1037/0021-9010.82.2.247] [Medline: 9109282]

Abbreviations

HP: hypotheses
RQ: research question

Edited by S Badawy; submitted 06.Aug.2025; peer-reviewed by D Dinh, J Du; comments to author 04.Nov.2025; revised version received 28.Jan.2026; accepted 12.Feb.2026; published 17.Apr.2026.

Please cite as:
Russ AJ, Bullo A, Schulz PJ
Motivational Drivers for Teachers as Informal Health Educators to Initiate In-Class Discussions With Adolescents About Smoking: Moderated Mediation Study Using Attribution Theory
JMIR Pediatr Parent 2026;9:e81959
URL: https://pediatrics.jmir.org/2026/1/e81959
doi:10.2196/81959
PMID:35913051

Predicting Infant Sleep Patterns From Postpartum Maternal Mental Health Measures: Machine Learning Approach

Rawan AlSaad[1], PhD; Raghad Burjaq[2], PhD; Majid AlAbdulla[3,4], MD; Alaa Abd-alrazaq[1], PhD; Javaid Sheikh[1], MD; Rajat Thomas[1], PhD

[1]Weill Cornell Medical College in Qatar, 2700 Education City, Doha, Qatar
[2]Women's Wellness and Research Center, Hamad Medical Corporation, Doha, Qatar
[3]Mental Health Services, Hamad Medical Corporation, Doha, Qatar
[4]College of Medicine, Qatar University, Doha, Qatar

Corresponding Author:
Rawan AlSaad, PhD
Weill Cornell Medical College in Qatar, 2700 Education City, Doha, Qatar

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.

(JMIR Pediatr Parent 2026;9:e78937) doi:10.2196/78937

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].

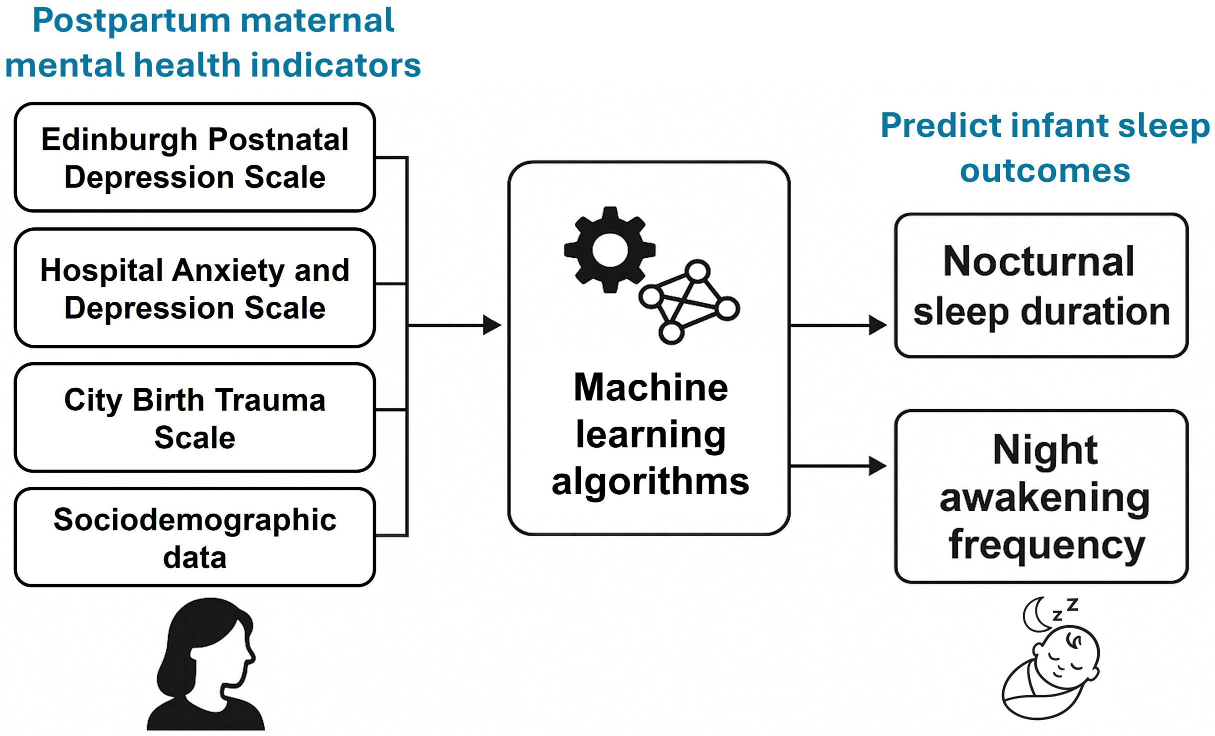
A growing body of research [6-12] has demonstrated that maternal mental health (MMH) symptoms during the postpartum period, including depression [13,14], anxiety [8,15], and childbirth-related post-traumatic stress disorder (CB-PTSD) [16,17], are associated with alterations in infant sleep architecture. However, the underlying mechanisms through which these maternal conditions influence infant sleep remain 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.

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 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 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.

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.

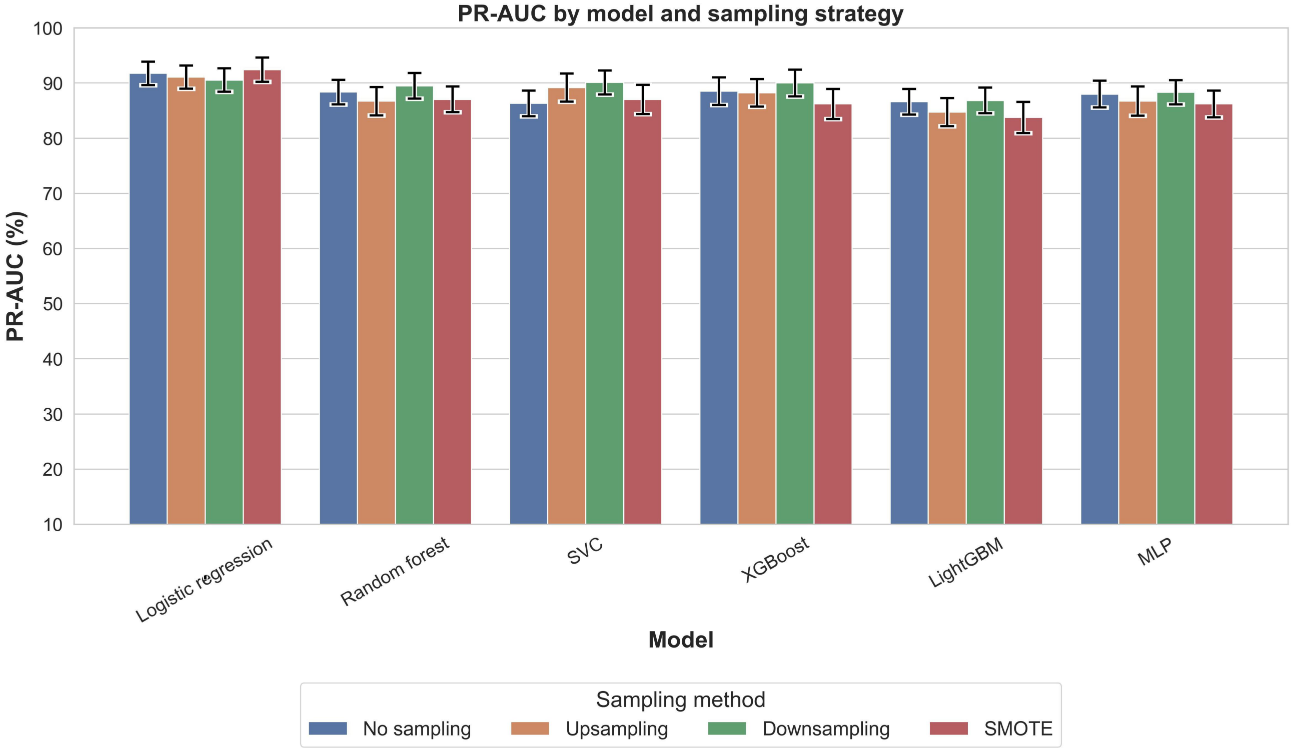


Figure 3. Comparison of accuracy across models and sampling methods for outcome nocturnal sleep duration. Accuracy represents the overall proportion of correct predictions, combining both positive and negative cases, and provides a broad measure of model correctness. LightGBM: light gradient boosting machine; MLP: multilayer perceptron; SMOTE: synthetic minority oversampling technique; SVC: support vector classifier; XGBoost: extreme gradient boosting.

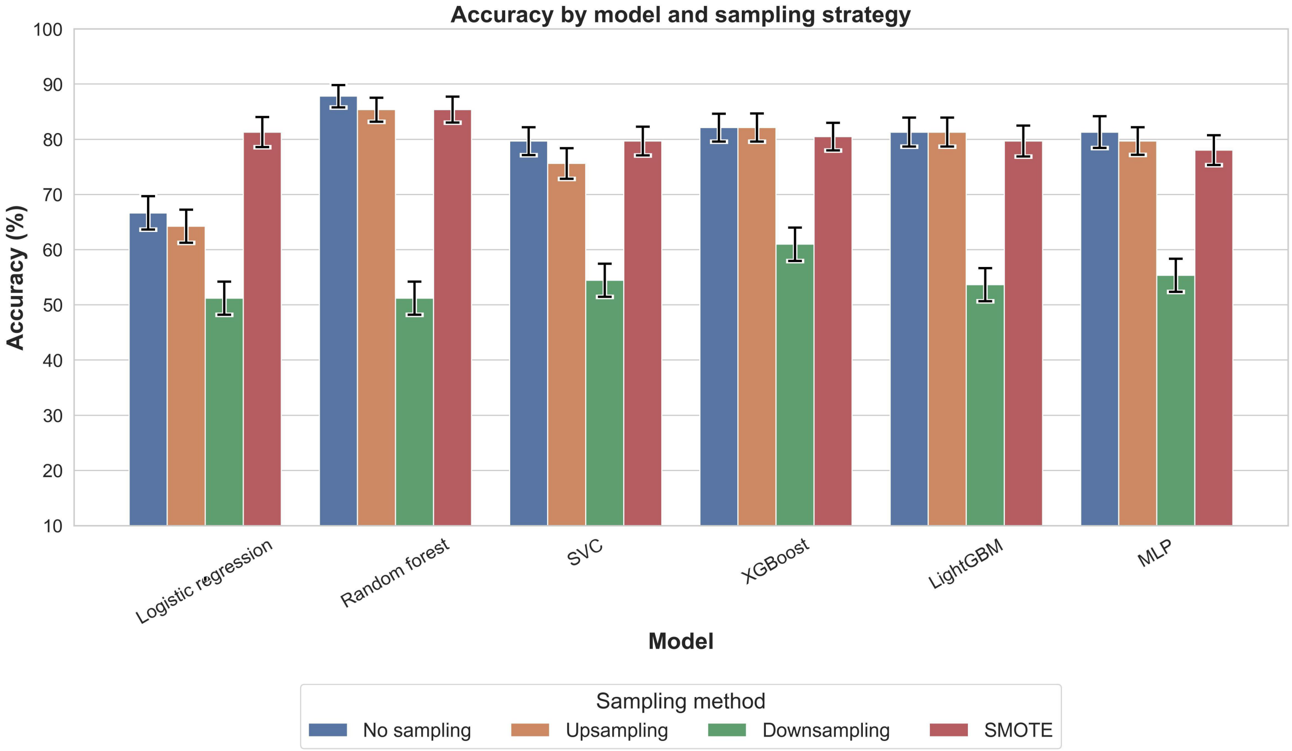
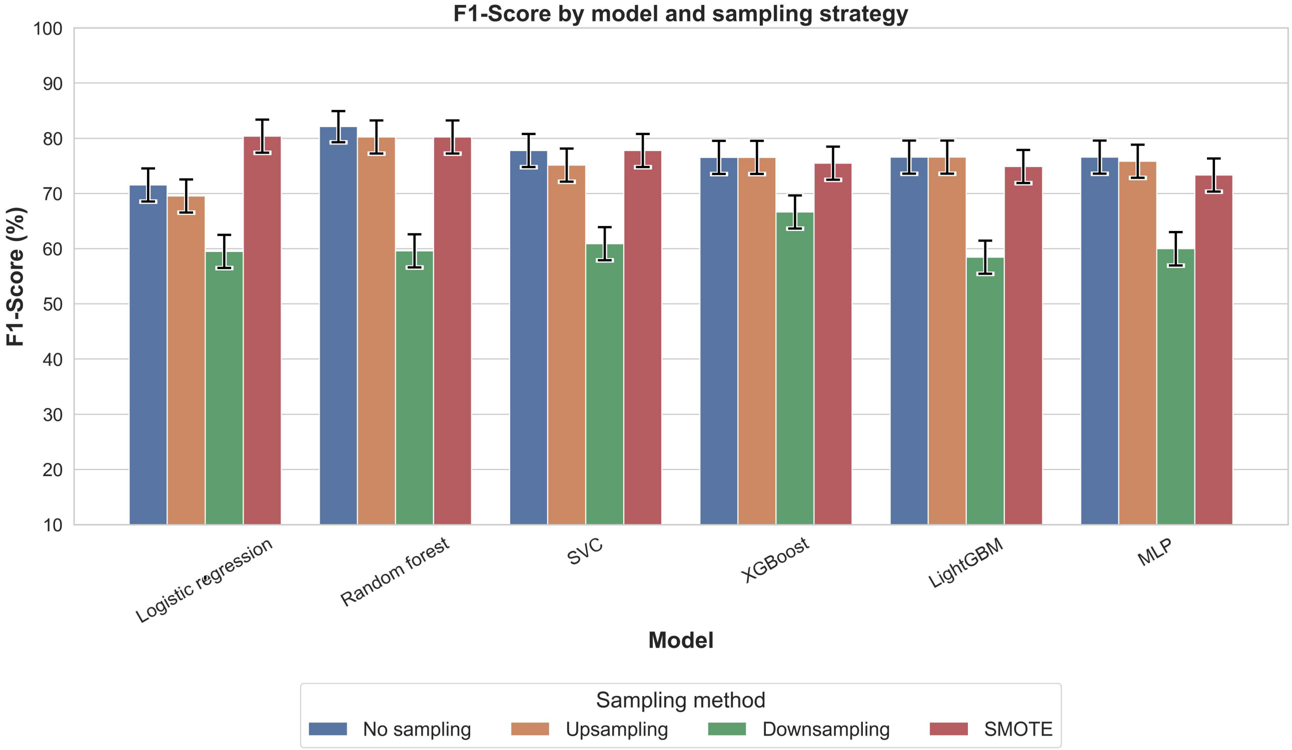


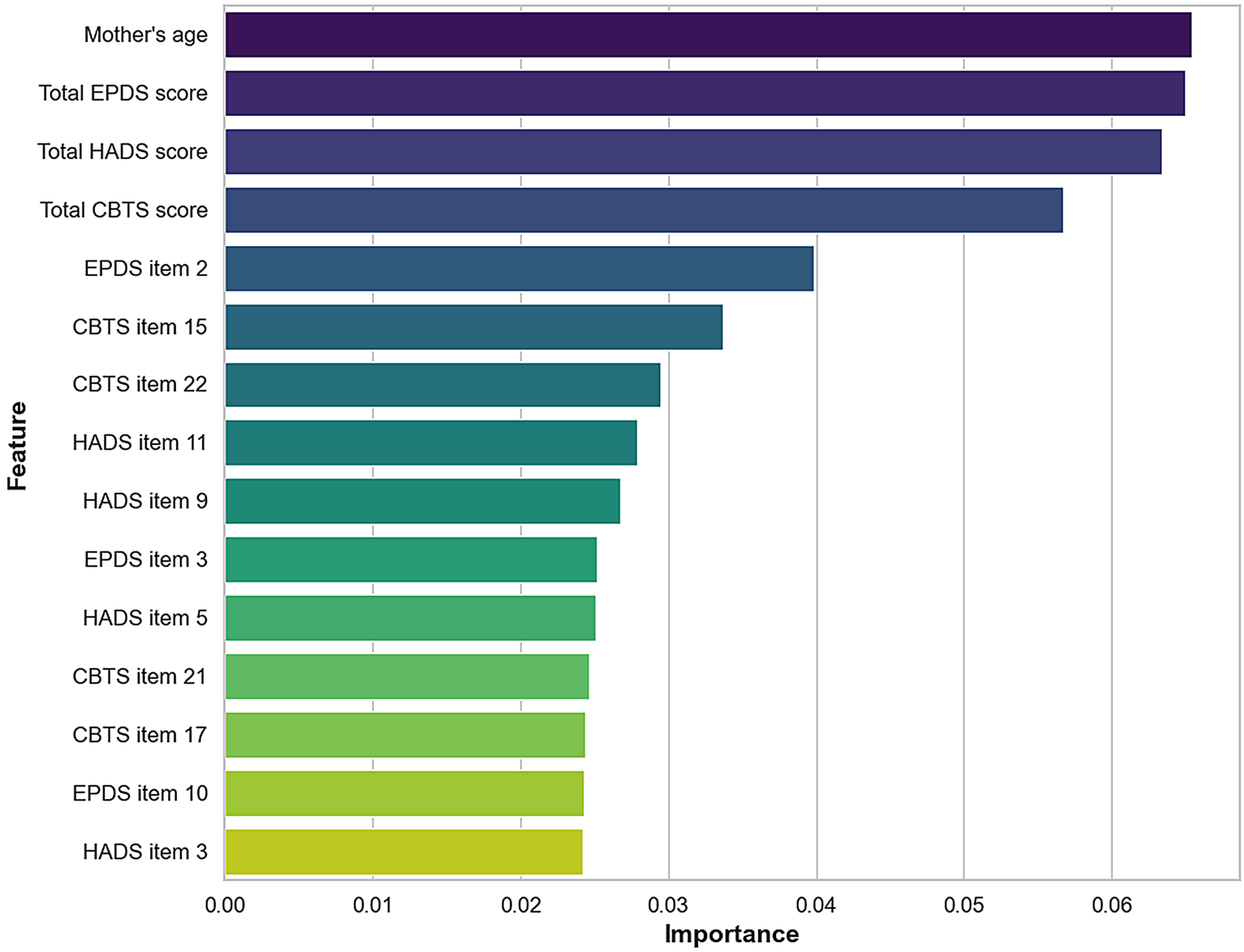
Figure 4. Comparison of F_1-score across models and sampling methods for outcome nocturnal sleep duration. The F_1-score balances precision and recall, making it a valuable metric for assessing model performance in the context of imbalanced datasets. LightGBM: light gradient boosting machine; MLP: multilayer 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.

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.

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.

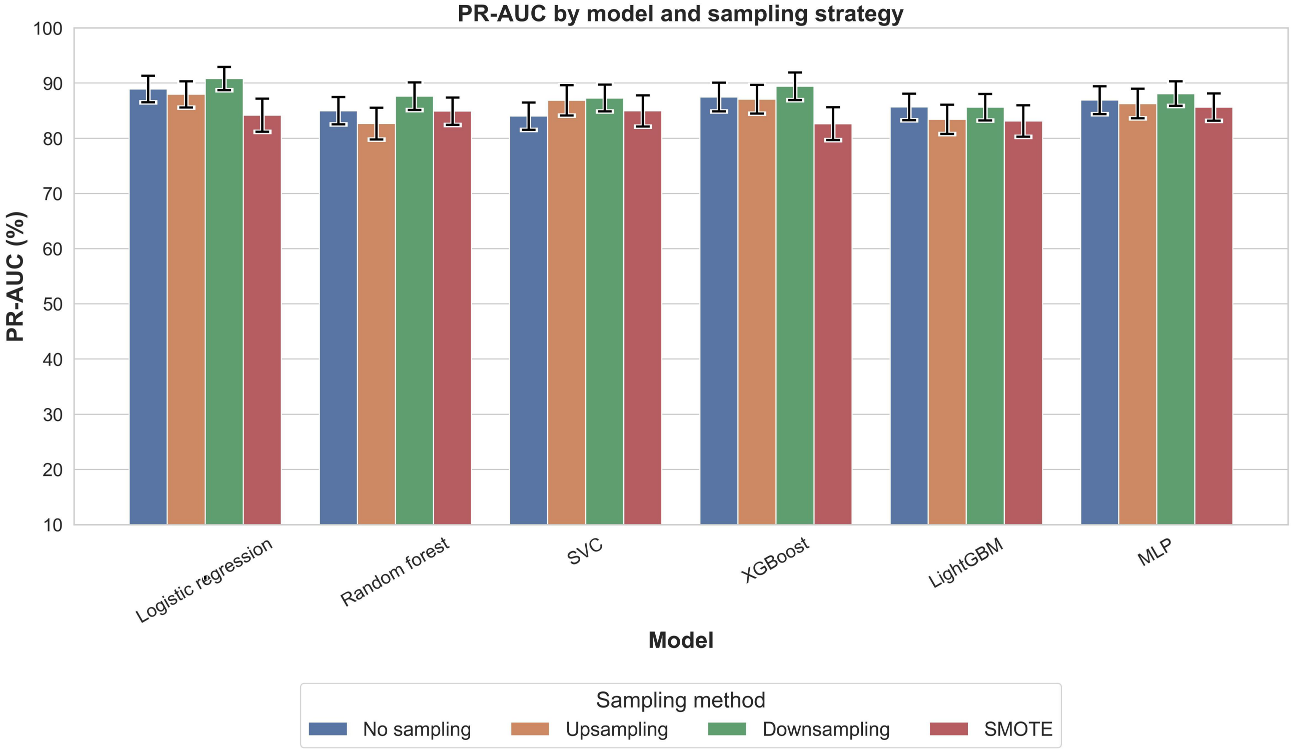


Figure 7. Comparison of accuracy across models and sampling methods for outcome night awakenings frequency. LightGBM: light gradient boosting machine; MLP: multilayer perceptron; SMOTE: synthetic minority oversampling technique; SVC: support vector classifier; XGBoost: extreme gradient boosting.

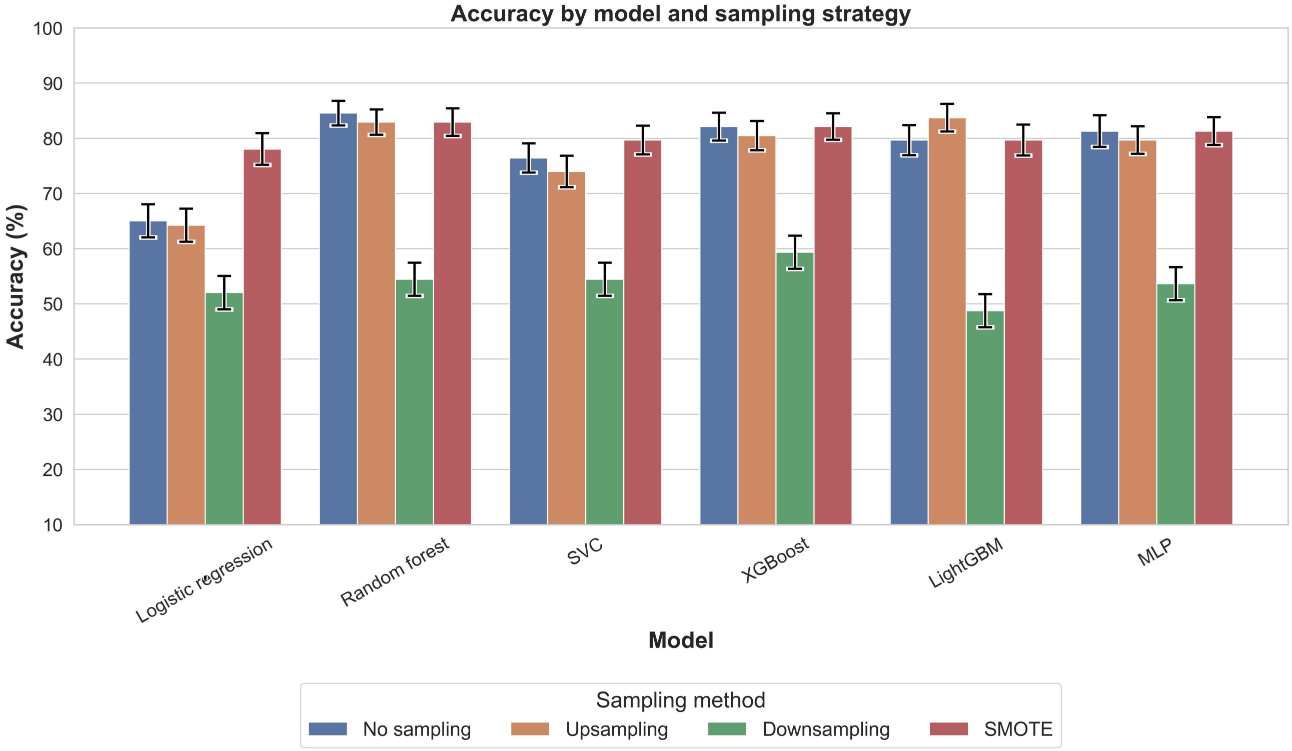
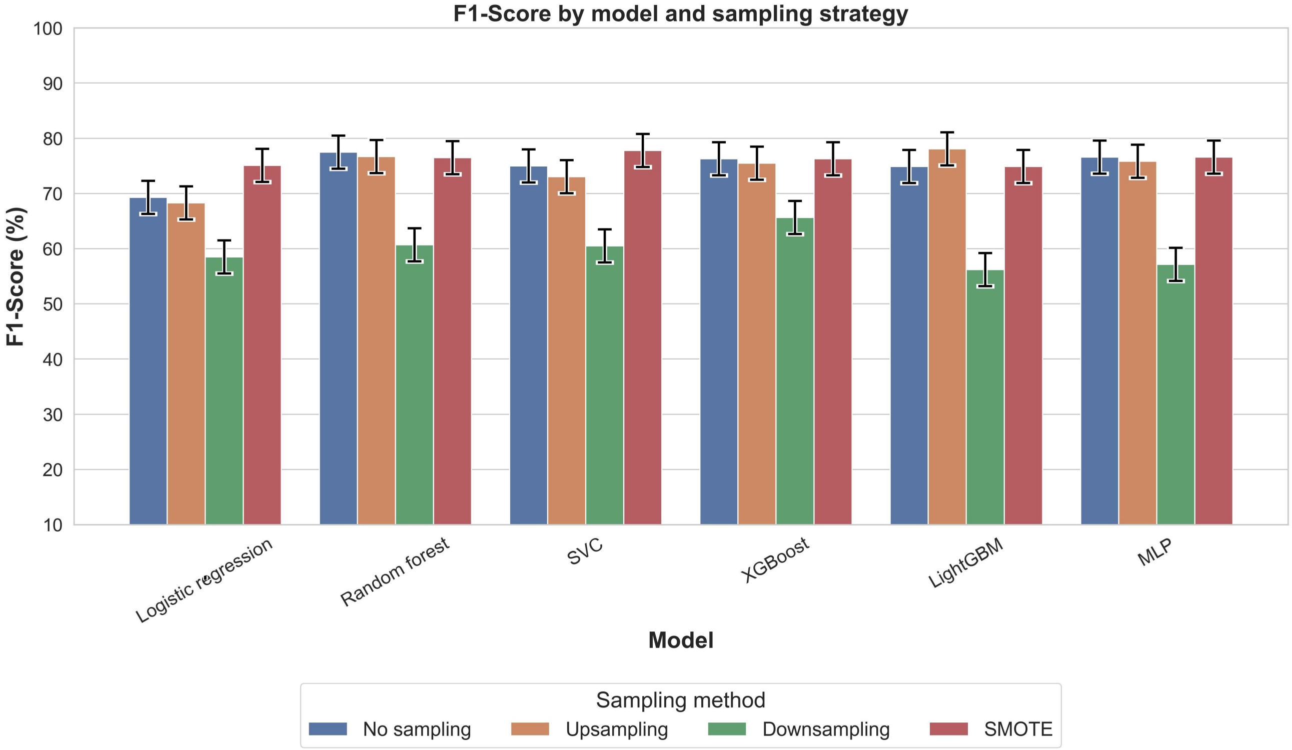


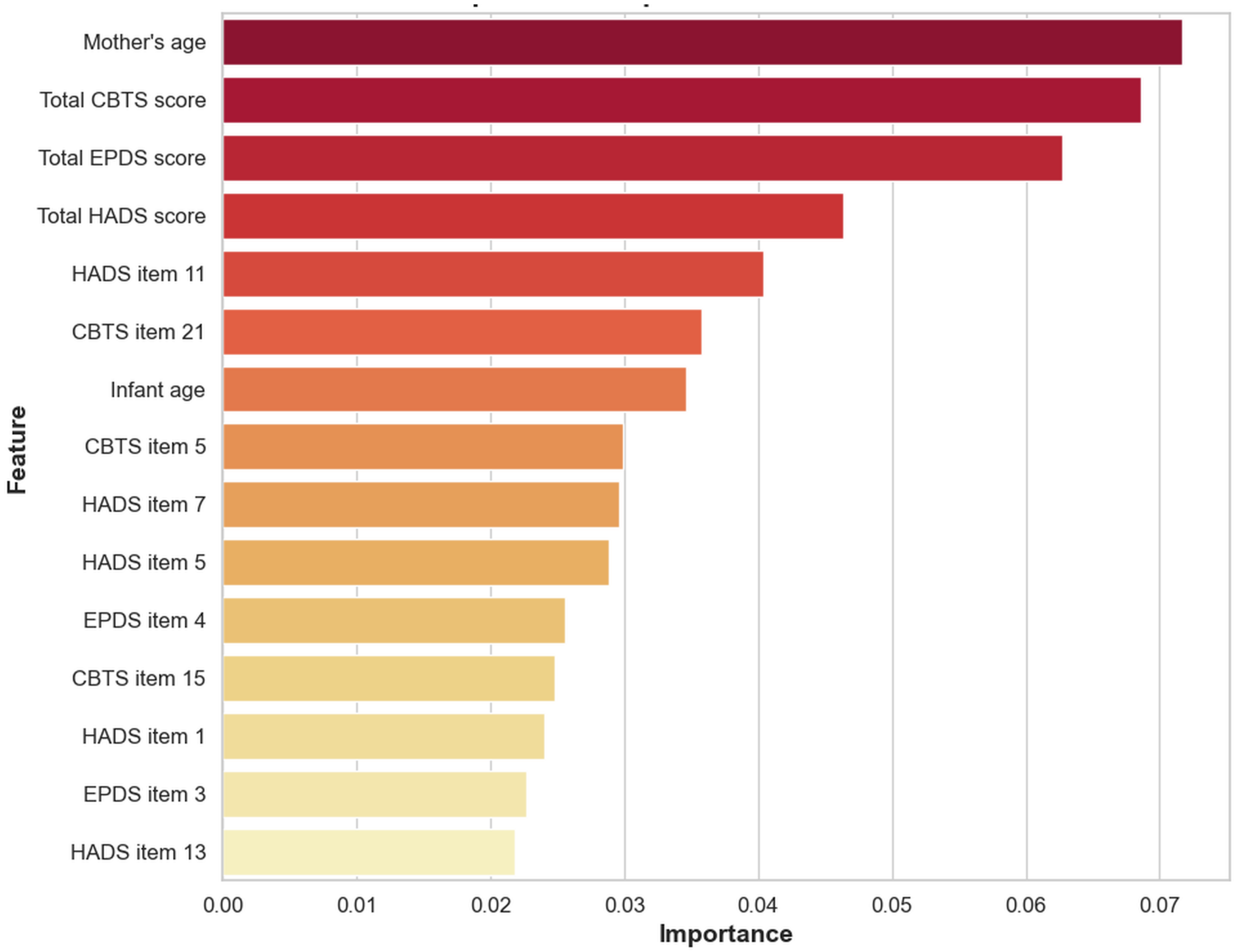
Figure 8. Comparison of F_1-score across models and sampling methods for outcome night awakenings frequency. LightGBM: light gradient boosting machine; MLP: multilayer perceptron; SMOTE: synthetic minority oversampling technique; SVC: support vector classifier; XGBoost: extreme gradient boosting.



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.

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.

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 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]

References

1. Finkel MA, Duong N, Hernandez A, et al. Associations of infant sleep characteristics with childhood cognitive outcomes. J Dev Behav Pediatr 2024;45(6):e560-e568. [doi: 10.1097/DBP.0000000000001311] [Medline: 39140879]
2. Butler B, Burdayron R, Mazor Goder G, et al. The association between infant sleep, cognitive, and psychomotor development: a systematic review. Sleep 2024 Nov 8;47(11):zsae174. [doi: 10.1093/sleep/zsae174] [Medline: 39158050]
3. Andrade Correia LT, Coimbra DG, Gitaí DLG, Gitaí LLG, de Andrade TG. Associations between chronotype, sleep quality, maternal mental health, and child development in mother-infant dyads. Sleep Med 2023 Jun;106:90-96. [doi: 10.1016/j.sleep.2023.03.023] [Medline: 37075531]
4. Liang X, Zhang X, Wang Y, van IJzendoorn MH, Wang Z. Sleep problems and infant motor and cognitive development across the first two years of life: the Beijing longitudinal study. Infant Behav Dev 2022 Feb;66:101686. [doi: 10.1016/j.infbeh.2021.101686] [Medline: 35007866]
5. Hernandez-Reif M, Gungordu N. Infant sleep behaviors relate to their later cognitive and language abilities and morning cortisol stress hormone levels. Infant Behav Dev 2022 May;67:101700. [doi: 10.1016/j.infbeh.2022.101700] [Medline: 35158217]
6. Cai S, Phua DY, Tham EKH, et al. Mid-pregnancy and postpartum maternal mental health and infant sleep in the first year of life. J Sleep Res 2023 Jun;32(3):e13804. [doi: 10.1111/jsr.13804] [Medline: 36511597]

7. Mazandarani AA, Zare Bahramadbadi M. Maternal self-efficacy as a moderator in the relationship between infant/toddler sleep and maternal mental health. Behav Sleep Med 2025;23(4):515-525. [doi: 10.1080/15402002.2025.2483961] [Medline: 40125868]
8. Mathiasen S, Parsons CE, Fusaroli R, Paavonen EJ, Karlsson H, Karlsson L. Maternal depression and anxiety symptoms across pregnancy and the postnatal period: modest associations between depression symptoms and infant sleep outcomes. Sleep Med 2023 Dec;112:291-300. [doi: 10.1016/j.sleep.2023.10.006] [Medline: 37950940]
9. AlSaad R, Alabdulla M, Tabassum A, Sheikh J, Thomas R. From mother to infant: predicting infant temperament using maternal mental health measures and tabular machine learning models. Front Public Health 2025;13:1659987. [doi: 10.3389/fpubh.2025.1659987] [Medline: 41048269]
10. Škodová Z, Kelčíková S, Maskálová E, Mazúchová L. Infant sleep and temperament characteristics in association with maternal postpartum depression. Midwifery 2022 Feb;105:103232. [doi: 10.1016/j.midw.2021.103232] [Medline: 34971869]
11. Sandoz V, Horsch A. Dataset of the distinct influence of different maternal mental health symptom profiles on infant sleep during the first year postpartum: a cross-sectional survey. Zenodo. 2021. URL: https://zenodo.org/records/5070945 [accessed 2026-01-14]
12. Sandoz V, Lacroix A, Stuijfzand S, Bickle Graz M, Horsch A. Maternal mental health symptom profiles and infant sleep: a cross-sectional survey. Diagnostics (Basel) 2022 Jul 4;12(7):1625. [doi: 10.3390/diagnostics12071625] [Medline: 35885530]
13. Dias CC, Figueiredo B. Mother’s prenatal and postpartum depression symptoms and infant’s sleep problems at 6 months. Infant Ment Health J 2020 Sep;41(5):614-627. [doi: 10.1002/imhj.21869] [Medline: 32589320]
14. Rudzik AEF, Robinson-Smith L, Tugwell F, Ball HL. Relationships between postpartum depression, sleep, and infant feeding in the early postpartum: an exploratory analysis. Front Psychiatry 2023;14:1133386. [doi: 10.3389/fpsyt.2023.1133386] [Medline: 37032920]
15. Wang S, Cai Z, Gao G, Yan S. Correlation between maternal anxiety during mid-pregnancy and subsequent infant sleep issues: a cross-sectional study from 2015 to 2016. Int J Gen Med 2024;17:623-633. [doi: 10.2147/IJGM.S445604] [Medline: 38410242]
16. Sorondo BM, Reeb-Sutherland BC. Associations between infant temperament, maternal stress, and infants’ sleep across the first year of life. Infant Behav Dev 2015 May;39:131-135. [doi: 10.1016/j.infbeh.2015.02.010] [Medline: 25837288]
17. Dagla M, Dagla C, Mrvoljak-Theodoropoulou I, Kavakou AT, Rigoutsou E, Antoniou E. Infant sleep difficulties at the 6th week and the 12th month postpartum: what is their relationship with maternal mental health and other perinatal factors? Mater Sociomed 2021 Mar;33(1):21-25. [doi: 10.5455/msm.2021.33.21-25] [Medline: 34012345]
18. Lin X, Zhai R, Mo J, Sun J, Chen P, Huang Y. How do maternal emotion and sleep conditions affect infant sleep: a prospective cohort study. BMC Pregnancy Childbirth 2022 Mar 23;22(1):237. [doi: 10.1186/s12884-022-04504-6] [Medline: 35321658]
19. AlSaad R, Youssef A, Kashani S, et al. Multimodal large language models for women’s reproductive mental health. Arch Womens Ment Health 2025 Dec;28(6):1369-1384. [doi: 10.1007/s00737-025-01633-7] [Medline: 41148324]
20. Wang X, de Groot ER, Tataranno ML, et al. Machine learning-derived active sleep as an early predictor of white matter development in preterm infants. J Neurosci 2024 Jan 31;44(5):e1024232023. [doi: 10.1523/JNEUROSCI.1024-23.2023] [Medline: 38124010]
21. Werth J, Radha M, Andriessen P, Aarts RM, Long X. Deep learning approach for ECG-based automatic sleep state classification in preterm infants. Biomed Signal Process Control 2020 Feb;56:101663. [doi: 10.1016/j.bspc.2019.101663]
22. Sentner T, Wang X, de Groot ER, et al. The Sleep Well Baby project: an automated real-time sleep-wake state prediction algorithm in preterm infants. Sleep 2022 Oct 10;45(10):zsac143. [doi: 10.1093/sleep/zsac143] [Medline: 35749799]
23. Chang KC, Hasegawa-Johnson M, McElwain NL, Islam B. Classification of infant sleep/wake states: cross-attention among large scale pretrained transformer networks using audio, ECG, and IMU data. Presented at: 2023 Asia Pacific Signal and Information Processing Association Annual Summit and Conference (APSIPA ASC); Oct 31 to Nov 3, 2023. [doi: 10.1109/APSIPAASC58517.2023.10317201]
24. Huang X, Huang M. Classification and recognition of infant sleeping positions based on dual model feature fusion. 2024 Jul 19 Presented at: AIAHPC ’24: Proceedings of the 2024 4th International Conference on Artificial Intelligence, Automation and High Performance Computing; Jul 19-21, 2024; Zhuhai, China p. 57-63 URL: https://dl.acm.org/doi/proceedings/10.1145/3690931 [doi: 10.1145/3690931.3690941]
25. Cox JL, Holden JM, Sagovsky R. Detection of postnatal depression. Development of the 10-item Edinburgh Postnatal Depression Scale. Br J Psychiatry 1987 Jun;150:782-786. [doi: 10.1192/bjp.150.6.782] [Medline: 3651732]
26. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand 1983 Jun;67(6):361-370. [doi: 10.1111/j.1600-0447.1983.tb09716.x] [Medline: 6880820]
27. Ayers S, Wright DB, Thornton A. Development of a measure of postpartum PTSD: the City Birth Trauma Scale. Front Psychiatry 2018;9:409. [doi: 10.3389/fpsyt.2018.00409] [Medline: 30279664]
28. Sadeh A. A brief screening questionnaire for infant sleep problems: validation and findings for an Internet sample. Pediatrics 2004 Jun;113(6):e570-e577. [doi: 10.1542/peds.113.6.e570] [Medline: 15173539]

29. Galland BC, Taylor BJ, Elder DE, Herbison P. Normal sleep patterns in infants and children: a systematic review of observational studies. Sleep Med Rev 2012 Jun;16(3):213-222. [doi: 10.1016/j.smrv.2011.06.001] [Medline: 21784676]
30. Sadeh A, Mindell JA, Luedtke K, Wiegand B. Sleep and sleep ecology in the first 3 years: a web-based study. J Sleep Res 2009 Mar;18(1):60-73. [doi: 10.1111/j.1365-2869.2008.00699.x] [Medline: 19021850]
31. Teti DM, Crosby B. Maternal depressive symptoms, dysfunctional cognitions, and infant night waking: the role of maternal nighttime behavior. Child Dev 2012;83(3):939-953. [doi: 10.1111/j.1467-8624.2012.01760.x] [Medline: 22506917]
32. Tikotzky L. Postpartum maternal sleep, maternal depressive symptoms and self-perceived mother-infant emotional relationship. Behav Sleep Med 2016;14(1):5-22. [doi: 10.1080/15402002.2014.940111] [Medline: 25127316]
33. Ran-Peled D, Horwitz A, Finkelstein O, Atzaba-Poria N, Tikotzky L. A longitudinal study of postpartum maternal sleep and sensitivity: examining depressive symptoms and social support as moderators. J Sleep Res 2025 Oct;34(5):e70056. [doi: 10.1111/jsr.70056] [Medline: 40170203]
34. Rawan-alsaad/ai_maternalmentalhealth_infantsleep. GitHub. URL: https://github.com/rawan-alsaad/AI_MaternalMentalHealth_InfantSleep [accessed 2026-01-21]

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

Edited by S Badawy; submitted 12.Jun.2025; peer-reviewed by AMA Elhenidy, PL Quah; revised version received 30.Nov.2025; accepted 24.Dec.2025; published 03.Feb.2026.

Please cite as:
AlSaad R, Burjaq R, AlAbdulla M, Abd-alrazaq A, Sheikh J, Thomas R
Predicting Infant Sleep Patterns From Postpartum Maternal Mental Health Measures: Machine Learning Approach
JMIR Pediatr Parent 2026;9:e78937
URL: https://pediatrics.jmir.org/2026/1/e78937
doi:10.2196/78937

Original Paper

Development and Usability Testing of the Mobile Childhood Asthma Management Program (mCHAMP) App: Sequential Mixed Methods Study

Robert J Lucero[1,2*], MPH, RN, PhD; Kristen Shear[3*], RN, PhD; Andrea Fidler[4], MPH, PhD; David Fedele[5], PhD; Yunpeng Xia[6], BSN, RN; David Janicke[7], PhD

[1]Chicano Studies Research Center, School of Nursing, University of California, Los Angeles, Los Angeles, CA, United States
[2]College of Nursing, University of Florida, Gainesville, FL, United States
[3]Center for Nursing Science and Clinical Inquiry, San Antonio Military Medical Center, San Antonio, TX, United States
[4]Department of Child and Adolescent Psychiatry and Behavioral Sciences, Children's Hospital of Philadelphia, Philadelphia, PA, United States
[5]Nemours Children Research, Nemours Children's Health System, Jacksonville, FL, United States
[6]School of Nursing, University of Alabama at Birmingham, Birmingham, AL, United States
[7]Department of Clinical and Health Psychology, University of Florida, Gainesville, FL, United States
[*]these authors contributed equally

Corresponding Author:
Robert J Lucero, MPH, RN, PhD
Chicano Studies Research Center
School of Nursing
University of California, Los Angeles
700 Tiverton Avenue
Los Angeles, CA, 90095
United States
Phone: 1 347 304 1238
Email: rlucero@sonnet.ucla.edu

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

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.

International Registered Report Identifier (IRRID): RR2-10.2196/13549

(JMIR Pediatr Parent 2026;9:e71681) doi:10.2196/71681

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].

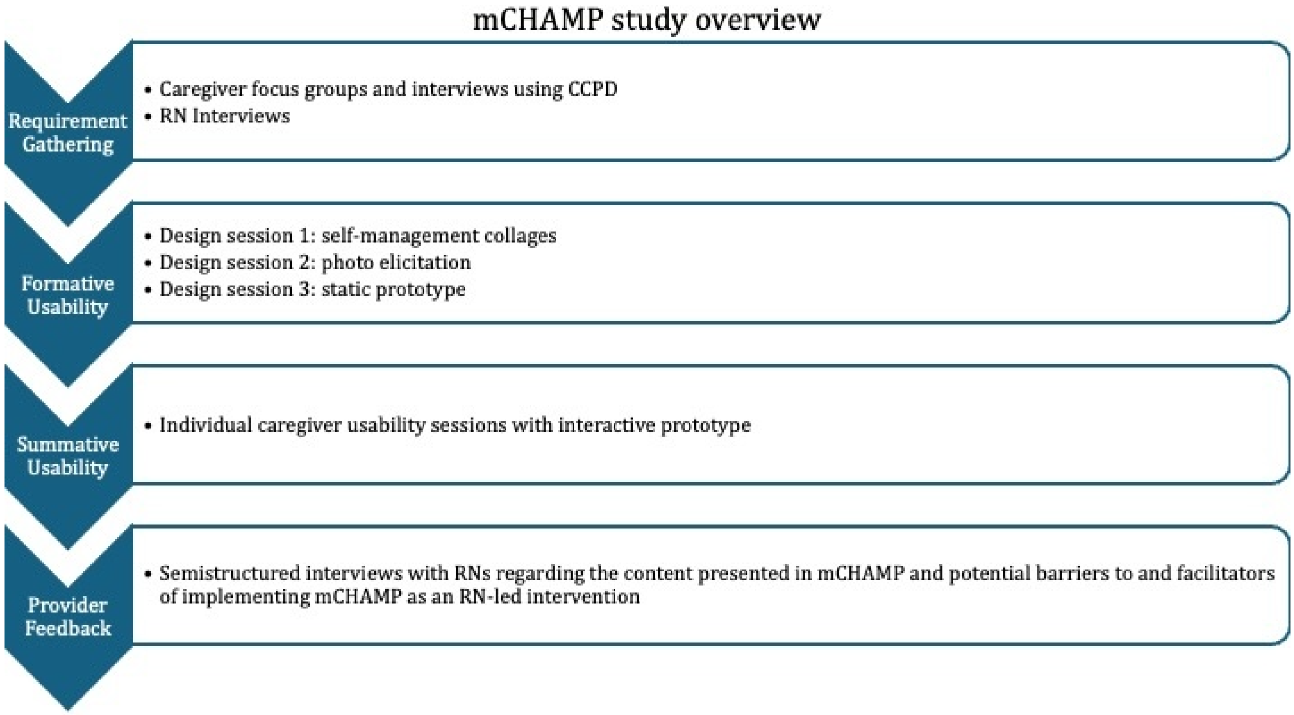
Objectives

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 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, 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.

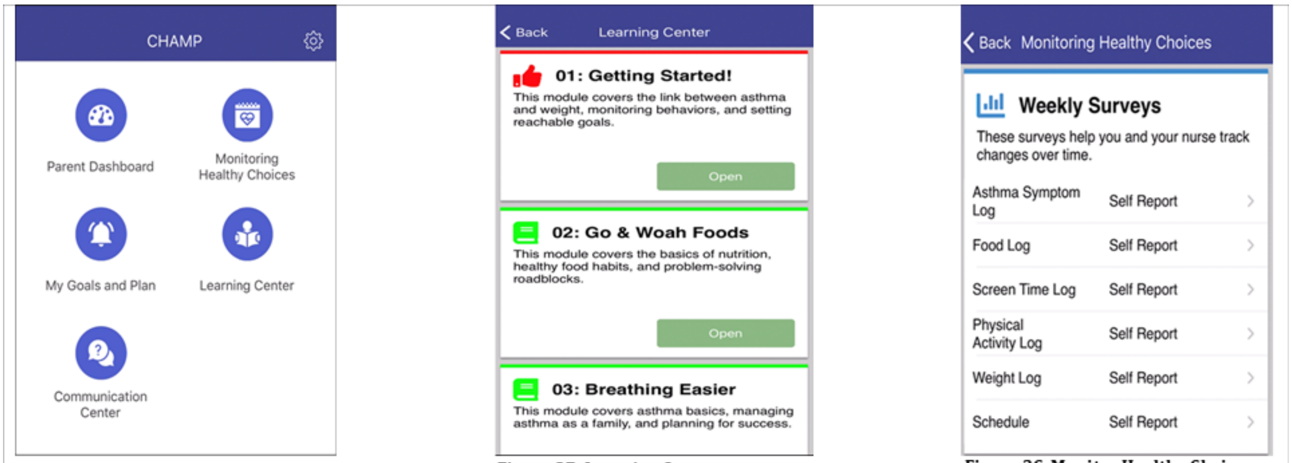
The summative usability target sample was 10 caregivers. Studies that include 10 participants in summative testing should find an average of 95% of system errors and a minimum of 82% of system errors [48]. In addition to caregivers, we targeted a sample size of 5 RNs for feedback on the final prototype.

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].

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.



01: Getting Started!
This module covers the link between asthma and weight, monitoring behaviors, and setting reachable goals.

02: Go & Woah Foods
This module covers the basics of nutrition, healthy food habits, and problem-solving roadblocks.

03: Breathing Easier
This module covers asthma basics, managing asthma as a family, and planning for success.

These surveys help you and your nurse track changes over time.

Asthma Symptom Log	Self Report
Food Log	Self Report
Screen Time Log	Self Report
Physical Activity Log	Self Report
Weight Log	Self Report
Schedule	Self Report

Figure 2A. mCHAMP Home Screen

Figure 2B. Learning Center

Figure 2C. Monitor Healthy Choices

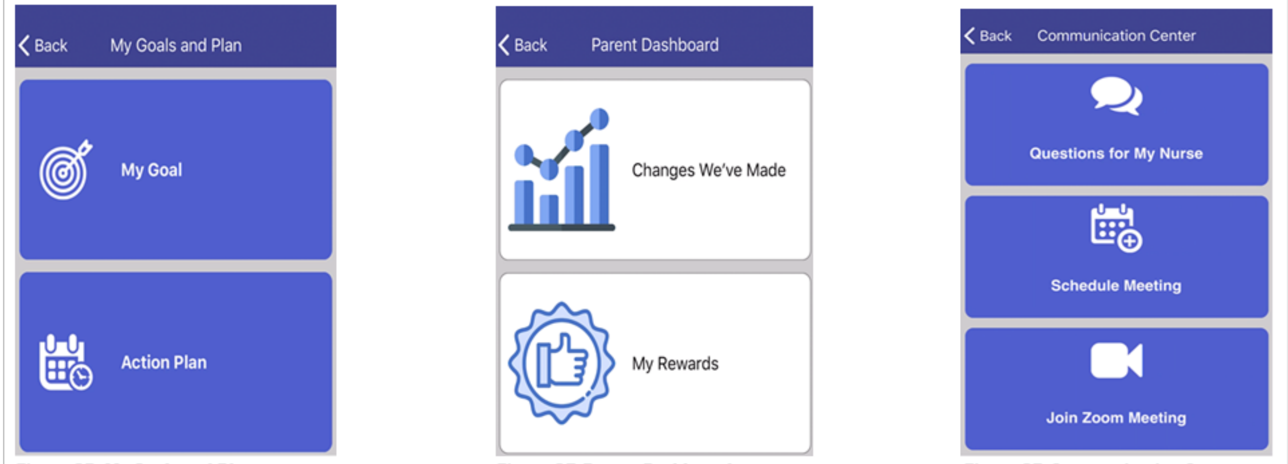


Figure 2D. My Goals and Plan

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 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).

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)

	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 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 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 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.

Acknowledgments

The views expressed in this paper are those of the authors and do not necessarily reflect the official policy or position of the Defense Health Agency, Brooke Army Medical Center, the Department of Defense, or any agencies under the US government. The University of Florida Health Quasi Endowment Fund provided financial support to RJL, DF, and DMJ for the development and dissemination of this study.

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.

References

1. Pate CA, Zahran HS, Qin X, Johnson C, Hummelman E, Malilay J. Asthma surveillance - United States, 2006-2018. MMWR Surveill Summ 2021 Sep 17;70(5):1-32 [FREE Full text] [doi: 10.15585/mmwr.ss7005a1] [Medline: 34529643]

2. Stierman B, Afful J, Carroll MD, Chen TC, Davy O, Fink S, et al. National health and nutrition examination survey 2017-March 2020 prepandemic data files-development of files and prevalence estimates for selected health outcomes. CDC Stacks. 2021 Jun 14. URL: https://stacks.cdc.gov/view/cdc/106273 [accessed 2025-10-28]
3. Lu KD, Forno E. Exercise and lifestyle changes in pediatric asthma. Curr Opin Pulm Med 2020 Jan;26(1):103-111 [FREE Full text] [doi: 10.1097/MCP.0000000000000636] [Medline: 31652153]
4. Peters U, Dixon AE, Forno E. Obesity and asthma. J Allergy Clin Immunol 2018 Apr;141(4):1169-1179 [FREE Full text] [doi: 10.1016/j.jaci.2018.02.004] [Medline: 29627041]
5. Okoniewski W, Lu KD, Forno E. Weight loss for children and adults with obesity and asthma. A systematic review of randomized controlled trials. Ann Am Thorac Soc 2019 May;16(5):613-625 [FREE Full text] [doi: 10.1513/AnnalsATS.201810-651SR] [Medline: 30605347]
6. Global strategy for asthma management and prevention updated 2022. Global Initiative for Asthma. 2022. URL: https://ginasthma.org/wp-content/uploads/2022/05/GINA-Main-Report-2022-FINAL-22-05-03-WMS.pdf [accessed 2022-06-21]
7. Spear BA, Barlow SE, Ervin C, Ludwig DS, Saelens BE, Schetzina KE, et al. Recommendations for treatment of child and adolescent overweight and obesity. Pediatrics 2007 Dec;120 Suppl 4:S254-S288. [doi: 10.1542/peds.2007-2329F] [Medline: 18055654]
8. Cloutier MM, Teach SJ, Lemanske RF, Blake KV. The 2020 focused updates to the NIH asthma management guidelines: key points for pediatricians. Pediatrics 2021 Jun;147(6):e2021050286 [FREE Full text] [doi: 10.1542/peds.2021-050286] [Medline: 33941586]
9. Golan M, Fainaru M, Weizman A. Role of behaviour modification in the treatment of childhood obesity with the parents as the exclusive agents of change. Int J Obes Relat Metab Disord 1998 Dec;22(12):1217-1224. [doi: 10.1038/sj.ijo.0800749] [Medline: 9877257]
10. Mansour ME, Lanphear BP, DeWitt TG. Barriers to asthma care in urban children: parent perspectives. Pediatrics 2000 Sep;106(3):512-519. [doi: 10.1542/peds.106.3.512] [Medline: 10969096]
11. Arnason A, Langarica N, Dugas LR, Mora N, Luke A, Markossian T. Family-based lifestyle interventions: what makes them successful? A systematic literature review. Prev Med Rep 2020 Dec 31;21:101299 [FREE Full text] [doi: 10.1016/j.pmedr.2020.101299] [Medline: 33511024]
12. Brigham EL, Goldenberg L, Stolfi A, Mueller GA, Forbis SG. Associations between parental health literacy, use of asthma management plans, and child's asthma control. Clin Pediatr (Phila) 2016 Feb;55(2):111-117. [doi: 10.1177/0009922815587089] [Medline: 25994320]
13. Meyers N, Glick AF, Mendelsohn AL, Parker RM, Sanders LM, Wolf MS, et al. Parents' use of technologies for health management: a health literacy perspective. Acad Pediatr 2020;20(1):23-30 [FREE Full text] [doi: 10.1016/j.acap.2019.01.008] [Medline: 30862511]
14. Chari R, Warsh J, Ketterer T, Hossain J, Sharif I. Association between health literacy and child and adolescent obesity. Patient Educ Couns 2014 Jan;94(1):61-66. [doi: 10.1016/j.pec.2013.09.006] [Medline: 24120396]
15. Wang KY, Chu NF, Lin SH, Chiang IC, Perng WC, Lai HR. Examining the causal model linking health literacy to health outcomes of asthma patients. J Clin Nurs 2014 Jul;23(13-14):2031-2042. [doi: 10.1111/jocn.12434] [Medline: 24329740]
16. Shone LP, Conn KM, Sanders L, Halterman JS. The role of parent health literacy among urban children with persistent asthma. Patient Educ Couns 2009 Jun;75(3):368-375 [FREE Full text] [doi: 10.1016/j.pec.2009.01.004] [Medline: 19233588]
17. Brown W, Odenthal D. The uses of telemedicine to improve asthma control. J Allergy Clin Immunol Pract 2015;3(2):300-301. [doi: 10.1016/j.jaip.2014.10.003] [Medline: 25609330]
18. Kahan S, Look M, Fitch A. The benefit of telemedicine in obesity care. Obesity (Silver Spring) 2022 Mar;30(3):577-586. [doi: 10.1002/oby.23382] [Medline: 35195367]
19. Netz M, Fedele DA, Sweenie R, Baker D, Light M, McQuaid EL. Asthma management responsibility, control, and quality of life among emerging adolescents. J Pediatr Psychol 2020 Jan 01;45(1):40-49. [doi: 10.1093/jpepsy/jsz069] [Medline: 31579923]
20. Horner SD, Timmerman GM, McWilliams BC. Feasibility study of a combined lifestyle behaviors and asthma self-management intervention for school-aged children. J Spec Pediatr Nurs 2018 Jul;23(3):e12224 [FREE Full text] [doi: 10.1111/jspn.12224] [Medline: 29972278]
21. Bandura A. Health promotion from the perspective of social cognitive theory. Psychol Health 1998;13(4):623-649. [doi: 10.1080/08870449808407422]
22. Bandura A. Health promotion by social cognitive means. Health Educ Behav 2004 Apr;31(2):143-164. [doi: 10.1177/1090198104263660] [Medline: 15090118]
23. Epstein LH, Paluch RA, Roemmich JN, Beecher MD. Family-based obesity treatment, then and now: twenty-five years of pediatric obesity treatment. Health Psychol 2007 Jul;26(4):381-391 [FREE Full text] [doi: 10.1037/0278-6133.26.4.381] [Medline: 17605557]
24. Janicke DM, Sallinen BJ, Perri MG, Lutes LD, Huerta M, Silverstein JH, et al. Comparison of parent-only vs family-based interventions for overweight children in underserved rural settings: outcomes from project STORY. Arch Pediatr Adolesc Med 2008 Dec;162(12):1119-1125 [FREE Full text] [doi: 10.1001/archpedi.162.12.1119] [Medline: 19047538]

25. Whitlock EP, O'Connor EA, Williams SB, Beil TL, Lutz KW. Effectiveness of weight management interventions in children: a targeted systematic review for the USPSTF. Pediatrics 2010 Feb;125(2):e396-e418. [doi: 10.1542/peds.2009-1955] [Medline: 20083531]
26. Janicke DM, Steele RG, Gayes LA, Lim CS, Clifford LM, Schneider EM, et al. Systematic review and meta-analysis of comprehensive behavioral family lifestyle interventions addressing pediatric obesity. J Pediatr Psychol 2014 Sep;39(8):809-825. [doi: 10.1093/jpepsy/jsu023] [Medline: 24824614]
27. Bravata DM, Sundaram V, Lewis R, Gienger A, Gould MK, McDonald KM, et al. In: Shojania KG, McDonald KM, Wachter RM, Owens DK, editors. Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies: Volume 5—Asthma Care. Rockville, MD: Agency for Healthcare Research and Quality; 2007.
28. Naar-King S, Ellis D, King PS, Lam P, Cunningham P, Secord E, et al. Multisystemic therapy for high-risk African American adolescents with asthma: a randomized clinical trial. J Consult Clin Psychol 2014 Jun;82(3):536-545 [FREE Full text] [doi: 10.1037/a0036092] [Medline: 24588407]
29. Garbutt JM, Sylvia S, Rook S, Schmandt M, Ruby-Ziegler C, Luby J, et al. Peer training to improve parenting and childhood asthma management skills: a pilot study. Ann Allergy Asthma Immunol 2015 Feb;114(2):148-149 [FREE Full text] [doi: 10.1016/j.anai.2014.10.023] [Medline: 25524747]
30. Cote MP, Byczkowski T, Kotagal U, Kirk S, Zeller M, Daniels S. Service quality and attrition: an examination of a pediatric obesity program. Int J Qual Health Care 2004 Apr;16(2):165-173. [doi: 10.1093/intqhc/mzh015] [Medline: 15051711]
31. Zeller M, Kirk S, Claytor R, Khoury P, Grieme J, Santangelo M, et al. Predictors of attrition from a pediatric weight management program. J Pediatr 2004 Apr;144(4):466-470. [doi: 10.1016/j.jpeds.2003.12.031] [Medline: 15069394]
32. Williams NA, Coday M, Somes G, Tylavsky FA, Richey PA, Hare M. Risk factors for poor attendance in a family-based pediatric obesity intervention program for young children. J Dev Behav Pediatr 2010;31(9):705-712 [FREE Full text] [doi: 10.1097/DBP.0b013e3181f17b1c] [Medline: 21057255]
33. Anderson M, Jiang J. Teens, social media and technology 2018. Pew Research Center. 2018 May 31. URL: https://www.pewresearch.org/internet/2018/05/31/teens-social-media-technology-2018/ [accessed 2025-10-14]
34. Krebs P, Duncan DT. Health app use among US mobile phone owners: a national survey. JMIR Mhealth Uhealth 2015 Nov 04;3(4):e101 [FREE Full text] [doi: 10.2196/mhealth.4924] [Medline: 26537656]
35. Schnall R, Higgins T, Brown W, Carballo-Dieguez A, Bakken S. Trust, perceived risk, perceived ease of use and perceived usefulness as factors related to mHealth technology use. Stud Health Technol Inform 2015;216:467-471 [FREE Full text] [Medline: 26262094]
36. Zhao J, Freeman B, Li M. Can mobile phone apps influence people's health behavior change? An evidence review. J Med Internet Res 2016 Oct 31;18(11):e287 [FREE Full text] [doi: 10.2196/jmir.5692] [Medline: 27806926]
37. Hamine S, Gerth-Guyette E, Faulx D, Green BB, Ginsburg AS. Impact of mHealth chronic disease management on treatment adherence and patient outcomes: a systematic review. J Med Internet Res 2015 Feb 24;17(2):e52 [FREE Full text] [doi: 10.2196/jmir.3951] [Medline: 25803266]
38. Fonseca JA, Costa-Pereira A, Delgado L, Fernandes L, Castel-Branco MG. Asthma patients are willing to use mobile and web technologies to support self-management. Allergy 2006 Mar;61(3):389-390. [doi: 10.1111/j.1398-9995.2006.01016.x] [Medline: 16436151]
39. Ramsey RR, Plevinsky JM, Kollin SR, Gibler RC, Guilbert TW, Hommel KA. Systematic review of digital interventions for pediatric asthma management. J Allergy Clin Immunol Pract 2020 Apr;8(4):1284-1293 [FREE Full text] [doi: 10.1016/j.jaip.2019.12.013] [Medline: 31870809]
40. Darling KE, Sato AF. Systematic review and meta-analysis examining the effectiveness of mobile health technologies in using self-monitoring for pediatric weight management. Child Obes 2017 Oct;13(5):347-355. [doi: 10.1089/chi.2017.0038] [Medline: 28471699]
41. Mohr DC, Schueller SM, Tomasino KN, Kaiser SM, Alam N, Karr C, et al. Comparison of the effects of coaching and receipt of app recommendations on depression, anxiety, and engagement in the IntelliCare platform: factorial randomized controlled trial. J Med Internet Res 2019 Aug 28;21(8):e13609 [FREE Full text] [doi: 10.2196/13609] [Medline: 31464192]
42. Dryman MT, McTeague LM, Olino TM, Heimberg RG. Evaluation of an open-access CBT-based internet program for social anxiety: patterns of use, retention, and outcomes. J Consult Clin Psychol 2017 Oct;85(10):988-999. [doi: 10.1037/ccp0000232] [Medline: 28650193]
43. Sargent GM, Forrest LE, Parker RM. Nurse delivered lifestyle interventions in primary health care to treat chronic disease risk factors associated with obesity: a systematic review. Obes Rev 2012 Dec;13(12):1148-1171 [FREE Full text] [doi: 10.1111/j.1467-789X.2012.01029.x] [Medline: 22973970]
44. Fedele D, Lucero R, Janicke D, Abu-Hasan M, McQuaid E, Moon J, et al. Protocol for the development of a behavioral family lifestyle intervention supported by mobile health to improve weight self-management in children with asthma and obesity. JMIR Res Protoc 2019 Jun 24;8(6):e13549 [FREE Full text] [doi: 10.2196/13549] [Medline: 31237240]
45. Fedele DA, Janicke DM, McQuaid EL, Abu-Hasan M, Baker D, Zou B, et al. A behavioral family intervention for children with overweight and asthma. Clin Pract Pediatr Psychol 2018 Sep;6(3):259-269 [FREE Full text] [doi: 10.1037/cpp0000237] [Medline: 30416909]

46. Lucero R, Sheehan B, Yen P, Velez O, Nobile-Hernandez D, Tiase V. Identifying consumer's needs of health information technology through an innovative participatory design approach among English- and Spanish-speaking urban older adults. Appl Clin Inform 2014 Dec 03;5(4):943-957 [FREE Full text] [doi: 10.4338/ACI-2014-07-RA-0058] [Medline: 25589909]
47. Sauro J, Lewis JR. Quantifying the User Experience: Practical Statistics for User Research. 2nd edition. Waltham, MA: Morgan Kaufmann; Aug 9, 2016.
48. Faulkner L. Beyond the five-user assumption: benefits of increased sample sizes in usability testing. Behav Res Methods Instrum Comput 2003 Aug;35(3):379-383. [doi: 10.3758/bf03195514] [Medline: 14587545]
49. Fruhling A, Lee S. Assessing the reliability, validity and adaptability of PSSUQ. In: Proceedings of the 11th Americas Conference on Information Systems. 2005 Presented at: AMCIS '05; August 11-14, 2005; Omaha, NE.
50. Winston S. Health Information National Trends Survey (HINTS.gov). Med Ref Serv Q 2021;40(2):215-223. [doi: 10.1080/02763869.2021.1912575] [Medline: 33970822]
51. Nielsen J. Chapter 2 - what is usability? In: Usability Engineering. San Francisco, CA: Morgan Kaufmann; 1993:23-48.
52. Nielsen J. Usability Engineering. San Francisco, CA: Morgan Kaufmann; 1993.
53. Sheehan B, Lucero RJ. Initial usability and feasibility evaluation of a personal health record-based self-management system for older adults. EGEMS (Wash DC) 2015 May 07;3(2):1152 [FREE Full text] [doi: 10.13063/2327-9214.1152] [Medline: 26290889]
54. Gustafson D, Wise M, Bhattacharya A, Pulvermacher A, Shanovich K, Phillips B, et al. The effects of combining web-based eHealth with telephone nurse case management for pediatric asthma control: a randomized controlled trial. J Med Internet Res 2012 Jul 26;14(4):e101 [FREE Full text] [doi: 10.2196/jmir.1964] [Medline: 22835804]
55. Almasi S, Shahbodaghi A, Asadi F. Efficacy of telemedicine for the management of asthma: a systematic review. Tanaffos 2022 Feb;21(2):132-145 [FREE Full text] [Medline: 36879729]
56. Cooley WC, McAllister JW, Sherrieb K, Kuhlthau K. Improved outcomes associated with medical home implementation in pediatric primary care. Pediatrics 2009 Jul;124(1):358-364. [doi: 10.1542/peds.2008-2600] [Medline: 19564320]
57. Hennessy EA, Johnson BT, Acabchuk RL, McCloskey K, Stewart-James J. Self-regulation mechanisms in health behavior change: a systematic meta-review of meta-analyses, 2006-2017. Health Psychol Rev 2020 Mar;14(1):6-42 [FREE Full text] [doi: 10.1080/17437199.2019.1679654] [Medline: 31662031]
58. Burke LE, Wang J, Sevick MA. Self-monitoring in weight loss: a systematic review of the literature. J Am Diet Assoc 2011 Jan;111(1):92-102 [FREE Full text] [doi: 10.1016/j.jada.2010.10.008] [Medline: 21185970]
59. Fowler LA, Grammer AC, Staiano AE, Fitzsimmons-Craft EE, Chen L, Yaeger LH, et al. Harnessing technological solutions for childhood obesity prevention and treatment: a systematic review and meta-analysis of current applications. Int J Obes (Lond) 2021 May;45(5):957-981 [FREE Full text] [doi: 10.1038/s41366-021-00765-x] [Medline: 33627775]
60. Basch E, Barbera L, Kerrigan CL, Velikova G. Implementation of patient-reported outcomes in routine medical care. Am Soc Clin Oncol Educ Book 2018 May 23;38:122-134 [FREE Full text] [doi: 10.1200/EDBK_200383] [Medline: 30231381]
61. Dixon BE, Jabour AM, Phillips EO, Marrero DG. An informatics approach to medication adherence assessment and improvement using clinical, billing, and patient-entered data. J Am Med Inform Assoc 2014;21(3):517-521 [FREE Full text] [doi: 10.1136/amiajnl-2013-001959] [Medline: 24076751]

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

Edited by S Badawy; submitted 23.Jan.2025; peer-reviewed by P Nohl-Deryk, K Biswas; comments to author 31.May.2025; revised version received 03.Sep.2025; accepted 10.Sep.2025; published 20.Mar.2026.

Please cite as:
Lucero RJ, Shear K, Fidler A, Fedele D, Xia Y, Janicke D
Development and Usability Testing of the Mobile Childhood Asthma Management Program (mCHAMP) App: Sequential Mixed Methods Study
JMIR Pediatr Parent 2026;9:e71681
URL: https://pediatrics.jmir.org/2026/1/e71681
doi:10.2196/71681
PMID:

Mobile Apps and Websites With Breastfeeding-Related Content in Germany: Cross-Sectional and Evaluation Study

Monika Ziebart[1,2], MSc; Vanessa Jäger[1,2], MPH, Dr rer hum biol; Melissa A Theurich[3], MPH, Dr rer hum biol; Berthold Viktor Koletzko[1,2], MD, Dr Med

[1]Division of Metabolic and Nutritional Medicine, Department of Pediatrics, Dr. von Hauner Children's Hospital, Ludwig-Maximilians-University Munich Hospital, Lindwurmstr. 4, Munich, Bavaria, Germany

[2]Ludwig-Maximilians-University Munich Hospital, German Center for Child and Adolescent Health (DZKJ), Munich, Bavaria, Germany

[3]Division of Neonatology, Dr. von Hauner Children's Hospital & Perinatal Center, Ludwig-Maximilians-University Munich Hospital, Munich, Bavaria, Germany

Corresponding Author:
Monika Ziebart, MSc
Division of Metabolic and Nutritional Medicine, Department of Pediatrics, Dr. von Hauner Children's Hospital, Ludwig-Maximilians-University Munich Hospital, Lindwurmstr. 4, Munich, Bavaria, Germany

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.

(JMIR Pediatr Parent 2026;9:e78128) doi:10.2196/78128

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 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.

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.

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 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.

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.

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.

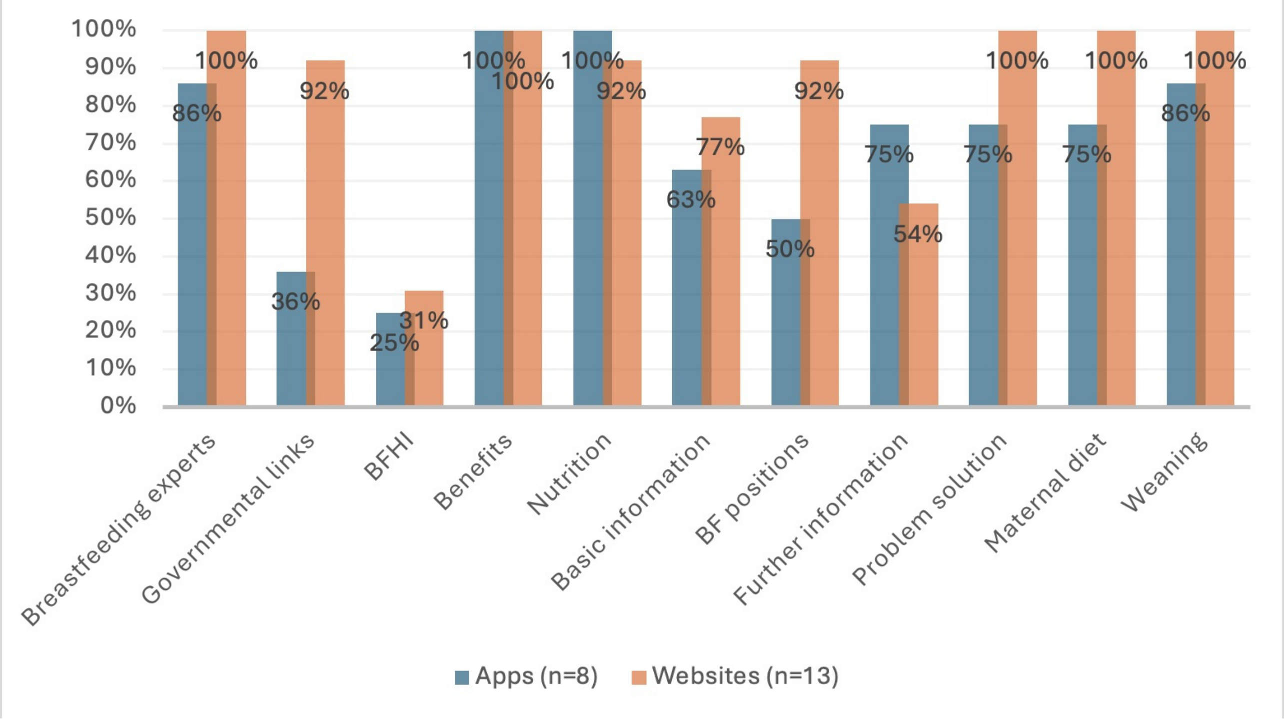
[c] IBCLC: international board certified lactation consultant.

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).

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].

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.

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].

Acknowledgments

We would like to thank Julia Papst for reviewing the apps and websites. We would like to thank Frances Strobl for providing comments and copyediting.

Funding

This work was financially supported in part by the Child Health Foundation (Stiftung Kindergesundheit, www.kindergesundheit.de), Munich and the German Federal Ministry of Education and Research (Bundesministerium für Bildung und Forschung, BMBF) as part of the German Center for Child and Adolescent Health (DZKJ), 01GL2406A. BVK is the Else Kröner Seniorprofessor of Pediatrics at LMU–University of Munich, financially supported by the charitable Else Kröner-Fresenius-Foundation, LMU Medical Faculty and LMU University Hospitals.

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]

References

1. Baumann E, Czerwinski F, Rosset M, Seelig M, Suhr R. Wie informieren sich die Menschen in Deutschland zum Thema Gesundheit? Erkenntnisse aus der ersten Welle von HINTS Germany [Article in German]. Bundesgesundheitsbl Gesundheitsforsch Gesundheitsschutz 2020 Sep;63(9):1151-1160. [doi: 10.1007/s00103-020-03192-x]
2. Demirci JR, Cohen SM, Parker M, Holmes A, Bogen DL. Access, use, and preferences for technology-based perinatal and breastfeeding support among childbearing women. J Perinat Educ 2016;25(1):29-36. [doi: 10.1891/1058-1243.25.1.29] [Medline: 26848248]
3. Slomian J, Bruyère O, Reginster JY, Emonts P. The internet as a source of information used by women after childbirth to meet their need for information: a web-based survey. Midwifery 2017 May;48:46-52. [doi: 10.1016/j.midw.2017.03.005] [Medline: 28324809]
4. Carter B. Parenting: a glut of information. J Child Health Care 2007 Jun;11(2):82-84. [doi: 10.1177/1367493507079621] [Medline: 17494983]
5. O’Higgins A, Murphy OC, Egan A, Mullaney L, Sheehan S, Turner MJ. The use of digital media by women using the maternity services in a developed country. Ir Med J 2014;107(10):313-315. [Medline: 25556255]
6. mHealth: new horizons for health through mobile technologies: second global survey on eHealth. : World Health Organization; 2011 URL: https://iris.who.int/server/api/core/bitstreams/ad1b13c0-7c82-47b4-8dd5-f0a26c3a3cc3/content [accessed 2026-02-11]
7. Uncovska M, Freitag B, Meister S, Fehring L. Patient acceptance of prescribed and fully reimbursed mHealth apps in Germany: an UTAUT2-based online survey study. J Med Syst 2023 Jan 27;47(1):14. [doi: 10.1007/s10916-023-01910-x] [Medline: 36705853]
8. Theurich MA, Weikert C, Abraham K, Koletzko B. Breastfeeding rate and promotion in selected European countries [Article in German with English abstract]. Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz 2018 Aug;61(8):926-936. [doi: 10.1007/s00103-018-2762-7] [Medline: 29943261]
9. Qian J, Wu T, Lv M, et al. The value of mobile health in improving breastfeeding outcomes among perinatal or postpartum women: systematic review and meta-analysis of randomized controlled trials. JMIR Mhealth Uhealth 2021 Jul 16;9(7):e26098. [doi: 10.2196/26098] [Medline: 34269681]
10. Lau Y, Htun TP, Tam WSW, Klainin-Yobas P. Efficacy of e-technologies in improving breastfeeding outcomes among perinatal women: a meta-analysis. Matern Child Nutr 2016 Jul;12(3):381-401. [doi: 10.1111/mcn.12202] [Medline: 26194599]
11. Blackmore A, Howell B, Romme K, et al. The effectiveness of virtual lactation support: a systematic review and meta-analysis. J Hum Lact 2022 Aug;38(3):452-465. [doi: 10.1177/08903344221099914] [Medline: 35695423]
12. Hughson JAP, Daly JO, Woodward-Kron R, Hajek J, Story D. The rise of pregnancy apps and the implications for culturally and linguistically diverse women: narrative review. JMIR Mhealth Uhealth 2018 Nov 16;6(11):e189. [doi: 10.2196/mhealth.9119] [Medline: 30446483]
13. Chan KL, Chen M. Effects of social media and mobile health apps on pregnancy care: meta-analysis. JMIR Mhealth Uhealth 2019 Jan 30;7(1):e11836. [doi: 10.2196/11836] [Medline: 30698533]
14. Alianmoghaddam N, Phibbs S, Benn C. “I did a lot of Googling”: a qualitative study of exclusive breastfeeding support through social media. Women Birth 2019 Apr;32(2):147-156. [doi: 10.1016/j.wombi.2018.05.008] [Medline: 29921552]
15. Ziebart M, Kammermeier M, Koletzko B, Patro-Golab B. Mobile applications for promoting and supporting breastfeeding: systematic review and meta-analysis. Matern Child Nutr 2025 Jan;21(1):e13733. [doi: 10.1111/mcn.13733] [Medline: 39390945]
16. Biviji R, Williams KS, Vest JR, Dixon BE, Cullen T, Harle CA. Consumer perspectives on maternal and infant health apps: qualitative content analysis. J Med Internet Res 2021 Sep 1;23(9):e27403. [doi: 10.2196/27403] [Medline: 34468323]
17. MacMillan Uribe AL, DiFilippo KN, Jarnell K, Patterson JA. Evaluation of commercially available infant-feeding mobile applications using App Quality Evaluation Tool. J Nutr Educ Behav 2023 Aug;55(8):604-611. [doi: 10.1016/j.jneb.2023.05.249] [Medline: 37389498]
18. Virani A, Duffett-Leger L, Letourneau N. Parenting apps review: in search of good quality apps. mHealth 2019;5:44. [doi: 10.21037/mhealth.2019.08.10] [Medline: 31620471]
19. Zhao J, Freeman B, Li M. How do infant feeding apps in China measure up? A content quality assessment. JMIR Mhealth Uhealth 2017 Dec 6;5(12):e186. [doi: 10.2196/mhealth.8764] [Medline: 29212627]
20. Cheng H, Tutt A, Llewellyn C, et al. Content and quality of infant feeding smartphone apps: five-year update on a systematic search and evaluation. JMIR Mhealth Uhealth 2020 May 27;8(5):e17300. [doi: 10.2196/17300] [Medline: 32459187]
21. Artieta-Pinedo I, Paz-Pascual C, Grandes G, Villanueva G, Ema Q Group. An evaluation of Spanish and English on-line information sources regarding pregnancy, birth and the postnatal period. Midwifery 2018 Mar;58:19-26. [doi: 10.1016/j.midw.2017.12.002] [Medline: 29277038]
22. Brunelli L, De Vita C, Cenedese F, et al. Gaps and future challenges of Italian apps for pregnancy and postnatal care: systematic search on app stores. J Med Internet Res 2021 Aug 10;23(8):e29151. [doi: 10.2196/29151] [Medline: 34383668]
23. von Elm E, Altman DG, Egger M, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. Ann Intern Med 2007 Oct 16;147(8):573-577. [doi: 10.7326/0003-4819-147-8-200710160-00010] [Medline: 17938396]

24. Stoyanov SR, Hides L, Kavanagh DJ, Wilson H. Development and validation of the user version of the Mobile Application Rating Scale (uMARS). JMIR Mhealth Uhealth 2016 Jun 10;4(2):e72. [doi: 10.2196/mhealth.5849] [Medline: 27287964]
25. Messner EM, Terhorst Y, Barke A, et al. The German version of the Mobile App Rating Scale (MARS-G): development and validation study. JMIR Mhealth Uhealth 2020 Mar 27;8(3):e14479. [doi: 10.2196/14479] [Medline: 32217504]
26. Doak CC, Doak LG, Root JH. Teaching patients with low literacy skills. Am J Nurs 1996 Dec;96(12):16M. [doi: 10.1097/00000446-199612000-00022]
27. Doak CC, Doak LG, Root JH. Suitability assessment of materials for evaluation of health-related information for adults. : Practice Development Inc URL: https://moodle2.units.it/pluginfile.php/290571/mod_folder/content/0/sam.pdf?forcedownload=1 [accessed 2026-02-11]
28. Schöll P. Flesch-index berechnen - kostenlos [Website in German]. Fleschindex. URL: https://fleschindex.de [accessed 2022-11-23]
29. Amstad T. Wie verständlich sind unsere zeitungen? [Dissertation] [Website in German]. : Zurich; 1978 URL: https://kansalliskirjasto.finna.fi/Record/fikka.108133 [accessed 2026-02-10]
30. Google [Website in German]. URL: www.google.de [accessed 2023-10-07]
31. Microsoft Bing [Website in German]. URL: www.bing.de [accessed 2023-10-07]
32. Google Trends [Website in German]. URL: https://trends.google.de/trends/ [accessed 2023-10-07]
33. Keyword ideas. Ubersuggest. URL: https://ubersuggest.zendesk.com/hc/en-us/sections/4405443414555-Keyword-Ideas [accessed 2023-10-07]
34. Morahan-Martin JM. How internet users find, evaluate, and use online health information: a cross-cultural review. Cyberpsychol Behav 2004 Oct;7(5):497-510. [doi: 10.1089/cpb.2004.7.497] [Medline: 15667044]
35. Health-related web site evaluation form. : Carlbring Research; 2020 URL: https://www.carlbring.se/form/itform_eng.pdf [accessed 2022-05-31]
36. Koletzko B, Bauer CP, Cierpka M, et al. Ernährung und Bewegung von Säuglingen und stillenden Frauen [Article in German]. Monatsschr Kinderheilkd 2016 Sep;164(9):771-798. [doi: 10.1007/s00112-016-0147-2]
37. IRR: various coefficients of interrater reliability and agreement. 2019. URL: https://CRAN.R-project.org/package=irr [accessed 2026-02-11]
38. R: a language and environment for statistical computing. R Foundation for Statistical Computing. 2023. URL: https://www.R-project.org/ [accessed 2026-02-11]
39. Familie [Website in German]. URL: https://www.familie.de [accessed 2026-02-12]
40. Kindergesundheit-Info [Website in German]. URL: https://www.kindergesundheit-info.de [accessed 2026-02-12]
41. Babelli [Website in German]. URL: https://www.babelli.de [accessed 2026-02-12]
42. Team Muttermilch [Website in German]. URL: https://teammuttermilch.de [accessed 2026-02-12]
43. Medela [Website in German]. URL: https://www.medela.de [accessed 2026-02-12]
44. Enzyclopedia [Website in German]. Wikipedia. URL: https://de.wikipedia.org [accessed 2026-02-12]
45. Netdoktor [Website in German]. URL: https://www.netdoktor.de [accessed 2026-02-12]
46. Still-Lexikon [Website in German]. URL: https://www.still-lexikon.de [accessed 2026-02-12]
47. Eltern [Website in German]. URL: https://www.eltern.de [accessed 2026-02-12]
48. Lansinoh [Website in German]. URL: https://lansinoh.de [accessed 2026-02-12]
49. Apotheken Umschau [Website in German]. URL: https://www.apotheken-umschau.de [accessed 2026-02-12]
50. Hipp [Website in German]. URL: https://www.hipp.de [accessed 2026-02-12]
51. Windeln [Website in German]. URL: https://www.windeln.de/magazin [accessed 2026-02-12]
52. Taki S, Campbell KJ, Russell CG, Elliott R, Laws R, Denney-Wilson E. Infant feeding websites and apps: a systematic assessment of quality and content. Interact J Med Res 2015 Sep 29;4(3):e18. [doi: 10.2196/ijmr.4323] [Medline: 26420339]
53. Musgrave LM, Kizirian NV, Homer CSE, Gordon A. Mobile phone apps in Australia for improving pregnancy outcomes: systematic search on app stores. JMIR mhealth uHealth 2020 Nov 16;8(11):e22340. [doi: 10.2196/22340] [Medline: 33196454]
54. Dinour LM, Pole A. Evaluation of breastfeeding app features: content analysis study. JMIR Pediatr Parent 2022 Oct 26;5(4):e37581. [doi: 10.2196/37581] [Medline: 36287596]
55. Almohanna AA, Win KT, Meedya S. Effectiveness of internet-based electronic technology interventions on breastfeeding outcomes: systematic review. J Med Internet Res 2020 May 29;22(5):e17361. [doi: 10.2196/17361] [Medline: 32469315]
56. Jawad D, Cheng H, Wen LM, et al. Interactivity, quality, and content of websites promoting health behaviors during infancy: 6-year update of the systematic assessment. J Med Internet Res 2022 Oct 7;24(10):e38641. [doi: 10.2196/38641] [Medline: 36206031]
57. Ausländer und migranten in Deutschland [Website in German]. Mediendienst Integration. URL: https://mediendienst-integration.de/migration/bevoelkerung.html [accessed 2023-06-10]
58. Brauchma J, et al. Health promotion and overweight prevention-a systematic evaluation of available information materials with a focus on risk groups [Article in German]. Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz 2019 Dec;62(12):1522-1530. [doi: 10.1007/s00103-019-03031-8]

59. Qualifikationen in der Stillberatung [Website in German]. Europäisches Institut für Stillen und Laktation. URL: https://www.stillen-institut.com/de/qualifikationen-in-der-stillberatung.html#:~:text=Im%20deutschsprachigen%20Raum%20ist%20der,innen%20können%20und%20wissen%20müssen [accessed 2023-04-10]
60. Newby R, Brodribb W, Ware RS, Davies PSW. Internet use by first-time mothers for infant feeding support. J Hum Lact 2015 Aug;31(3):416-424. [doi: 10.1177/0890334415584319] [Medline: 25925637]
61. van Velthoven MH, Wyatt JC, Meinert E, Brindley D, Wells G. How standards and user involvement can improve app quality: a lifecycle approach. Int J Med Inform 2018 Oct;118:54-57. [doi: 10.1016/j.ijmedinf.2018.08.003] [Medline: 30153922]
62. Jones A, Bhaumik S, Morelli G, et al. Digital marketing of breast-milk substitutes: a systematic scoping review. Curr Nutr Rep 2022 Sep;11(3):416-430. [doi: 10.1007/s13668-022-00414-3] [Medline: 35507274]
63. Digital marketing of breastmilk substitutes: how social media and influencer marketing undermine informed choice. : Save the Children; 2024 URL: https://dylbw5db8047o.cloudfront.net/uploads/BMS-Final-Report.pdf [accessed 2026-02-11]
64. International code of marketing of breast-milk subsitutes. : World Health Organization; 1981 URL: https://iris.who.int/server/api/core/bitstreams/f6704ad6-4ce5-4f37-8562-5a64f0f693ae/content [accessed 2020-04-17]
65. Commission delegated regulation (EU) 2016/127. : Official Journal of the European Union; 2016 URL: https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32016R0127 [accessed 2026-02-12]
66. Verordnung über diätetische Lebensmittel (Diätverordnung) [Report in German]. : Bundesministerium der Justiz und für Verbraucherschutz; 2005 URL: https://faolex.fao.org/docs/pdf/ger89197.pdf [accessed 2026-02-12]
67. Guidance on regulatory measures aimed at restricting digital marketing of breast-milk substitutes. : World Health Organization; 2023 URL: https://iris.who.int/server/api/core/bitstreams/caf4eb9d-951d-4ecc-b7aa-1c5b86bbe570/content [accessed 2026-02-11]
68. Marketing of breast-milk substitutes: national implementation of the International Code, status report 2022. : World Health Organization; 2022 URL: https://iris.who.int/server/api/core/bitstreams/99dbb0e0-daf3-4296-b496-6f09cb5eeffa/content [accessed 2026-02-11]
69. Afgis - aktionsforum gesundheitsinformationssystem [Website in German]. URL: https://www.afgis.de [accessed 2023-09-27]
70. Stiftung gesundheit - wissen ist die beste medizin [Website in German]. URL: https://www.stiftung-gesundheit.de [accessed 2023-09-27]
71. Medisuch [Website in German]. URL: https://www.medisuch.de/ueberMedisuch.asp [accessed 2023-09-27]
72. Health on the net foundation [Website in German]. Wikipedia. URL: https://de.wikipedia.org/wiki/Health_On_the_Net_Foundation [accessed 2023-09-27]
73. Gavine A, Marshall J, Buchanan P, et al. Remote provision of breastfeeding support and education: systematic review and meta-analysis. Matern Child Nutr 2022 Apr;18(2):e13296. [doi: 10.1111/mcn.13296] [Medline: 34964542]

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

Edited by S Badawy; submitted 02.Jun.2025; peer-reviewed by G Lenaerts, S Narayan; revised version received 27.Nov.2025; accepted 24.Dec.2025; published 16.Mar.2026.

Please cite as:
Ziebart M, Jäger V, Theurich MA, Koletzko BV
Mobile Apps and Websites With Breastfeeding-Related Content in Germany: Cross-Sectional and Evaluation Study
JMIR Pediatr Parent 2026;9:e78128
URL: https://pediatrics.jmir.org/2026/1/e78128
doi:10.2196/78128

Review Paper

Evaluating Mobile Information Apps for Parents of Preterm Infants After Hospital Discharge: Systematic App Review

Martine Jeukens-Visser[1,2], PhD; Monique Flierman[1,2,3], MSc; Eline Möller[1,2], PhD; Renate Giezeman[1,2], MSc; Raoul Engelbert[1,3], Prof Dr; Daniël Bossen[3], PhD

[1]Department of Rehabilitation Medicine, University of Amsterdam, Amsterdam UMC, Amsterdam, The Netherlands
[2]Amsterdam Reproduction and Development, Amsterdam, The Netherlands
[3]Faculty of Health, Sport and Physical Activity, Amsterdam University of Applied Sciences, Amsterdam, The Netherlands

Corresponding Author:
Daniël Bossen, PhD
Faculty of Health, Sport and Physical Activity
Amsterdam University of Applied Sciences
Tafelbergweg 51
Amsterdam, 1105 BD
The Netherlands
Phone: 31 205954111
Email: d.bossen@hva.nl

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.

(JMIR Pediatr Parent 2026;9:e67085) doi:10.2196/67085

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

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 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

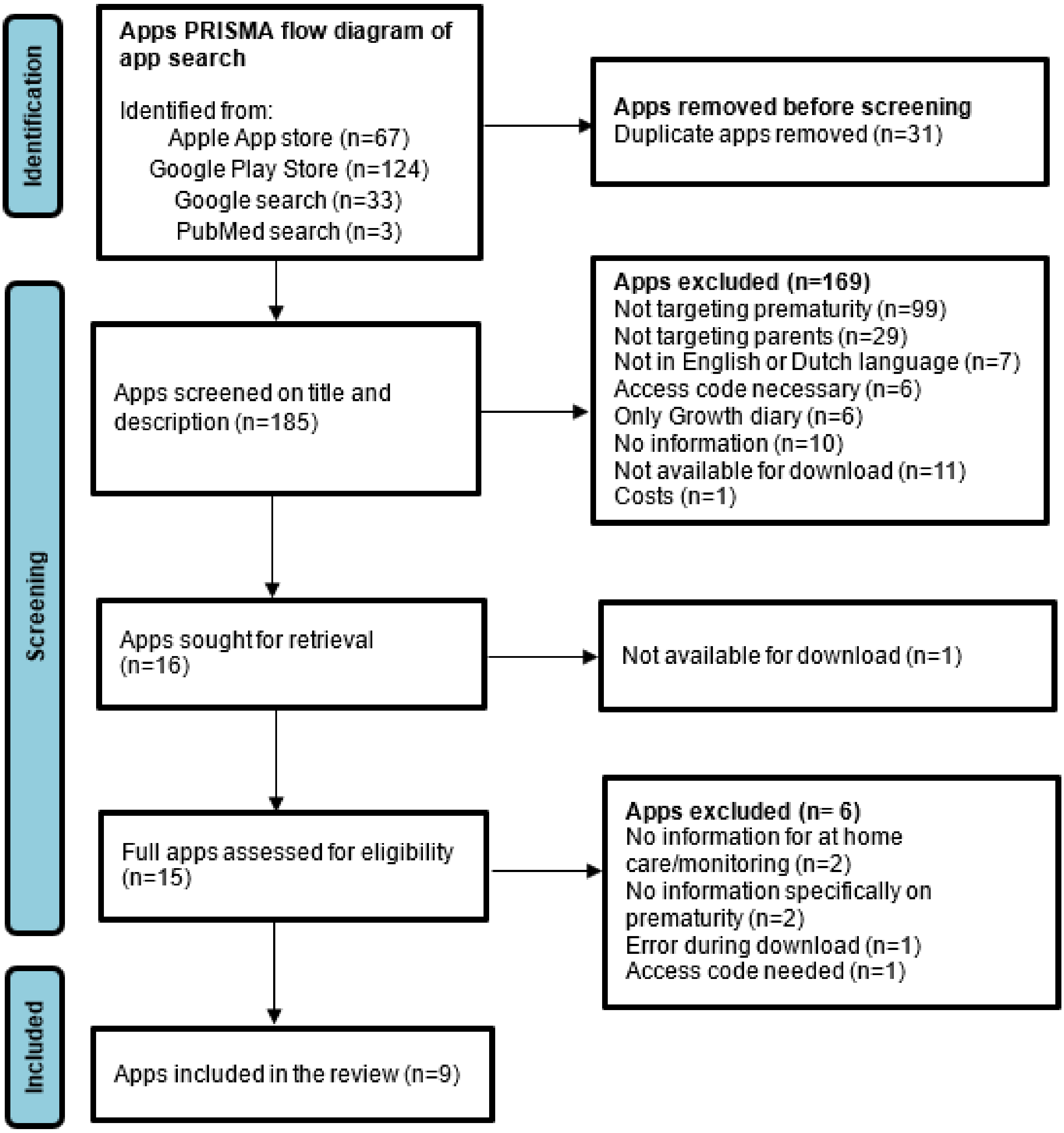
Data analysis was performed using IBM Statistical Package for Social Sciences software (IBM SPSS; version 26). The MARS item scores were averaged for the engagement, functionality, aesthetics, and information subscales. These scores for app quality were then averaged, creating a mean (SD) app quality 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.

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.

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 Mid-central 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

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).

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.

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, 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 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.

Funding

This research was financed by Regieorgaan SIA (RAAK.MKB13.004), part of the Netherlands Organization for Scientific Research (NWO).

Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA 2020 checklist.
[PDF File (Adobe PDF File), 69 KB - pediatrics_v9i1e67085_app1.pdf]

References

1. Ohuma EO, Moller A, Bradley E, Chakwera S, Hussain-Alkhateeb L, Lewin A, et al. National, regional, and global estimates of preterm birth in 2020, with trends from 2010: a systematic analysis. Lancet 2023;402(10409):1261-1271 [FREE Full text] [doi: 10.1016/S0140-6736(23)00878-4] [Medline: 37805217]
2. Edwards EM, Greenberg LT, Horbar JD, Gagliardi L, Adams M, Berger A, et al. Discharge age and weight for very preterm infants in six countries: 2012-2020. Neonatology 2023;120(2):208-216. [doi: 10.1159/000528013] [Medline: 36649689]
3. Petty J, Whiting L, Green J, Fowler C. Parents' views on preparation to care for extremely premature infants at home. Nurs Child Young People 2018. [doi: 10.7748/ncyp.2018.e1084] [Medline: 29975481]
4. Green J, Fowler C, Petty J, Whiting L. The transition home of extremely premature babies: An integrative review. J Neonatal Nurs 2021;27(1):26-32. [doi: 10.1016/j.jnn.2020.09.011]
5. Davis-Strauss S, Johnson E, Lubbe W. Information and support needs of parents with premature infants: an integrative review. J Early Interv 2020;43(3):199-220. [doi: 10.1177/1053815120957734]
6. Alderdice F, Gargan P, McCall E, Franck L. Online information for parents caring for their premature baby at home: a focus group study and systematic web search. Health Expect 2018;21(4):741-751 [FREE Full text] [doi: 10.1111/hex.12670] [Medline: 29380916]

7. Setiawan J, Mannix T, Sweet L. Understanding the effects of neonatal early discharge on parents: a literature review. J Perinat Neonatal Nurs 2019;33(2):170-188. [doi: 10.1097/JPN.0000000000000395] [Medline: 31021943]
8. Flierman M, Bossen D, de Boer R, Vriend E, van Nes F, van Kaam A, et al. Parents' information needs during the first year at home with their very premature born child; a qualitative study. PEC Innov 2024;4:100270 [FREE Full text] [doi: 10.1016/j.pecinn.2024.100270] [Medline: 38495319]
9. Orr T, Campbell-Yeo M, Benoit B, Hewitt B, Stinson J, McGrath P. Smartphone and internet preferences of parents: information needs and desired involvement in infant care and pain management in the NICU. Adv Neonatal Care 2017;17(2):131-138. [doi: 10.1097/ANC.0000000000000349] [Medline: 27759567]
10. Care4neo. 2025. URL: https://www.care4neo.nl/couveuseouders [accessed 2025-12-11]
11. Dol J, Richardson B, Boates T, Campbell-Yeo M. Learning to parent from Google? Evaluation of available online health evidence for parents of preterm infants requiring neonatal intensive care. Health Informatics J 2019;25(4):1265-1277 [FREE Full text] [doi: 10.1177/1460458217752564] [Medline: 29361867]
12. Leung CYY, Suskind DL. What parents know matters: parental knowledge at birth predicts caregiving behaviors at 9 months. J Pediatr 2020;221:72-80. [doi: 10.1016/j.jpeds.2019.12.021] [Medline: 31987656]
13. Chua JYX, Shorey S. Effectiveness of mobile application-based perinatal interventions in improving parenting outcomes: a systematic review. Midwifery 2022;114:103457 [FREE Full text] [doi: 10.1016/j.midw.2022.103457] [Medline: 35985142]
14. Eysenbach G, Powell J, Kuss O, Sa E. Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. JAMA 2002;287(20):2691-2700. [doi: 10.1001/jama.287.20.2691] [Medline: 12020305]
15. Richardson B, Dol J, Rutledge K, Monaghan J, Orovec A, Howie K, et al. Evaluation of mobile apps targeted to parents of infants in the neonatal intensive care unit: systematic app review. JMIR Mhealth Uhealth 2019;7(4):e11620 [FREE Full text] [doi: 10.2196/11620] [Medline: 30985282]
16. Spence CM, Stuyvenberg CL, Kane AE, Burnsed J, Dusing SC. Parent experiences in the NICU and transition to home. Int J Environ Res Public Health 2023;20(11):6050 [FREE Full text] [doi: 10.3390/ijerph20116050] [Medline: 37297654]
17. Granés L, Torà-Rocamora I, Palacio M, De la Torre L, Llupià A. Maternal educational level and preterm birth: exploring inequalities in a hospital-based cohort study. PLoS One 2023;18(4):e0283901. [doi: 10.1371/journal.pone.0283901] [Medline: 37018293]
18. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. Ann Intern Med 2011;155(2):97-107. [doi: 10.7326/0003-4819-155-2-201107190-00005] [Medline: 21768583]
19. Enlow E, Gray M, Wallace-Keeshen S, D'Agostino J, Abbasi S, Lorch S. Health literacy of parents of very preterm infants at NICU admission and discharge: a prospective cohort study. J Perinatol 2019;39(6):866-875. [doi: 10.1038/s41372-019-0340-y] [Medline: 30770882]
20. Donelle L, Hiebert B, Hall J. An investigation of mHealth and digital health literacy among new parents during COVID-19. Front Digit Health 2023;5:1212694 [FREE Full text] [doi: 10.3389/fdgth.2023.1212694] [Medline: 38333052]
21. Moher D, Shamseer L, Clarke M, Ghersi D, Liberati A, Petticrew M, PRISMA-P Group. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. Syst Rev 2015;4(1):1 [FREE Full text] [doi: 10.1186/2046-4053-4-1] [Medline: 25554246]
22. Grainger R, Devan H, Sangelaji B, Hay-Smith J. Issues in reporting of systematic review methods in health app-focused reviews: a scoping review. Health Informatics J 2020;26(4):2930-2945 [FREE Full text] [doi: 10.1177/1460458220952917] [Medline: 32914696]
23. Hall M, Challacombe F, Curran C, Shennan A, Story L. Googling preterm prelabour rupture of the membranes: a systematic review of patient information available on the internet. BJOG 2023;130(11):1298-1305. [doi: 10.1111/1471-0528.17498] [Medline: 37077130]
24. Stoyanov SR, Hides L, Kavanagh DJ, Zelenko O, Tjondronegoro D, Mani M. Mobile app rating scale: a new tool for assessing the quality of health mobile apps. JMIR Mhealth Uhealth 2015;3(1):e27 [FREE Full text] [doi: 10.2196/mhealth.3422] [Medline: 25760773]
25. Tency I, Van Hecke A, Coorevits P. Assessing the quality of pregnancy apps through development and validation of the Dutch version of the Mobile Application Rating Scale (MARS). 2019 Presented at: European Congress of Intrapartum Care; 2019; Turin p. A.
26. Shoemaker SJ, Wolf MS, Brach C. Development of the patient education materials assessment tool (PEMAT): a new measure of understandability and actionability for print and audiovisual patient information. Patient Educ Couns 2014;96(3):395-403 [FREE Full text] [doi: 10.1016/j.pec.2014.05.027] [Medline: 24973195]
27. Doron MW, Trenti-Paroli E, Linden DW. Supporting parents in the NICU: A new app from the US, 'MyPreemie'. J Neonatal Nurs 2013;19(6):303-307. [doi: 10.1016/j.jnn.2013.08.005]
28. Jani S, Nguyen A, Abraham Z, Scala M, Blumenfeld Y, Morton J, et al. PretermConnect: Leveraging mobile technology to mitigate social disadvantage in the NICU and beyond. Semin Perinatol 2021;45(4):151413 [FREE Full text] [doi: 10.1016/j.semperi.2021.151413] [Medline: 33888330]

29. Lee H, Jin S, Henning-Smith C, Lee J, Lee J. Role of health literacy in health-related information-seeking behavior online: cross-sectional study. J Med Internet Res 2021;23(1):e14088 [FREE Full text] [doi: 10.2196/14088] [Medline: 33502332]
30. Polizzi C, Perricone G, Morales MR, Burgio S. A study of maternal competence in preterm birth condition, during the transition from hospital to home: an early intervention program's proposal. Int J Environ Res Public Health 2021;18(16):8670 [FREE Full text] [doi: 10.3390/ijerph18168670] [Medline: 34444418]
31. Garfield CF, Kerrigan E, Christie R, Jackson KL, Lee YS. A mobile health intervention to support parenting self-efficacy in the neonatal intensive care unit from admission to home. J Pediatr 2022;244:92-100. [doi: 10.1016/j.jpeds.2022.01.004] [Medline: 35033562]
32. Estacio EV, Whittle R, Protheroe J. The digital divide: examining socio-demographic factors associated with health literacy, access and use of internet to seek health information. J Health Psychol 2019;24(12):1668-1675. [doi: 10.1177/1359105317695429] [Medline: 28810415]
33. Giebel GD, Speckemeier C, Abels C, Plescher F, Börchers K, Wasem J, et al. Problems and barriers related to the use of digital health applications: scoping review. J Med Internet Res 2023;25:e43808 [FREE Full text] [doi: 10.2196/43808] [Medline: 37171838]
34. Noorbergen TJ, Adam MTP, Teubner T, Collins CE. Using co-design in mobile health system development: a qualitative study with experts in co-design and mobile health system development. JMIR Mhealth Uhealth 2021;9(11):e27896 [FREE Full text] [doi: 10.2196/27896] [Medline: 34757323]
35. van Gemert-Pijnen JEWC, Nijland N, van Limburg M, Ossebaard HC, Kelders SM, Eysenbach G, et al. A holistic framework to improve the uptake and impact of eHealth technologies. J Med Internet Res 2011;13(4):e111 [FREE Full text] [doi: 10.2196/jmir.1672] [Medline: 22155738]
36. Garfield CF, Lee YS, Kim HN, Rutsohn J, Kahn JY, Mustanski B, et al. Supporting parents of premature infants transitioning from the NICU to home: a pilot randomized control trial of a smartphone application. Internet Interv 2016;4(Pt 2):131-137 [FREE Full text] [doi: 10.1016/j.invent.2016.05.004] [Medline: 27990350]
37. Huang Z, Benyoucef M. A systematic literature review of mobile application usability: addressing the design perspective. Univ Access Inf Soc 2022;22(3):715-735. [doi: 10.1007/s10209-022-00903-w]
38. The MARS and PEMAT scores from two independent reviewers. Figshare. 2025. URL: https://figshare.com/s/646475d0d75cdf995771 [accessed 2025-12-15]

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

Edited by J zhang; submitted 01.Oct.2024; peer-reviewed by I Tency, A Perez-Navarro; comments to author 29.May.2025; revised version received 12.Nov.2025; accepted 08.Dec.2025; published 19.Jan.2026.

Please cite as:
Jeukens-Visser M, Flierman M, Möller E, Giezeman R, Engelbert R, Bossen D
Evaluating Mobile Information Apps for Parents of Preterm Infants After Hospital Discharge: Systematic App Review
JMIR Pediatr Parent 2026;9:e67085
URL: https://pediatrics.jmir.org/2026/1/e67085
doi:10.2196/67085
PMID:

Assessing Caregiver Comfort With Linking the Health Care System and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC)

K Alexander Soltany[1], MD, MPH; Kristina H Lewis[2], MD, MPH, SM; Beatriz Ospino-Sanchez[2], BS; Angelina Pack[2], AA; Kimberly Montez[3], MD, MPH

[1]Office of Student Affairs, Wake Forest University School of Medicine, Winston-Salem, NC, United States

[2]Department of Epidemiology & Prevention, Wake Forest University School of Medicine, Winston-Salem, NC, United States

[3]Department of Pediatrics, Wake Forest University School of Medicine, One Medical Center Blvd, Winston-Salem, NC, United States

Corresponding Author:
Kimberly Montez, MD, MPH
Department of Pediatrics, Wake Forest University School of Medicine, One Medical Center Blvd, Winston-Salem, NC, United States

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.

(JMIR Pediatr Parent 2026;9:e89731) doi:10.2196/89731

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].

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).

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.

Funding

This project was supported by a grant from Healthy Eating Research, a national program of the Robert Wood Johnson Foundation. This project was also supported by the Wake Forest University School of Medicine Clinical and Translational Science Institute, funded by the National Center for Advancing Translational Sciences (NCATS), National Institutes of Health, through Grant Award Number UM1TR004929. The funding organizations had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

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]

References

1. WIC benefits and services. USDA food and nutrition service. 2025. URL: https://www.fns.usda.gov/wic/benefits-services [accessed 2025-06-24]
2. Venkataramani M, Ogunwole SM, Caulfield LE, et al. Maternal, infant, and child health outcomes associated with the special supplemental nutrition program for women, infants, and children: a systematic review. Ann Intern Med 2022 Oct;175(10):1411-1422. [doi: 10.7326/M22-0604] [Medline: 36063550]
3. Davis RA, Leavitt HB, Chau M. A review of interventions to increase WIC enrollment and participation. J Community Health 2022 Dec;47(6):990-1000. [doi: 10.1007/s10900-022-01131-2] [Medline: 35962868]
4. Bailey-Davis L, Kling SMR, Cochran WJ, et al. Integrating and coordinating care between the Women, Infants, and Children Program and pediatricians to improve patient-centered preventive care for healthy growth. Transl Behav Med 2018 Nov 21;8(6):944-952. [doi: 10.1093/tbm/ibx046] [Medline: 29370433]
5. McCall A, Strahley AE, Martin-Fernandez KW, et al. WIC staff and healthcare professional perceptions of an EHR intervention to facilitate referrals to and improve communication and coordination with WIC: A qualitative study. J Clin Transl Sci 2024;8(1):e47. [doi: 10.1017/cts.2024.488] [Medline: 38510692]
6. Monroe BS, Rengifo LM, Wingler MR, et al. Assessing and improving WIC enrollment in the primary care setting: a quality initiative. Pediatrics 2023 Aug 1;152(2):e2022057613. [doi: 10.1542/peds.2022-057613] [Medline: 37439134]
7. Epic CommunityLink. Epic. 2023. URL: https://link.epic.com [accessed 2024-01-16]
8. National survey of WIC participants. : United States Department of Agriculture; 2001 URL: https://fns-prod.azureedge.us/sites/default/files/WICSurvey.pdf [accessed 2026-05-01]
9. Hager ER, Quigg AM, Black MM, et al. Development and validity of a 2-item screen to identify families at risk for food insecurity. Pediatrics 2010 Jul;126(1):e26-e32. [doi: 10.1542/peds.2009-3146] [Medline: 20595453]
10. Ali S, Gibbs SE, Wiseman K, et al. A qualitative study to understand parental, health care provider and WIC nutritionist perspectives on early childhood beverage choices for WIC-enrolled families in a Southeastern US health system. Matern Child Health J 2025 May;29(5):628-638. [doi: 10.1007/s10995-025-04075-w] [Medline: 40167858]
11. Ashbrook A, Essel K, Montez K, Bennett-Tejes D. Screen and intervene: a toolkit for pediatricians to address food insecurity. : Food Research & Action Center; 2021 URL: https://frac.org/wp-content/uploads/FRAC_AAP_Toolkit_2021_032122.pdf [accessed 2025-10-25]
12. Health care providers outreach toolkit. : National WIC Association; 2024 URL: https://media.nwica.org/hcp%20toolkit%20-%20with%20how%20to%20establish%20referral%20and%20data%20sharing%20process.pdf [accessed 2026-05-01]

13. Summary of the HIPAA privacy rule. United States Department of Health and Human Services. 2025. URL: https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html [accessed 2026-03-23]

Abbreviations:

EHR: electronic health record
FI: food insecurity
WIC: Special Supplemental Nutrition Program for Women, Infants, and Children

Edited by M Balcarras; submitted 16.Dec.2025; peer-reviewed by J Perdomo, Y Ma; revised version received 21.Apr.2026; accepted 21.Apr.2026; published 06.May.2026.

Please cite as:
Soltany KA, Lewis KH, Ospino-Sanchez B, Pack A, Montez K
Assessing Caregiver Comfort With Linking the Health Care System and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC)
JMIR Pediatr Parent 2026;9:e89731
URL: https://pediatrics.jmir.org/2026/1/e89731
doi:10.2196/89731

Clinician Perspectives on Commonly Used Online Sexual and Reproductive Health Resources for Adolescents: Qualitative Analysis

Cambray Smith[1,2,3], PhD; Sarah Rebbeor[3], MS; Elizabeth Pleasants[4], MPH, DrPH; Leah Frerichs[1], PhD; Bianca A Allison[5], MPH, MD

[1]Department of Health Policy and Management, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, 135 Dauer Dr., 1101 McGavran-Greenberg Hall CB #7411, Chapel Hill, NC, United States

[2]Medical Scientist Training Program, School of Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

[3]School of Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

[4]Center for Women's Health Research, School of Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

[5]Department of Pediatrics, School of Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

Corresponding Author:
Cambray Smith, PhD
Department of Health Policy and Management, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, 135 Dauer Dr., 1101 McGavran-Greenberg Hall CB #7411, Chapel Hill, NC, United States

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.

(JMIR Pediatr Parent 2026;9:e89643) doi:10.2196/89643

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.

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.

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 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).

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)

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 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.

Acknowledgments

The authors thank the participants for sharing their insight and Melissa Gilkey, PhD; Betsy Sleath, PhD; and Christopher Shea, PhD for assistance with the broader qualitative study. The authors also thank Youth Reproductive Equity members for helpful feedback on high-level findings and manuscript framing.

Microsoft Copilot based on the GPT-4 architecture was used to assist with decreasing the word count after the full manuscript had been drafted and reviewed by multiple coauthors. No other artificial intelligence was used for any part of this project. The authors take full responsibility for the content edited. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health, Triangle Community Foundation, or the authors' institutions.

Funding

Research reported in this publication was supported by the Eunice Kennedy Shriver National Institute of Child Health & Human Development of the National Institutes of Health under award F30HD116454 (CS) and the National Center for Advancing Translational Science under award 1K12TR004416 (BAA). CS is a recipient of the Gertrude B. Elion Mentored Medical Student Research Award of Triangle Community Foundation. The funders had no involvement in the study design, data collection, analysis, interpretation, or the writing of the manuscript.

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]

References

1. Kelleher E, Moreno MA. Hot topics in social media and reproductive health. J Pediatr Adolesc Gynecol 2020 Dec;33(6):619-622. [doi: 10.1016/j.jpag.2020.06.016] [Medline: 32599170]
2. Allison BA, Odom RM, Vear K, Hoopes AJ, Maslowsky J. A nationwide sample of adolescents and young adults share where they would go online for abortion information after Dobbs v. Jackson. J Adolesc Health 2023 Dec;73(6):1153-1157. [doi: 10.1016/j.jadohealth.2023.05.010] [Medline: 37389530]
3. Kirkpatrick CE, Lawrie LL. TikTok as a source of health information and misinformation for young women in the United States: survey study. JMIR Infodemiology 2024 May 21;4:e54663. [doi: 10.2196/54663] [Medline: 38772020]
4. Wang ML, Togher K. Health misinformation on social media and adolescent health. JAMA Pediatr 2024 Feb 1;178(2):109-110. [doi: 10.1001/jamapediatrics.2023.5282] [Medline: 38079180]
5. Smith C, Rebbeor S, Gilkey MB, et al. Clinician recommendations for discussing online health information with adolescents: a qualitative study. J Prim Care Community Health 2026 Apr 6;17:21501319261437319. [doi: 10.1177/21501319261437319] [Medline: 41943225]
6. Kowalski CP, Nevedal AL, Finley EP, et al. Planning for and Assessing Rigor in Rapid Qualitative Analysis (PARRQA): a consensus-based framework for designing, conducting, and reporting. Implement Sci 2024 Oct 11;19(1):71. [doi: 10.1186/s13012-024-01397-1] [Medline: 39394597]
7. Antonishak J, Suellentrop K, Steiner RJ, Lloyd L, Axelson SM. Catalyzing technology-based innovation in teen pregnancy prevention: an implementation model and findings from a human-centered design initiative. Prev Sci 2023 Dec;24(Suppl 2):185-195. [doi: 10.1007/s11121-023-01523-3] [Medline: 37466808]
8. Caballero TM, Carvajal DN, Crockett AH, Wilkinson TA. Supporting sexual and reproductive health for immigrant families across the lifespan. Acad Pediatr 2024 Jul;24(5S):19-24. [doi: 10.1016/j.acap.2023.05.021] [Medline: 38991797]
9. Chen J, Wang Y. Social media use for health purposes: systematic review. J Med Internet Res 2021 May 12;23(5):e17917. [doi: 10.2196/17917] [Medline: 33978589]
10. Sexual & reproductive health resources for adolescents and young adults. Society for Adolescent Health and Medicine. 2025. URL: https://adolescenthealth.org/resources/resources-for-adolescents-and-parents/sexual-reproductive-health-resources-for-adolescents-and-young-adults [accessed 2025-11-04]

Abbreviations

SRH: sexual and reproductive health

Edited by M Balcarras, S Badawy; submitted 15.Dec.2025; peer-reviewed by N Levitz, T Albritton; revised version received 02.Mar.2026; accepted 04.Mar.2026; published 23.Apr.2026.

Please cite as:
Smith C, Rebbeor S, Pleasants E, Frerichs L, Allison BA
Clinician Perspectives on Commonly Used Online Sexual and Reproductive Health Resources for Adolescents: Qualitative Analysis
JMIR Pediatr Parent 2026;9:e89643
URL: https://pediatrics.jmir.org/2026/1/e89643
doi:10.2196/89643

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

Nursat Jahan[1], BS; Seung Yup Lee[2], PhD; Nafisa Anjum[1], MS; Monica Swahn[3], PhD; Sangsun Choi[4], PhD; Andrew Peachey[5], DrPH; Sweta Sneha[6], PhD; Chitalu Kabwe[7], PhD; Nazmus Sakib[1], PhD

[1]College of Computing and Software Engineering, Kennesaw State University, Marietta Campus, J3218 Atrium Building, Marietta, GA, United States
[2]Department of Electrical and Computer Engineering, Kennesaw State University, Marietta Campus, Marietta, GA, United States
[3]School of Public Health, Virginia Commonwealth University, Richmond, VA, United States
[4]School of Communication & Media, Kennesaw State University, Kennesaw Campus, Kennesaw, GA, United States
[5]Department of Health Promotion and Physical Education, Kennesaw State University, Kennesaw Campus, Kennesaw, GA
[6]Wright School of Business, Dalton State College, Dalton, GA
[7]Michael A. Leven School of Management, Kennesaw State University, Kennesaw Campus, Kennesaw, GA, United States

Corresponding Author:
Nazmus Sakib, PhD
College of Computing and Software Engineering, Kennesaw State University, Marietta Campus, J3218 Atrium Building, Marietta, GA, United States

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.

Trial Registration: PROSPERO 2025 CRD420251172487; https://tinyurl.com/3djampu6

(JMIR Pediatr Parent 2026;9:e76937) doi:10.2196/76937

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].

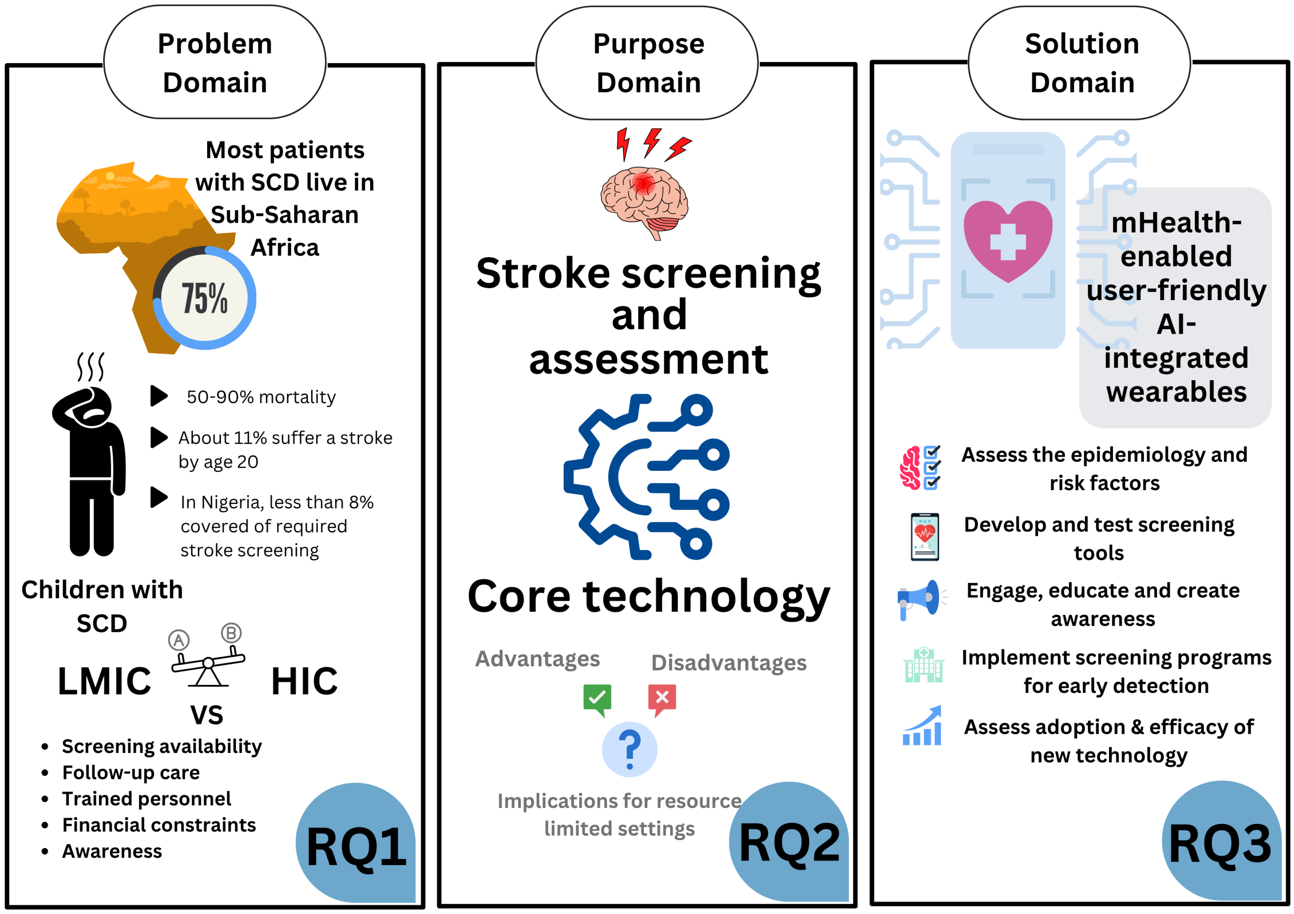
mHealth technologies can significantly impact the management of SCD, especially in LRS [26]. For instance, mobile apps can monitor symptoms such as pain episodes [27,28], track disease progression, and enable timely interventions while also supporting patient engagement [29-31]. Overall, mHealth solutions 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 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.

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.

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 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

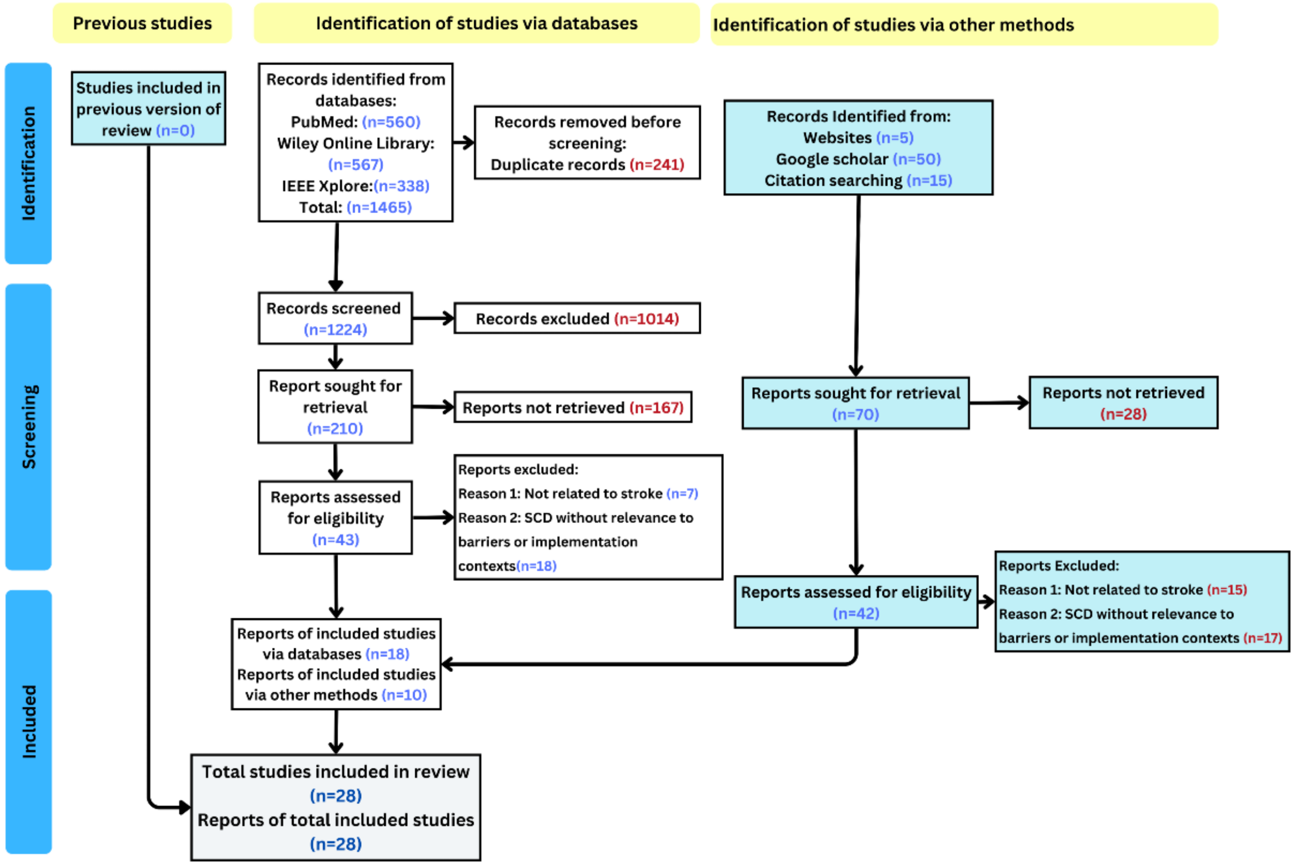
This study did not involve online surveys or web-based data collection. All analyzed data were obtained from previously published peer-reviewed studies, and 1 clearly identified preprint study was found through database searches. Therefore, the CHERRIES (Checklist for Reporting Results of Internet E-Surveys) 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 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, 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].

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].

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].

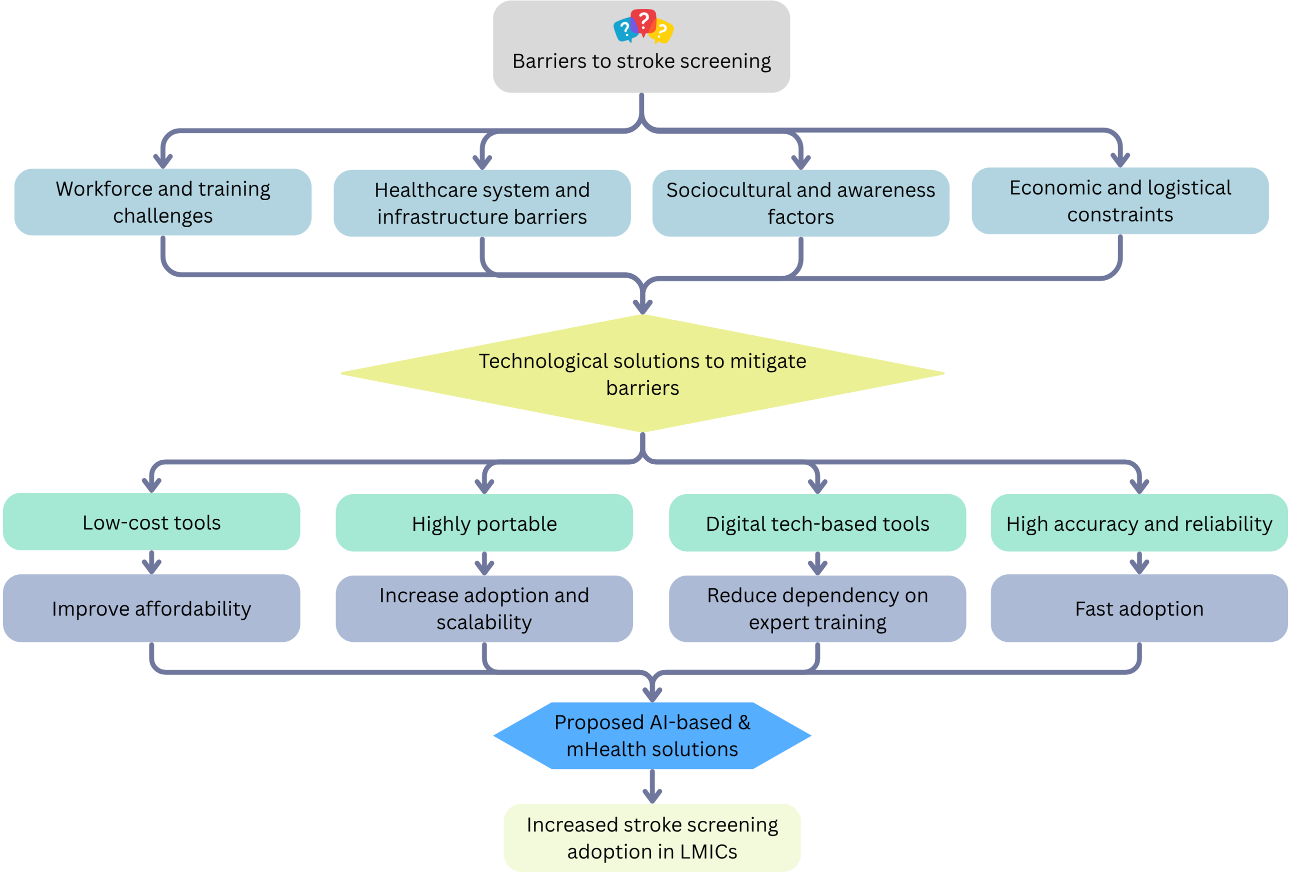
Outcomes and Challenges

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

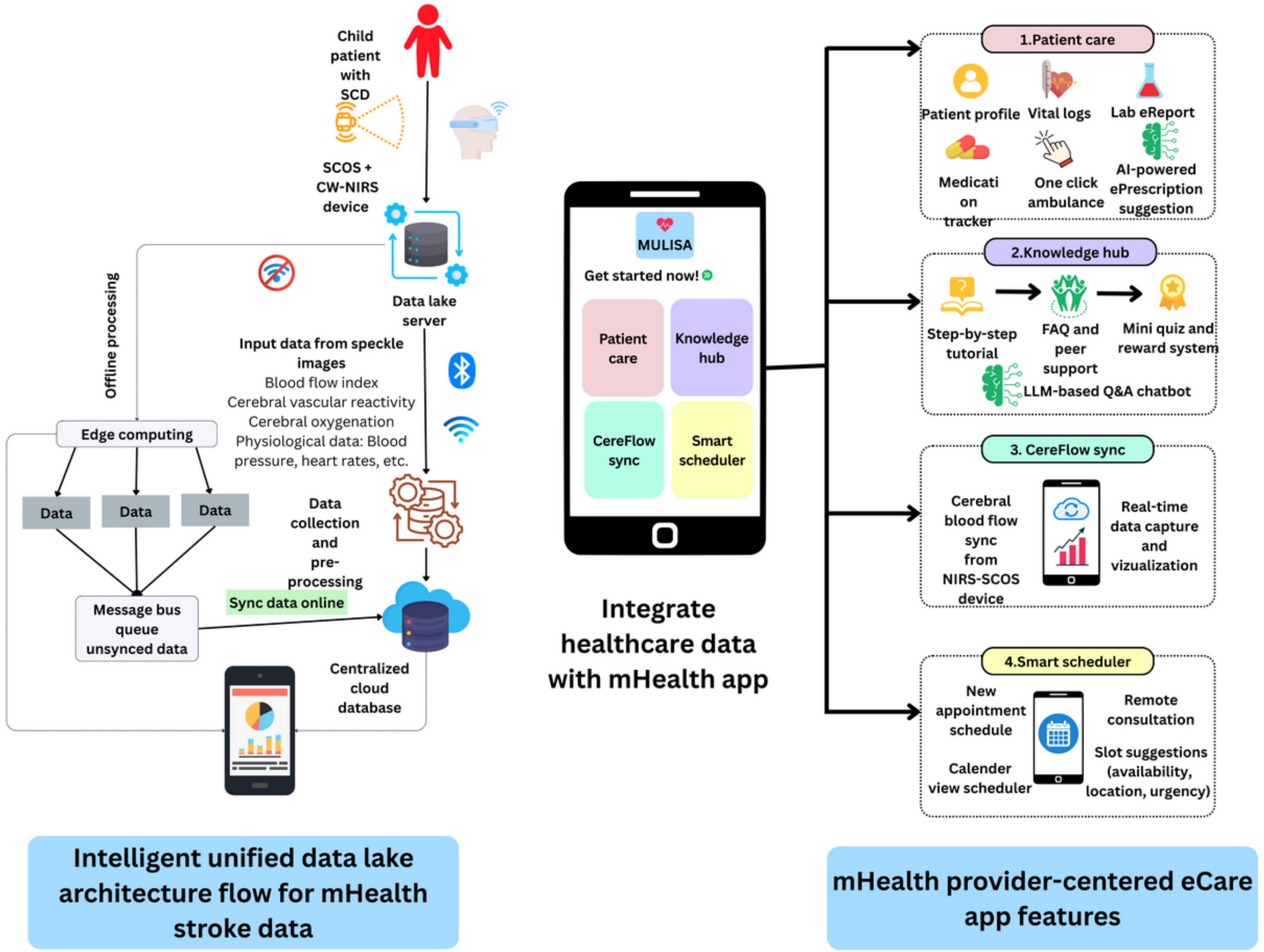
We integrate our findings from RQ1 and RQ2 to build a conceptual framework that illustrates how various barriers in LRS impact stroke screening accessibility and how different aspects of technological solutions for stroke screening can lead to an innovative approach that increases the adoption of stroke 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 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

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 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.

Acknowledgments

The authors thank the mHealth Research Laboratory at Kennesaw State University for their contributions to this systematic review. The authors also appreciate the valuable input of our multidisciplinary collaborators who contributed to the conceptual development of the modular unified lightweight intelligent stroke assistant (MULISA) framework. The authors did not use generative artificial intelligence to write any portions of this manuscript.

Funding

This study was supported by Kennesaw State University Office of Research Grand Grant Challenge Fall 2024.

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]

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]

References

1. Grosse SD, Odame I, Atrash HK, Amendah DD, Piel FB, Williams TN. Sickle cell disease in Africa: a neglected cause of early childhood mortality. Am J Prev Med 2011 Dec;41(6 Suppl 4):S398-S405. [doi: 10.1016/j.amepre.2011.09.013] [Medline: 22099364]
2. Aygun B, Odame I. A global perspective on sickle cell disease. Pediatr Blood Cancer 2012 Aug;59(2):386-390. [doi: 10.1002/pbc.24175] [Medline: 22535620]
3. Adams RJ, McKie VC, Hsu L, et al. Prevention of a first stroke by transfusions in children with sickle cell anemia and abnormal results on transcranial Doppler ultrasonography. N Engl J Med 1998 Jul 2;339(1):5-11. [doi: 10.1056/NEJM199807023390102] [Medline: 9647873]
4. Ndeezi G, Kiyaga C, Hernandez AG, et al. Burden of sickle cell trait and disease in the Uganda Sickle Surveillance Study (US3): a cross-sectional study. Lancet Glob Health 2016 Mar;4(3):e195-e200. [doi: 10.1016/S2214-109X(15)00288-0] [Medline: 26833239]
5. Tusuubira SK, Nakayinga R, Mwambi B, Odda J, Kiconco S, Komuhangi A. Knowledge, perception and practices towards sickle cell disease: a community survey among adults in Lubaga division, Kampala Uganda. BMC Public Health 2018 Apr 27;18(1):561. [doi: 10.1186/s12889-018-5496-4] [Medline: 29703184]
6. Obeagu EI, Obeagu GU. Living with sickle cell in Uganda: a comprehensive perspective on challenges, coping strategies, and health interventions. Medicine (Abingdon) 2024;103(51):e41062. [doi: 10.1097/MD.0000000000041062]
7. Stocks J, Ibrahim S, Park L, Huchko M. Mobile phone ownership and use among women screening for cervical cancer in a community-based setting in western Kenya: Observational study. JMIR Public Health Surveill 2022 Jun 7;8(6):e28885. [doi: 10.2196/28885] [Medline: 35671089]
8. Hong W. Advances and opportunities of mobile health in the postpandemic era: smartphonization of wearable devices and wearable deviceization of smartphones. JMIR Mhealth Uhealth 2024 Jan 22;12:e48803. [doi: 10.2196/48803] [Medline: 38252596]
9. Evidence-based management of sickle cell disease: expert panel report, 2014. : National Heart, Lung, and Blood Institute; 2014 URL: https://www.nhlbi.nih.gov/sites/default/files/media/docs/sickle-cell-disease-report%20020816_0.pdf [accessed 2026-02-04]
10. Galadanci AA, Galadanci NA, Jibir BW, et al. Approximately 40 000 children with sickle cell anemia require screening with TCD and treating with hydroxyurea for stroke prevention in three states in northern Nigeria. Am J Hematol 2019 Nov;94(11):E305-E307. [doi: 10.1002/ajh.25616]
11. Kanter J, Phillips S, Schlenz AM, et al. Transcranial Doppler screening in a current cohort of children with sickle cell anemia: results from the DISPLACE study. J Pediatr Hematol Oncol 2021 Nov 1;43(8):e1062-e1068. [doi: 10.1097/MPH.0000000000002103] [Medline: 33625093]
12. Guy D, Bagnall R, Morgan RL, et al. Impact of transcranial Doppler screening on stroke prevention in children and adolescents with sickle cell disease: a systematic review and meta-analysis. Blood Rev 2025 Jan;69:101253. [doi: 10.1016/j.blre.2024.101253] [Medline: 39710547]
13. Purkayastha S, Sorond F. Transcranial Doppler ultrasound: technique and application. Semin Neurol 2012 Sep;32(4):411-420. [doi: 10.1055/s-0032-1331812] [Medline: 23361485]
14. Idro R, Boehme AK, Kawooya M, et al. Brain magnetic resonance imaging and angiography in children with sickle cell anaemia in uganda in a cross-sectional sample. J Stroke Cerebrovasc Dis 2022 Apr;31(4):106343. [doi: 10.1016/j.jstrokecerebrovasdis.2022.106343] [Medline: 35158150]
15. Strumph K, Morrone K, Dhillon P, et al. Impact of magnetic resonance angiography parameters on stroke prevention therapy in pediatric patients with sickle cell anemia. Pediatr Blood Cancer 2023 Feb;70(2):e30109. [doi: 10.1002/pbc.30109] [Medline: 36441603]
16. Baltensperger A, Mirsky D, Maloney J, et al. Cost and utility of routine contrast-enhanced neck MRA in a pediatric MRI stroke evaluation protocol. AJNR Am J Neuroradiol 2019 Dec;40(12):2143-2145. [doi: 10.3174/ajnr.A6315] [Medline: 31727745]

17. Radenovic L. Cerebral ischemia biomarkers: Their roles in early diagnosis and prognosis with potential clinical applications. Brain Heart 2024 Aug;2(3):2750. [doi: 10.36922/bh.2750]
18. Bamodu OA, Chan L, Wu CH, Yu SF, Chung CC. Beyond diagnosis: leveraging routine blood and urine biomarkers to predict severity and functional outcome in acute ischemic stroke. Heliyon 2024 Feb 29;10(4):e26199. [doi: 10.1016/j.heliyon.2024.e26199] [Medline: 38380044]
19. Green NS, Rosano C, Bangirana P, et al. Neurofilament light chain: a potential biomarker for cerebrovascular disease in children with sickle cell anaemia. Br J Haematol 2023 Nov;203(3):460-467. [doi: 10.1111/bjh.19036] [Medline: 37581299]
20. Huang YX, Mahler S, Abedi A, et al. Correlating stroke risk with non-invasive cerebrovascular perfusion dynamics using a portable speckle contrast optical spectroscopy laser device. Biomed Opt Express 2024 Oct 1;15(10):6083-6097. [doi: 10.1364/BOE.534796] [Medline: 39421763]
21. Taha BA, Kadhim AC, Addie AJ, et al. Optical spectroscopy of cerebral blood flow for tissue interrogation in ischemic stroke diagnosis. ACS Chem Neurosci 2025 Mar 5;16(5):895-907. [doi: 10.1021/acschemneuro.4c00809] [Medline: 39979233]
22. Haveman ME, van Rossum MC, Vaseur RME, et al. Continuous monitoring of vital signs with wearable sensors during daily life activities: validation study. JMIR Form Res 2022 Jan 7;6(1):e30863. [doi: 10.2196/30863] [Medline: 34994703]
23. Chauhan GK, Vavken P, Jacob C. Mobile apps and wearable devices for cardiovascular health: narrative review. JMIR Mhealth Uhealth 2025 Apr 4;13:e65782. [doi: 10.2196/65782] [Medline: 40184552]
24. Anliker U, Ward JA, Lukowicz P, et al. AMON: a wearable multiparameter medical monitoring and alert system. IEEE Trans Inform Technol Biomed 2004 Dec;8(4):415-427. [doi: 10.1109/TITB.2004.837888]
25. Swahn MH, Gittner KB, Lyons MJ, et al. Advancing mHealth research in low-resource settings: young women's insights and implementation challenges with wearable smartwatch devices in Uganda. Sensors (Basel) 2024 Aug 29;24(17):5591. [doi: 10.3390/s24175591] [Medline: 39275502]
26. Kumar R, Das A. The potential of mHealth as a game changer for the management of sickle cell disease in India. JMIR Mhealth Uhealth 2021 Apr 13;9(4):e25496. [doi: 10.2196/25496] [Medline: 33847598]
27. Lu L, Zhang J, Xie Y, et al. Wearable health devices in health care: narrative systematic review. JMIR Mhealth Uhealth 2020 Nov 9;8(11):e18907. [doi: 10.2196/18907] [Medline: 33164904]
28. Martin CL, Bakker CJ, Breth MS, et al. The efficacy of mobile health interventions used to manage acute or chronic pain: a systematic review. Res Nurs Health 2021 Feb;44(1):111-128. [doi: 10.1002/nur.22097] [Medline: 33341989]
29. Birkhoff SD, Smeltzer SC. Perceptions of smartphone user‐centered mobile health tracking apps across various chronic illness populations: an integrative review. J Nurs Scholarsh 2017 Jul;49(4):371-378. [doi: 10.1111/jnu.12298] [Medline: 28605151]
30. Sleurs K, Seys SF, Bousquet J, et al. Mobile health tools for the management of chronic respiratory diseases. Allergy 2019 Jul;74(7):1292-1306. [doi: 10.1111/all.13720] [Medline: 30644567]
31. El-Rashidy N, El-Sappagh S, Islam SMR, El-Bakry HM, Abdelrazek S. Mobile health in remote patient monitoring for chronic diseases: Principles, trends, and challenges. Diagnostics (Basel) 2021 Mar 29;11(4):607. [doi: 10.3390/diagnostics11040607] [Medline: 33805471]
32. Thompson AN, Dawson DR, Legasto-Mulvale JM, et al. Mobile technology–based interventions for stroke self-management support: scoping review. JMIR Mhealth Uhealth 2023 Dec 6;11:e46558. [doi: 10.2196/46558] [Medline: 38055318]
33. Afolalu OO, Akpor OA, Afolalu SA, Afolalu OF, Oyewole HB, Oke AO. Sickle cell disease epidemiology and management in africa: current trends and future directions in digital health technologies. Presented at: 2024 IEEE 5th International Conference on Electro-Computing Technologies for Humanity (NIGERCON); Nov 26-28, 2024. [doi: 10.1109/NIGERCON62786.2024.10926989]
34. Cronin RM, Quaye N, Liu X, et al. Usage of a multipurpose mHealth app among adults with sickle cell disease: randomized controlled trial. JMIR Form Res 2025 Jun 5;9:e67906. [doi: 10.2196/67906] [Medline: 40472251]
35. Niyomyart A, Ruksakulpiwat S, Benjasirisan C, et al. Current status of barriers to mHealth access among patients with stroke and steps toward the digital health era: systematic review. JMIR Mhealth Uhealth 2024 Aug 22;12:e54511. [doi: 10.2196/54511] [Medline: 39173152]
36. Eaton C, Vallejo N, McDonald X, et al. User engagement with mHealth interventions to promote treatment adherence and self-management in people with chronic health conditions: systematic review. J Med Internet Res 2024 Sep 24;26:e50508. [doi: 10.2196/50508] [Medline: 39316431]
37. Iribarren SJ, Akande TO, Kamp KJ, Barry D, Kader YG, Suelzer E. Effectiveness of mobile apps to promote health and manage disease: systematic review and meta-analysis of randomized controlled trials. JMIR Mhealth Uhealth 2021 Jan 11;9(1):e21563. [doi: 10.2196/21563] [Medline: 33427672]
38. Hankins JS, Shah N, DiMartino L, et al. Integration of mobile health into sickle cell disease care to increase hydroxyurea utilization: protocol for an efficacy and implementation study. JMIR Res Protoc 2020 Jul 14;9(7):e16319. [doi: 10.2196/16319] [Medline: 32442144]
39. van Zyl C, Badenhorst M, Hanekom S, Heine M. Unravelling “low-resource settings”: a systematic scoping review with qualitative content analysis. BMJ Glob Health 2021 Jun;6(6):e005190. [doi: 10.1136/bmjgh-2021-005190] [Medline: 34083239]

40. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021 Mar 29;372:n71. [doi: 10.1136/bmj.n71] [Medline: 33782057]
41. Ahmed KKM, Al Dhubaib BE. Zotero: a bibliographic assistant to researcher. J Pharmacol Pharmacother 2011 Oct;2(4):303-305. [doi: 10.4103/0976-500X.85940] [Medline: 22025866]
42. Phillips SM, Schlenz AM, Mueller M, Melvin CL, Adams RJ, Kanter J. Identified barriers and facilitators to stroke risk screening in children with sickle cell anemia: results from the DISPLACE consortium. Implement Sci Commun 2021 Aug 10;2(1):87. [doi: 10.1186/s43058-021-00192-z] [Medline: 34376249]
43. Edwards JG, Humphrey DT, Mueller M, et al. Socioeconomic status and stroke risk in pediatric sickle cell disease: a DISPLACE study secondary analysis. Pediatr Blood Cancer 2026 Jan;73(1):e32112. [doi: 10.1002/pbc.32112]
44. Nri-Ezedi CA, Efobi CC, Campbell A. Diagnostic potential of platelet-neutrophil ratio (PNR) for stroke risk in sickle cell anaemia children authors and affiliations. Authorea Preprints. Preprint posted online on Jun 9, 2024. [doi: 10.22541/au.172081281.17980876/v1]
45. Cai T, Wong K, Wang JZ, et al. M 3 stroke: multi-modal mobile AI for emergency triage of mild to moderate acute strokes. Presented at: 2024 IEEE EMBS International Conference on Biomedical and Health Informatics (BHI); Nov 10-13, 2024. [doi: 10.1109/BHI62660.2024.10913652]
46. Bello-Manga H, Haliru L, Ahmed K, et al. Barriers and facilitators to a task-shifted stroke prevention program for children with sickle cell anemia in a community hospital: a qualitative study. Implement Sci Commun 2024 Jan 15;5(1):10. [doi: 10.1186/s43058-023-00534-z] [Medline: 38225633]
47. Ghafuri DL, Covert Greene B, Musa B, et al. Capacity building for primary stroke prevention teams in children living with sickle cell anemia in Africa. Pediatr Neurol 2021 Dec;125:9-15. [doi: 10.1016/j.pediatrneurol.2021.08.010] [Medline: 34563875]
48. Bello-Manga H, Haliru L, Ahmed KA, et al. Primary prevention of stroke in children with sickle cell Anemia in Nigeria: protocol for a mixed methods implementation study in a community hospital. JMIR Res Protoc 2022 Jun 13;11(6):e37927. [doi: 10.2196/37927] [Medline: 35700018]
49. Ghafuri DL, Abdullahi SU, Dambatta AH, et al. Establishing sickle cell disease stroke prevention teams in Africa is feasible: program evaluation using the RE-AIM framework. J Pediatr Hematol Oncol 2022 Jan 1;44(1):e56-e61. [doi: 10.1097/MPH.0000000000002179] [Medline: 34001783]
50. Anand Kumar M, Abirami N, Guru Prasad MS, Mohankumar M. Stroke disease prediction based on ECG signals using deep learning techniques. Presented at: 2022 International Conference on Computational Intelligence and Sustainable Engineering Solutions (CISES); May 20-21, 2022. [doi: 10.1109/CISES54857.2022.9844403]
51. Vasa S, Savani S, Thaker A, Bhangale P. StrokeAlert: early detection of minor strokes. Presented at: 2024 4th International Conference on Advancement in Electronics & Communication Engineering (AECE); Nov 22-23, 2024. [doi: 10.1109/AECE62803.2024.10911730]
52. Shah M, Sahasranaman K, Sondur C, Nadagire R, Bhatia G. CDSS based mobile application for stroke assistance. Presented at: 2024 Second International Conference on Inventive Computing and Informatics (ICICI); Jun 11-12, 2024. [doi: 10.1109/ICICI62254.2024.00078]
53. Sharma M, Kaur I, Saini G, Thakur V, Mishra A. Predictive modeling for stroke risk assessment using machine learning. Presented at: 2024 International Conference on Intelligent Systems for Cybersecurity (ISCS); May 3-4, 2024. [doi: 10.1109/ISCS61804.2024.10581155]
54. Latham TS, Czabanowska K, Babich S, Yego-Kosgei F, Shook LM, Ware RE. Primary stroke screening and hydroxyurea treatment for sickle cell anemia in pediatric healthcare settings in East and Central Africa: a narrative review of capacity gaps and opportunities. Public Health Rev 2025;46:1608359. [doi: 10.3389/phrs.2025.1608359] [Medline: 40443481]
55. Mwangi LW, Abuga JA, Cottrell E, Kariuki SM, Kinyanjui SM, Newton C. Barriers to access and utilization of healthcare by children with neurological impairments and disability in low-and middle-income countries: a systematic review. Wellcome Open Res 2022 Mar;6:61. [doi: 10.12688/wellcomeopenres.16593.1]
56. Chen YH, Sawan M. Trends and challenges of wearable multimodal technologies for stroke risk prediction. Sensors (Basel) 2021 Jan 11;21(2):460. [doi: 10.3390/s21020460] [Medline: 33440697]
57. Zeng L, Li G, Xu J, et al. A wearable device for dynamic monitoring of cerebral blood flow based on electromagnetic coupling sensing. IEEE Sensors J 2023;23(23):29571-29584. [doi: 10.1109/JSEN.2023.3324309]
58. Tembo D, Moons P, Tshimanga T, et al. Optimizing transcranial Doppler screening for stroke prevention in young African children with sickle cell disease. Pediatr Blood Cancer 2025 Sep;72(9):e31861. [doi: 10.1002/pbc.31861]
59. Voi V, Gutierrez-Valle V, Cuzzubbo D, et al. Limited access to transcranial Doppler screening and stroke prevention for children with sickle cell disease in Europe: results of a multinational EuroBloodNet survey. Pediatr Blood Cancer 2024 Oct;71(10):e31190. [doi: 10.1002/pbc.31190] [Medline: 38984411]
60. Nieves RM, Latham T, Marte N, et al. Stroke prevention in Hispanic children with sickle cell anemia: the SACRED trial. Blood Adv 2025 Apr 22;9(8):1791-1800. [doi: 10.1182/bloodadvances.2024014327] [Medline: 39820633]
61. Mat Said Z, Musa KI, Tengku Ismail TA, et al. The effectiveness of Stroke Riskometer™ in improving stroke risk awareness in Malaysia: a study protocol of a cluster-randomized controlled trial. Neuroepidemiology 2021;55(6):436-446. [doi: 10.1159/000518853] [Medline: 34535608]

62. Olawade DB, Aderinto N, Clement David-Olawade A, et al. Integrating AI-driven wearable devices and biometric data into stroke risk assessment: a review of opportunities and challenges. Clin Neurol Neurosurg 2025 Feb;249:108689. [doi: 10.1016/j.clineuro.2024.108689] [Medline: 39675149]
63. Yusro M, Syam R, Idrus A, Apriyansa A. A machine learning-based mobile health application for early stroke risk prediction and prevention. Presented at: 2025 4th International Conference on Creative Communication and Innovative Technology (ICCIT); Aug 15-16, 2024. [doi: 10.1109/ICCIT65724.2025.11167669]
64. Paul L, Thomson K, Asibey SO, et al. Views of service users, their family or carers, and health care professionals on telerehabilitation for people with neurological conditions in Ghana: qualitative study. JMIR Mhealth Uhealth 2024 Mar 27;12:e49501. [doi: 10.2196/49501] [Medline: 38536218]
65. Saparamadu AADNS, Fernando P, Zeng P, et al. User-centered design process of an mHealth app for health professionals: case study. JMIR Mhealth Uhealth 2021 Mar 26;9(3):e18079. [doi: 10.2196/18079] [Medline: 33769297]
66. Anisha SA, Sen A, Bain C. Evaluating the potential and pitfalls of AI-powered conversational agents as humanlike virtual health carers in the remote management of noncommunicable diseases: scoping review. J Med Internet Res 2024 Jul 16;26:e56114. [doi: 10.2196/56114] [Medline: 39012688]
67. Giordanengo A, Årsand E, Woldaregay AZ, et al. Design and prestudy assessment of a dashboard for presenting self-collected health data of patients with diabetes to clinicians: Iterative approach and qualitative case study. JMIR Diabetes 2019 Jul 9;4(3):e14002. [doi: 10.2196/14002] [Medline: 31290396]
68. Feroz AS, De Vera K, Bragagnolo ND, Saleem S, Bhutta Z, Seto E. Understanding the needs of a mobile phone-based telemonitoring program for pregnant women at high risk for pre-eclampsia: interpretive qualitative description study. JMIR Form Res 2022 Feb 24;6(2):e32428. [doi: 10.2196/32428] [Medline: 35200152]

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

Edited by S Badawy; submitted 04.May.2025; peer-reviewed by A Kumurenzi, N Schulze; revised version received 30.Jan.2026; accepted 11.Feb.2026; published 06.Apr.2026.

Please cite as:
Jahan N, Lee SY, Anjum N, Swahn M, Choi S, Peachey A, Sneha S, Kabwe C, Sakib N
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
JMIR Pediatr Parent 2026;9:e76937
URL: https://pediatrics.jmir.org/2026/1/e76937
doi:10.2196/76937

Virtual, Augmented, Mixed, and Immersive Technologies for Prenatal and Childbirth Education: Scoping Review

Susanna Pardini[1], PsyD, PhD; Olga Navarro Martínez[2], MBA, PhD; Oscar Mayora Ibarra[1], PhD

[1]Digital Health Research Unit, Centre for Health and Wellbeing, Fondazione Bruno Kessler, Via Sommarive, 18, Trento, Italy

[2]Nursing Education and Care Research Group (GRIECE), Nursing Department, Faculty of Nursing and Podiatry, Universitat de València, Menéndez y Pelayo, Valencia, Spain

Corresponding Author:
Susanna Pardini, PsyD, PhD
Digital Health Research Unit, Centre for Health and Wellbeing, Fondazione Bruno Kessler, Via Sommarive, 18, Trento, Italy

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

(JMIR Pediatr Parent 2026;9:e83621) doi:10.2196/83621

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].

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 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.

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.

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).

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.

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.

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		

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		

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.

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.

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)

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)

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

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)

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)

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.

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.

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.

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.

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.

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.

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.

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		

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.

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]			

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.

[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.

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.

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.

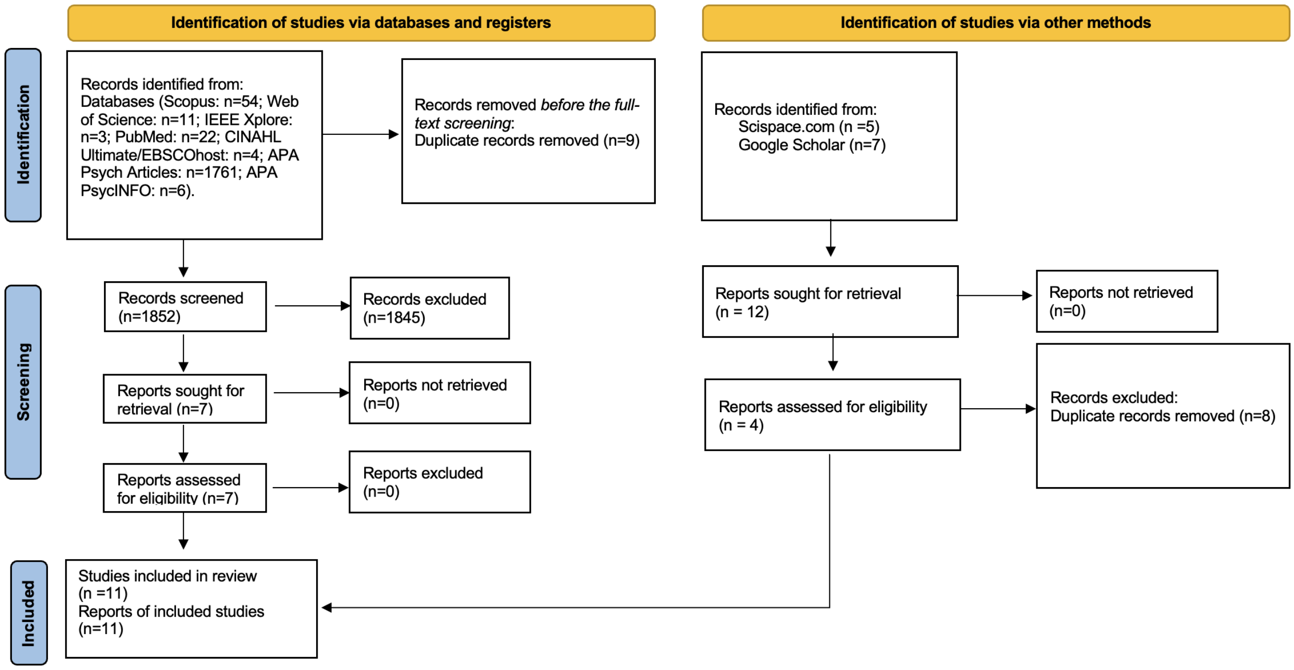
Throughout the analysis, we used an inductive, data-driven approach, allowing the themes to emerge organically from the data without reliance on preexisting theoretical models [50]. In parallel, we complemented this bottom-up strategy with a top-down perspective: the extraction and interpretation of 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.

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 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.

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 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 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, 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 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 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.

Acknowledgments

FORTHEM Post-Doctoral Research Stays with Non-Academic Partners (2025) https://www.forthem-alliance.eu/

Funding

This research project was funded by Hub Life Science—Digital Health (LSH-DH) PNC-E3-2022-23683267—DHEAL-COM Project—CUP: C63C22001970001 and funded by the Italian Ministry of Health under the National Complementary Plan "Innovative Health Ecosystem" (Piano Nazionale Complementare Ecosistema Innovativo della Salute) - Unique Investment Code (Codice univoco investimento): PNC-E.3. This publication reflects only the authors' view, and the Italian Ministry of Health is not responsible for any use that may be made of the information it contains.

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]

References

1. Gagnon AJ, Sandall J. Individual or group antenatal education for childbirth or parenthood, or both. Cochrane Database Syst Rev 2007 Jul 18;2007(3):CD002869. [doi: 10.1002/14651858.CD002869.pub2] [Medline: 17636711]
2. Brixval CS, Axelsen SF, Thygesen LC, Due P, Koushede V. Antenatal education in small classes may increase childbirth self-efficacy: results from a Danish randomised trial. Sex Reprod Healthc 2016 Dec;10:32-34. [doi: 10.1016/j.srhc.2016.03.003]
3. Zaman A, Fadlalmola HA, Ibrahem SE, et al. The role of antenatal education on maternal self-efficacy, fear of childbirth, and birth outcomes: a systematic review and meta-analysis. Eur J Midwifery 2025;9:1-16. [doi: 10.18332/ejm/200747] [Medline: 40041601]
4. Albarqi MN. The impact of prenatal care on the prevention of neonatal outcomes: a systematic review and meta-analysis of global health interventions. Healthcare (Basel) 2025 May 6;13(9):1076. [doi: 10.3390/healthcare13091076] [Medline: 40361853]
5. Jalal SM, Alsebeiy SH, Alshealah NMJ. Stress, anxiety, and depression during pregnancy: a survey among antenatal women attending primary health centers. Healthcare (Basel) 2024 Nov 7;12(22):2227. [doi: 10.3390/healthcare12222227] [Medline: 39595425]
6. Mohammed HH, Hamed A, Afefy N, Sherif NA, Ibrahim SM. The effectiveness of nurse-led antenatal education on maternal self-efficacy: an evidence-based approach. BMC Nurs 2025 Jul 10;24(1):895. [doi: 10.1186/s12912-025-03471-5] [Medline: 40640815]
7. Heaman MI, Moffatt M, Elliott L, et al. Barriers, motivators and facilitators related to prenatal care utilization among inner-city women in Winnipeg, Canada: a case-control study. BMC Pregnancy Childbirth 2014 Jul 15;14:227. [doi: 10.1186/1471-2393-14-227] [Medline: 25023478]
8. Kuo TC, Au HK, Chen SR, et al. Effects of an integrated childbirth education program to reduce fear of childbirth, anxiety, and depression, and improve dispositional mindfulness: a single-blind randomised controlled trial. Midwifery 2022 Oct;113:103438. [doi: 10.1016/j.midw.2022.103438] [Medline: 35963072]

9. Hassanzadeh R, Abbas-Alizadeh F, Meedya S, Mohammad-Alizadeh-Charandabi S, Mirghafourvand M. Fear of childbirth, anxiety and depression in three groups of primiparous pregnant women not attending, irregularly attending and regularly attending childbirth preparation classes. BMC Womens Health 2020 Aug 14;20(1):180. [doi: 10.1186/s12905-020-01048-9] [Medline: 32799875]
10. Størksen HT, Garthus-Niegel S, Adams SS, Vangen S, Eberhard-Gran M. Fear of childbirth and elective caesarean section: a population-based study. BMC Pregnancy Childbirth 2015 Sep 17;15(1):221. [doi: 10.1186/s12884-015-0655-4] [Medline: 26382746]
11. Motz L, Brückner RM, Schmidt B. Improving birth preparation with the hypnosis online course “The Peaceful Birth”: a randomized controlled study. Front Psychol 2025;16:1508790. [doi: 10.3389/fpsyg.2025.1508790] [Medline: 39901971]
12. Alizadeh-Dibazari Z, Maghalain M, Mirghafourvand M. The effect of non-pharmacological prenatal interventions on fear of childbirth: an overview of systematic reviews and meta-analysis. BMC Psychiatry 2024 Jun 4;24(1):415. [doi: 10.1186/s12888-024-05870-5] [Medline: 38834980]
13. Zhou J, Zhu Z, Li R, Guo X, Li D. Comparative efficacy of non-pharmacological interventions on fear of childbirth for pregnant women: a systematic review and network meta-analysis. Front Psychol 2025;16:1530311. [doi: 10.3389/fpsyg.2025.1530311] [Medline: 40144029]
14. Athinaidou AM, Vounatsou E, Pappa I, Harizopoulou VC, Sarantaki A. Influence of antenatal education on birth outcomes: a systematic review focusing on primiparous women. Cureus 2024 Jul;16(7):e64508. [doi: 10.7759/cureus.64508] [Medline: 39139345]
15. Soriano-Vidal FJ, Vila-Candel R, Soriano-Martín PJ, Tejedor-Tornero A, Castro-Sánchez E. The effect of prenatal education classes on the birth expectations of Spanish women. Midwifery 2018 May;60:41-47. [doi: 10.1016/j.midw.2018.02.002] [Medline: 29486388]
16. Abadi Marzoni Z, Bakouei F, Aghajani Delavar M, Hamidia A, Sepidarkish M. Midwife-led psycho-education intervention to reduce childbirth fear: a quasi-experimental study. Health Educ Res 2024 May 11;39(3):245-253. [doi: 10.1093/her/cyae017] [Medline: 38687635]
17. Lee H. A unified conceptual model of immersive experience in extended reality. Comput Hum Behav Rep 2025 May;18:100663. [doi: 10.1016/j.chbr.2025.100663]
18. Zweifach SM, Triola MM. Extended reality in medical education: driving adoption through provider-centered design. Digit Biomark 2019;3(1):14-21. [doi: 10.1159/000498923] [Medline: 32095765]
19. Radianti J, Majchrzak TA, Fromm J, Wohlgenannt I. A systematic review of immersive virtual reality applications for higher education: design elements, lessons learned, and research agenda. Comput Educ 2020 Apr;147:103778. [doi: 10.1016/j.compedu.2019.103778]
20. Riva G. Virtual reality in clinical psychology. In: Reference Module in Neuroscience and Biobehavioral Psychology: Elsevier; 2020. [doi: 10.1016/B978-0-12-818697-8.00006-6]
21. Xu N, Chen S, Liu Y, Jing Y, Gu P. The effects of virtual reality in maternal delivery: systematic review and meta-analysis. JMIR Serious Games 2022 Nov 23;10(4):e36695. [doi: 10.2196/36695] [Medline: 36416881]
22. Foronda CL, Fernandez-Burgos M, Nadeau C, Kelley CN, Henry MN. Virtual simulation in nursing education: a systematic review spanning 1996 to 2018. Simul Healthc 2020;15(1):46-54. [doi: 10.1097/SIH.0000000000000411]
23. Xie J, Zeng Q. Application of virtual reality technology combined with moderate perineal protection in natural childbirth. Ginekol Pol 2023;94(12):978-983. [doi: 10.5603/GP.a2022.0134] [Medline: 36448347]
24. Shi X, Liang C, Ren H, Liao C, Yue N. The effect of virtual reality on pregnant women and fetuses: a systematic review and meta-analysis of randomized controlled trials. Arch Gynecol Obstet 2025 Aug;312(2):337-350. [doi: 10.1007/s00404-025-07971-2] [Medline: 40366438]
25. Navas-Bonilla CDR, Guerra-Arango JA, Oviedo-Guado DA, Murillo-Noriega DE. Inclusive education through technology: a systematic review of types, tools and characteristics. Front Educ 2025;10. [doi: 10.3389/feduc.2025.1527851]
26. Baradwan S, Khadawardi K, Badghish E, et al. The impact of virtual reality on pain management during normal labor: a systematic review and meta-analysis of randomized controlled trials. Sex Reprod Healthc 2022 Jun;32:100720. [doi: 10.1016/j.srhc.2022.100720]
27. Visan IG, Toma CV, Petca R, Petrescu GED, Noditi AR, Petca A. Exploring the efficacy of virtual reality training in obstetric procedures and patient care-a systematic review. Healthcare (Basel) 2025 Apr 1;13(7):784. [doi: 10.3390/healthcare13070784] [Medline: 40218081]
28. WHO recommendations on antenatal care for a positive pregnancy experience. World Health Organization. 2016. URL: https://iris.who.int/bitstream/handle/10665/250796/9789241549912-eng.pdf;sequence=1 [accessed 2025-09-02]
29. Maita KC, Maniaci MJ, Haider CR, et al. The impact of digital health solutions on bridging the health care gap in rural areas: a scoping review. Perm J 2024 Sep 16;28(3):130-143. [doi: 10.7812/TPP/23.134] [Medline: 39135461]
30. Schnitman G, Wang T, Kundu S, et al. The role of digital patient education in maternal health: a systematic review. Patient Educ Couns 2022 Mar;105(3):586-593. [doi: 10.1016/j.pec.2021.06.019] [Medline: 34183217]
31. Cox CL. An interaction model of client health behavior: theoretical prescription for nursing. ANS Adv Nurs Sci 1982 Oct;5(1):41-56 [FREE Full text] [doi: 10.1097/00012272-198210000-00007] [Medline: 6817699]

32. Şimşek Çetinkaya Ş, Şahin B, Solmaz N, Koç BN. The effect of high-fidelity simulation based education on self-efficacy and childbirth fear in pregnant women. J Reprod Infant Psychol 2025 Jul 15:1-15. [doi: 10.1080/02646838.2025.2528809] [Medline: 40660971]
33. Huang X, Huss J, North L, Williams K, Boyd-Devine A. Cognitive and motivational benefits of a theory-based immersive virtual reality design in science learning. Comput Educ Open 2023 Dec;4:100124. [doi: 10.1016/j.caeo.2023.100124]
34. Lee B, Lim HJ, Park J, et al. Efficacy of virtual reality program for mental health promotion in pregnant women. Clin Psychopharmacol Neurosci 2025 Feb 28;23(1):32-41. [doi: 10.9758/cpn.23.1127] [Medline: 39820110]
35. Hajesmaeel-Gohari S, Sarpourian F, Shafiei E. Virtual reality applications to assist pregnant women: a scoping review. BMC Pregnancy Childbirth 2021 Mar 25;21(1):249. [doi: 10.1186/s12884-021-03725-5] [Medline: 33765969]
36. Tricco AC, Lillie E, Zarin W, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med 2018 Oct 2;169(7):467-473. [doi: 10.7326/M18-0850] [Medline: 30178033]
37. Sarkis-Onofre R, Catalá-López F, Aromataris E, Lockwood C. How to properly use the PRISMA Statement. Syst Rev 2021 Apr 19;10(1):117. [doi: 10.1186/s13643-021-01671-z] [Medline: 33875004]
38. Munn Z, Peters MDJ, Stern C, Tufanaru C, McArthur A, Aromataris E. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. BMC Med Res Methodol 2018 Nov 19;18(1):143. [doi: 10.1186/s12874-018-0611-x] [Medline: 30453902]
39. The use of virtual reality in prenatal course programs for parents: a scoping review. OSF. URL: https://doi.org/10.17605/OSF.IO/4UZY7 [accessed 2026-03-10]
40. Caballero-Galilea M, Esteban-Gonzalo L, Esteban-Gonzalo S, González-Pascual JL. Effectiveness of an immersive virtual reality intervention to reduce anxiety during pregnancy: a quasiexperimental single-group pre-post study. BMC Pregnancy Childbirth 2025 Sep 24;25(1):941. [doi: 10.1186/s12884-025-08097-8] [Medline: 40993631]
41. Siivola M, Tiainen E, Ekholm E, Leinonen T, Malmi L. Virtual reality childbirth education with 360° videos. J Perinat Educ 2023 Jan 1;32(1):35-47. [doi: 10.1891/JPE-2021-0021] [Medline: 36632515]
42. Siivola M, Leinonen T, Malmi L. Advantages of virtual reality childbirth education. Comput Educ X Real 2024;4:100058. [doi: 10.1016/j.cexr.2024.100058]
43. Tang K, Gerling K, Geurts L. Challenges and opportunities for playful technology in health prevention: using virtual reality to supplement breastfeeding education. 2022 Presented at: 2022 IEEE Conference on Virtual Reality and 3D User Interfaces Abstracts and Workshops (VRW); Mar 12-16, 2022; Christchurch, New Zealand p. 406-409. [doi: 10.1109/VRW55335.2022.00088]
44. Tang K, Gerling K, Geurts L. Virtual feed: design and evaluation of a virtual reality simulation addressing the lived experience of breastfeeding. 2022 Apr 29 Presented at: CHI ’22; Apr 29 to May 5, 2022; New Orleans LA USA p. 1-17 URL: https://dl.acm.org/doi/proceedings/10.1145/3491102 [accessed 2026-03-10] [doi: 10.1145/3491102.3517620]
45. Noben L, Goossens S, Truijens SEM, et al. A virtual reality video to improve information provision and reduce anxiety before cesarean delivery: randomized controlled trial. JMIR Ment Health 2019 Dec 18;6(12):e15872. [doi: 10.2196/15872] [Medline: 31850850]
46. Setiawan A, Agiwahyuanto F, Arsiwi P. A virtual reality teaching simulation for exercise during pregnancy. Int J Emerg Technol Learn 2019 Jan 17;14(1):34. [doi: 10.3991/ijet.v14i01.8944]
47. Park S, Kim H. Development and effect of prenatal education programs using virtual reality for pregnant women hospitalized with preterm labor: experimental study. J Med Internet Res 2025 Jun 30;27:e75585. [doi: 10.2196/75585] [Medline: 40587895]
48. Montoya-Moncada A, Cuero-Ríos L, Rodríguez-Morales F, Perdigón M, Agudelo-Pérez S. Exploring the role of mixed reality education in maternal self efficacy and satisfaction with breastfeeding. Sci Rep 2025 Aug 5;15(1):28484. [doi: 10.1038/s41598-025-14319-y] [Medline: 40764648]
49. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
50. Naeem M, Ozuem W, Howell K, Ranfagni S. A step-by-step process of thematic analysis to develop a conceptual model in qualitative research. Int J Qual Methods 2023 Oct;22. [doi: 10.1177/16094069231205789]
51. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021 Mar 29;372:n71. [doi: 10.1136/bmj.n71] [Medline: 33782057]
52. Attribution 4.0 international (CC BY 4.0). Creative Commons. URL: https://creativecommons.org/licenses/by/4.0/ [accessed 2026-03-30]
53. Nezhad HM, Ashourioun AH, Sadeghdaghighi A. The effect of virtual reality for anxiety and pain in dentistry: a systematic review and meta-analysis. Community Dent Health 2024 Nov 29;41(4):248-255. [doi: 10.1922/CDH_00160Nezhad08] [Medline: 39535423]
54. Bashir Z, Misquith C, Shahab A, Has P, Bukhari S. The impact of virtual reality on anxiety and functional capacity in cardiac rehabilitation: a systematic review and meta-analysis. Curr Probl Cardiol 2023 May;48(5):101628. [doi: 10.1016/j.cpcardiol.2023.101628] [Medline: 36736604]

55. Schröder D, Wrona KJ, Müller F, Heinemann S, Fischer F, Dockweiler C. Impact of virtual reality applications in the treatment of anxiety disorders: a systematic review and meta-analysis of randomized-controlled trials. J Behav Ther Exp Psychiatry 2023 Dec;81:101893. [doi: 10.1016/j.jbtep.2023.101893] [Medline: 37453405]
56. Wang LJ, Casto B, Luh JY, Wang SJ. Virtual reality-based education for patients undergoing radiation therapy. J Cancer Educ 2022 Jun;37(3):694-700. [doi: 10.1007/s13187-020-01870-7] [Medline: 32970303]
57. Baradwan S, Hafedh B, Alyafi M, et al. The effect of virtual reality application on pain and anxiety during episiotomy repair: a systematic review and meta-analysis of randomized controlled trials. Int Urogynecol J 2024 Oct;35(10):1943-1953. [doi: 10.1007/s00192-024-05867-4] [Medline: 39042152]
58. García-González J, Martínez-Navarro A, Romero-Del Rey R, et al. State-trait anxiety levels and vital signs of pregnant women following intervention with virtual reality during the nonstress test: a randomized controlled trial. J Affect Disord 2024 Jun 15;355:308-314. [doi: 10.1016/j.jad.2024.03.148] [Medline: 38548203]
59. Eker A, Karadeniz EY, Aşkan F. The effect of virtual reality headsets on breast milk production and anxiety in mothers of preterm infants. BMC Pregnancy Childbirth 2025 Jul 3;25(1):710. [doi: 10.1186/s12884-025-07819-2] [Medline: 40610937]
60. Özer E, Çetinkaya Şen Y, Canlı S, Güvenç G. Effects of virtual reality interventions on the parameters of normal labor: a systematic review and meta-analysis of randomized controlled trials. A meta-analysis of virtual reality interventions on the parameters of normal labor. Pain Manag Nurs 2024 Feb;25(1):93-99. [doi: 10.1016/j.pmn.2023.09.012] [Medline: 37880013]
61. Watkins AE, El Zerbi C, McGovern R, Rankin J. Exploration of fathers' mental health and well-being concerns during the transition to fatherhood, and paternal perinatal support: scoping review. BMJ Open 2024 Nov 12;14(11):e078386. [doi: 10.1136/bmjopen-2023-078386] [Medline: 39532383]
62. Leahy-Warren P, Philpott L, Elmir R, Schmied V. Fathers' perceptions and experiences of support to be a parenting partner during the perinatal period: a scoping review. J Clin Nurs 2023 Jul;32(13-14):3378-3396. [doi: 10.1111/jocn.16460] [Medline: 35898120]
63. Griffith DM, Jaeger EC, Pepperman P, et al. Fathers' perspectives on fatherhood and paternal involvement during pregnancy and childbirth. Health Educ Behav 2023 Dec;50(6):802-809. [doi: 10.1177/10901981231199710] [Medline: 37787463]
64. Comrie-Thomson L, Gopal P, Eddy K, et al. How do women, men, and health providers perceive interventions to influence men's engagement in maternal and newborn health? A qualitative evidence synthesis. Soc Sci Med 2021 Dec;291:114475. [doi: 10.1016/j.socscimed.2021.114475] [Medline: 34695645]
65. Prajjwal P, Chandrasekar KK, Battula P, et al. The efficacy of virtual reality-based rehabilitation in improving motor function in patients with stroke: a systematic review and meta-analysis. Ann Med Surg (Lond) 2024 Aug;86(9):5425-5438. [doi: 10.1097/MS9.0000000000002403]
66. Kilic U, Arar M, Oruc MA. The effect of virtual reality on the breastfeeding process: a randomized controlled study. J Perinatol 2024 Nov;44(11):1611-1616. [doi: 10.1038/s41372-024-02077-0] [Medline: 39085438]

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

XR: extended reality

Edited by S Badawy; submitted 08.Sep.2025; peer-reviewed by F Geusens, M Siivola; revised version received 28.Nov.2025; accepted 24.Dec.2025; published 01.May.2026.

Please cite as:
Pardini S, Navarro Martínez O, Mayora Ibarra O
Virtual, Augmented, Mixed, and Immersive Technologies for Prenatal and Childbirth Education: Scoping Review
JMIR Pediatr Parent 2026;9:e83621
URL: https://pediatrics.jmir.org/2026/1/e83621
doi:10.2196/83621

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

Lin Wang[1*], BS; Guangjun Xu[2*], PhD; Dan Li[1], MS; Xiuyan Gao[1], BS; Jin Zhao[3], MS; Yajun He[4], MS; Shaolong Liu[1], BS; Hong Guo[5], PhD; Xiumei Bu[1], PhD

[1]Liaoning University of Traditional Chinese Medicine, No. 79, Chongshan Road, Huanggu District, Shenyang, Liaoning Province, China
[2]Liaoyang Vocational College of Technology, Liaoyang, Liaoning Province, China
[3]Health Service Center of Liaoning Province, Shenyang, Liaoning Province, China
[4]Liaoning Nursing Association, Shenyang, Liaoning Province, China
[5]Shenyang Medical College, Shenyang, Liaoning Province, China
[*]these authors contributed equally

Corresponding Author:
Xiumei Bu, PhD
Liaoning University of Traditional Chinese Medicine, No. 79, Chongshan Road, Huanggu District, Shenyang, Liaoning Province, China

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

(JMIR Pediatr Parent 2026;9:e82814) doi:10.2196/82814

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 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, 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 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.

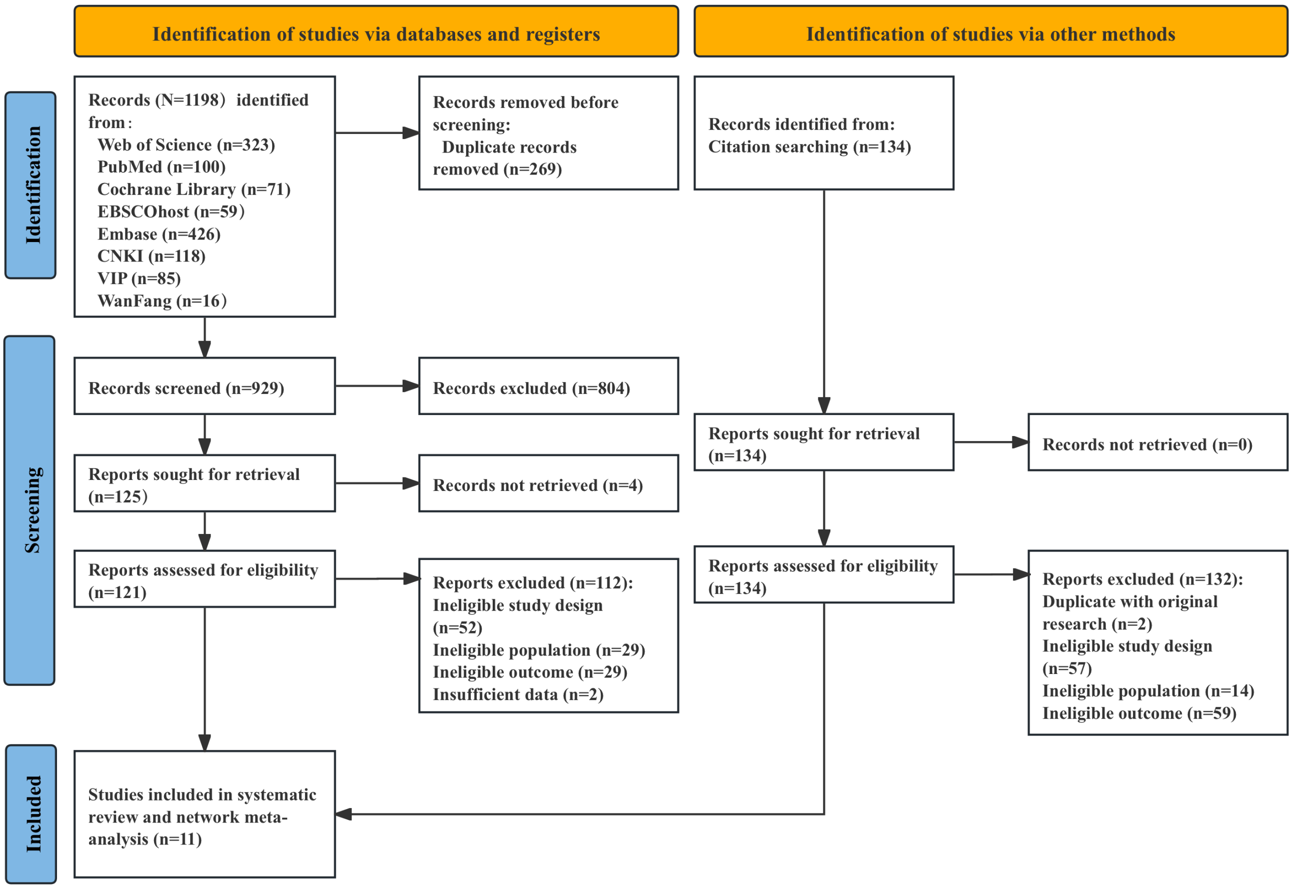
Building on descriptive analyses, exploratory NMA was conducted. Evidence networks were visualized using the "network" command to illustrate direct and indirect comparisons among distinct VR technologies. For closed loops within the network, node-splitting was performed to test for consistency; in cases 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.

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.

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]

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

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[j]/3F[k]	16M/15F	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]

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—LEGO 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	Wait-list control—no VR or structured social skills intervention during the study period	6 weeks	60 min	1 session/week	PEP-3[r]

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, sandplay therapy twice weekly, no digital component	6 months	30 min	3 sessions/week	ATEC[s]

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

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/phase	ABC

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[z]; 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.

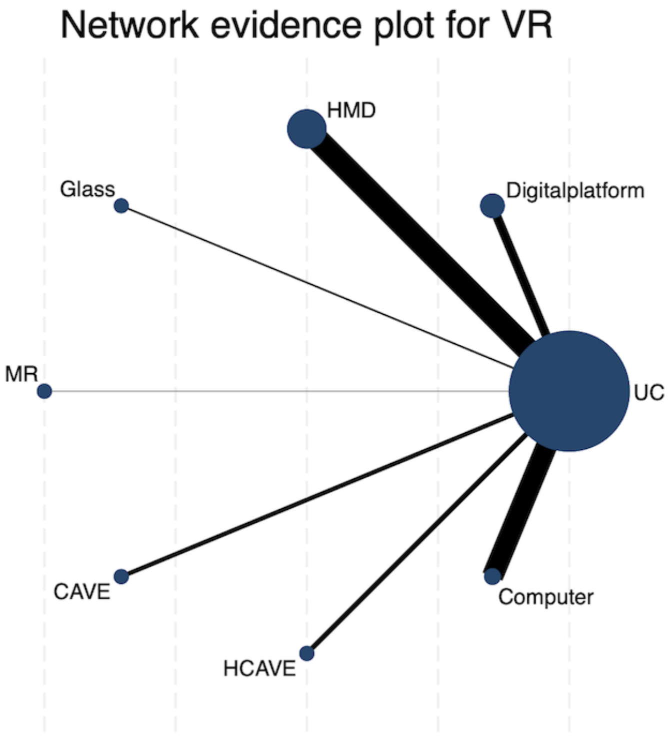
[x] SSIS: Social Skills Improvement System.

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 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.

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 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 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.

Acknowledgments

The authors confirm that no generative artificial intelligence tools were used in the preparation of this manuscript. All content is original, and the authors take full responsibility for its accuracy and integrity.

Funding

The authors declared no financial support was received for this work.

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]

References

1. Guha M. Diagnostic and Statistical Manual of Mental Disorders: DSM-5 (5th edition). Ref Rev 2014 Mar 11;28(3):36-37. [doi: 10.1108/RR-10-2013-0256]
2. Lord C, Elsabbagh M, Baird G, Veenstra-Vanderweele J. Autism spectrum disorder. The Lancet 2018 Aug;392(10146):508-520. [doi: 10.1016/S0140-6736(18)31129-2]
3. Christensen DL, Baio J, Van Naarden Braun K, et al. Prevalence and characteristics of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2012. MMWR Surveill Summ 2016 Apr 1;65(3):1-23. [doi: 10.15585/mmwr.ss6503a1] [Medline: 27031587]

4. Zhou H, Xu X, Yan W, et al. Prevalence of autism spectrum disorder in China: a nationwide multi-center population-based study among children aged 6 to 12 years. Neurosci Bull 2020 Sep;36(9):961-971. [doi: 10.1007/s12264-020-00530-6] [Medline: 32607739]
5. Neuhaus E, Webb SJ, Bernier RA. Linking social motivation with social skill: the role of emotion dysregulation in autism spectrum disorder. Dev Psychopathol 2019 Aug;31(3):931-943. [doi: 10.1017/S0954579419000361] [Medline: 30957732]
6. Chan N, Fenning RM, Neece CL. Prevalence and phenomenology of anxiety in preschool-aged children with autism spectrum disorder. Res Child Adolesc Psychopathol 2023 Jan;51(1):33-45. [doi: 10.1007/s10802-022-00964-8] [Medline: 36048376]
7. Matson JL, editor. Handbook of Social Behavior and Skills in Children: Springer International Publishing; 2017. [doi: 10.1007/978-3-319-64592-6]
8. de la Torre-Ubieta L, Won H, Stein JL, Geschwind DH. Advancing the understanding of autism disease mechanisms through genetics. Nat Med 2016 Apr;22(4):345-361. [doi: 10.1038/nm.4071] [Medline: 27050589]
9. Kuodza GE, Kawai R, LaSalle JM. Intercontinental insights into autism spectrum disorder: a synthesis of environmental influences and DNA methylation. Environ Epigenet 2024;10(1):dvae023. [doi: 10.1093/eep/dvae023] [Medline: 39703685]
10. Eissa N, Al-Houqani M, Sadeq A, Ojha SK, Sasse A, Sadek B. Current enlightenment about etiology and pharmacological treatment of autism spectrum disorder. Front Neurosci 2018;12:304. [doi: 10.3389/fnins.2018.00304] [Medline: 29867317]
11. Genovese A, Butler MG. Clinical assessment, genetics, and treatment approaches in autism spectrum disorder (ASD). Int J Mol Sci 2020 Jul 2;21(13):4726. [doi: 10.3390/ijms21134726] [Medline: 32630718]
12. Hyman SL, Levy SE, Myers SM, Council on Children With Disabilities, Section on Developmental and Behavioral Pediatrics. Identification, evaluation, and management of children with autism spectrum disorder. Pediatrics 2020 Jan;145(1):e20193447. [doi: 10.1542/peds.2019-3447] [Medline: 31843864]
13. Williams BF, Williams RL. Effective Programs for Treating Autism Spectrum Disorder: Applied Behavior Analysis Models, 1st edition: Routledge; 2010. [doi: 10.4324/9780203855034]
14. Wong CM, Aljunied M, Chan DKL, et al. 2023 clinical practice guidelines on autism spectrum disorder in children and adolescents in Singapore. Ann Acad Med Singap 2024 Apr 29;53(4):541-552. [doi: 10.47102/annals-acadmedsg.2023307] [Medline: 38920181]
15. Rogge N, Janssen J. The economic costs of autism spectrum disorder: a literature review. J Autism Dev Disord 2019 Jul;49(7):2873-2900. [doi: 10.1007/s10803-019-04014-z] [Medline: 30976961]
16. Shamir A, Margalit M, editors. Technology and Students with Special Educational Needs: New Opportunities and Future Directions, 1st edition: Routledge; 2014. [doi: 10.4324/9781315540795]
17. Rauschnabel PA, Felix R, Hinsch C, Shahab H, Alt F. What is XR? Towards a framework for augmented and virtual reality. Comput Human Behav 2022 Aug;133:107289. [doi: 10.1016/j.chb.2022.107289]
18. Maggio MG, Latella D, Maresca G, et al. Virtual reality and cognitive rehabilitation in people with stroke: an overview. J Neurosci Nurs 2019 Apr;51(2):101-105. [doi: 10.1097/JNN.0000000000000423] [Medline: 30649091]
19. He D, Cao S, Le Y, Wang M, Chen Y, Qian B. Virtual reality technology in cognitive rehabilitation application: bibliometric analysis. JMIR Serious Games 2022 Oct 19;10(4):e38315. [doi: 10.2196/38315] [Medline: 36260388]
20. Adjorlu A, Hoeg ER, Mangano L, Serafin S. Daily living skills training in virtual reality to help children with autism spectrum disorder in a real shopping scenario. Presented at: 2017 IEEE International Symposium on Mixed and Augmented Reality (ISMAR-Adjunct); Oct 9-13, 2017. [doi: 10.1109/ISMAR-Adjunct.2017.93]
21. Didehbani N, Allen T, Kandalaft M, Krawczyk D, Chapman S. Virtual reality social cognition training for children with high functioning autism. Comput Human Behav 2016 Sep;62:703-711. [doi: 10.1016/j.chb.2016.04.033]
22. Farashi S, Bashirian S, Jenabi E, Razjouyan K. Effectiveness of virtual reality and computerized training programs for enhancing emotion recognition in people with autism spectrum disorder: a systematic review and meta-analysis. Int J Dev Disabil 2024;70(1):110-126. [doi: 10.1080/20473869.2022.2063656] [Medline: 38456137]
23. Herrero JF, Lorenzo G. An immersive virtual reality educational intervention on people with autism spectrum disorders (ASD) for the development of communication skills and problem solving. Educ Inf Technol 2020 May;25(3):1689-1722. [doi: 10.1007/s10639-019-10050-0]
24. Zhang M, Ding H, Naumceska M, Zhang Y. Virtual reality technology as an educational and intervention tool for children with autism spectrum disorder: current perspectives and future directions. Behav Sci ;12(5):138. [doi: 10.3390/bs12050138]
25. Mittal P, Bhadania M, Tondak N, et al. Effect of immersive virtual reality-based training on cognitive, social, and emotional skills in children and adolescents with autism spectrum disorder: a meta-analysis of randomized controlled trials. Res Dev Disabil 2024 Aug;151:104771. [doi: 10.1016/j.ridd.2024.104771] [Medline: 38941690]
26. Hutton B, Salanti G, Caldwell DM, et al. The PRISMA extension statement for reporting of systematic reviews incorporating network meta-analyses of health care interventions: checklist and explanations. Ann Intern Med 2015 Jun 2;162(11):777-784. [doi: 10.7326/M14-2385] [Medline: 26030634]
27. Denizli-Gulboy H, Genc-Tosun D, Gulboy E. Evaluating augmented reality as evidence-based practice for individuals with autism spectrum disorder: a meta-analysis of single-case design studies. Int J Dev Disabil 2023;69(4):472-486. [doi: 10.1080/20473869.2021.1972741] [Medline: 37346255]

28. Sandgreen H, Frederiksen LH, Bilenberg N. Digital interventions for autism spectrum disorder: a meta-analysis. J Autism Dev Disord 2021 Sep;51(9):3138-3152. [doi: 10.1007/s10803-020-04778-9] [Medline: 33170393]
29. Xu F, Gage N, Zeng S, et al. The use of digital interventions for children and adolescents with autism spectrum disorder-a meta-analysis. J Autism Dev Disord 2026 Feb;56(2):499-515. [doi: 10.1007/s10803-024-06563-4] [Medline: 39325282]
30. Zhang Q, Wu R, Zhu S, et al. Facial emotion training as an intervention in autism spectrum disorder: a meta-analysis of randomized controlled trials. Autism Res 2021 Oct;14(10):2169-2182. [doi: 10.1002/aur.2565] [Medline: 34286900]
31. Higgins JPT, Altman DG, Gøtzsche PC, et al. The Cochrane Collaboration’s tool for assessing risk of bias in randomised trials. BMJ 2011 Oct 18;343:d5928. [doi: 10.1136/bmj.d5928] [Medline: 22008217]
32. Sterne JAC, Savović J, Page MJ, et al. RoB 2: a revised tool for assessing risk of bias in randomised trials. BMJ 2019 Aug 28;366:l4898. [doi: 10.1136/bmj.l4898] [Medline: 31462531]
33. Nikolakopoulou A, Higgins JPT, Papakonstantinou T, et al. CINeMA: an approach for assessing confidence in the results of a network meta-analysis. PLoS Med 2020 Apr;17(4):e1003082. [doi: 10.1371/journal.pmed.1003082] [Medline: 32243458]
34. Dias S, Welton NJ, Caldwell DM, Ades AE. Checking consistency in mixed treatment comparison meta-analysis. Stat Med 2010 Mar 30;29(7-8):932-944. [doi: 10.1002/sim.3767] [Medline: 20213715]
35. Salanti G, Ades AE, Ioannidis JPA. Graphical methods and numerical summaries for presenting results from multiple-treatment meta-analysis: an overview and tutorial. J Clin Epidemiol 2011 Feb;64(2):163-171. [doi: 10.1016/j.jclinepi.2010.03.016] [Medline: 20688472]
36. Egger M, Davey Smith G, Schneider M, Minder C. Bias in meta-analysis detected by a simple, graphical test. BMJ 1997 Sep 13;315(7109):629-634. [doi: 10.1136/bmj.315.7109.629] [Medline: 9310563]
37. Wang YY. Effects of immersive virtual reality technology on social skills in children with autism [Article in Chinese]. Chin J Sci Technol Database (Citation Ed) Med Health 2024;2:0116-0119 [FREE Full text]
38. Zhao JQ, Zhang XX, Lu Y, et al. Effect of family rehabilitation intervention for core symptoms of children with autism spectrum disorder based on virtual reality technology [Article in Chinese]. Chin Nurs Res 2021;35(23):4214-4217. [doi: 10.12102/j.issn.1009-6493.2021.23.014]
39. Voss C, Schwartz J, Daniels J, et al. Effect of wearable digital intervention for improving socialization in children with autism spectrum disorder: a randomized clinical trial. JAMA Pediatr 2019 May 1;173(5):446-454. [doi: 10.1001/jamapediatrics.2019.0285] [Medline: 30907929]
40. Sayis B, Ramirez R, Pares N. Mixed reality or LEGO game play? Fostering social interaction in children with autism. Virtual Real 2022 Jun;26(2):771-787. [doi: 10.1007/s10055-021-00580-9]
41. Yuan SNV, Ip HHS. Using virtual reality to train emotional and social skills in children with autism spectrum disorder. London J Prim Care (Abingdon) 2018;10(4):110-112. [doi: 10.1080/17571472.2018.1483000] [Medline: 30083244]
42. Zhao J, Zhang X, Lu Y, et al. Virtual reality technology enhances the cognitive and social communication of children with autism spectrum disorder. Front Public Health 2022;10:1029392. [doi: 10.3389/fpubh.2022.1029392]
43. Jiang MM, Wang DY, Li EY. The effect of VR eye tracking technology in children with autism [Article in Chinese]. J Int Psychiatry 2023;50(6):1403-1406. [doi: 10.13479/j.cnki.jip.2023.06.045]
44. Ip HHS, Wong SWL, Chan DFY, et al. Enhance emotional and social adaptation skills for children with autism spectrum disorder: a virtual reality enabled approach. Comput Educ 2018 Feb;117:1-15. [doi: 10.1016/j.compedu.2017.09.010]
45. Ye JH, Song QH, Zhao BT. To explore the application of virtual character interaction system in the clinical treatment of children with autism spectrum disorder [Article in Chinese]. Mater Child Health Care China 2020;35(16):3004-3006. [doi: 10.19829/j.zgfybj.issn.1001-4411.2020.16.023]
46. Wang YJ, Li HJ, Hu XR. Digital audio-visual integrated system combined with virtual reality technology in treatment of childhood autism: a case-control study [Article in Chinese]. Mater Child Heal Care Chin 2016;31(22):4777-4780 [FREE Full text]
47. Yuen HK, Spencer K, Edwards L, Kirklin K, Jenkins GR. A magic trick training program to improve social skills and self-esteem in adolescents with autism spectrum disorder. Am J Occup Ther 2023 Jan 1;77(1):7701205120. [doi: 10.5014/ajot.2023.049492] [Medline: 36806382]
48. Mawdsley D, Bennetts M, Dias S, Boucher M, Welton NJ. Model‐based network meta‐analysis: a framework for evidence synthesis of clinical trial data. CPT Pharmacom & Syst Pharma 2016 Aug;5(8):393-401. [doi: 10.1002/psp4.12091]
49. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021 Mar 29;372:n71. [doi: 10.1136/bmj.n71] [Medline: 33782057]
50. Astafeva D, Syunyakov T, Shapievskii D, et al. Virtual reality / augmented reality (vr/ar) approach to develop social and communication skills in children and adolescents with autism spectrum disorders without intellectual impairment. Psychiatr Danub 2024 Sep;36(Suppl 2):361-370. [Medline: 39378497]
51. Newbutt N, Bradley R, Conley I. Using virtual reality head-mounted displays in schools with autistic children: views, experiences, and future directions. Cyberpsychol Behav Soc Netw 2020 Jan;23(1):23-33. [doi: 10.1089/cyber.2019.0206] [Medline: 31502866]
52. Bradley R, Newbutt N. Autism and virtual reality head-mounted displays: a state of the art systematic review. J Enabling Technol 2018 Nov 7;12(3):101-113. [doi: 10.1108/JET-01-2018-0004]

53. Lahiri U, Bekele E, Dohrmann E, Warren Z, Sarkar N. Design of a virtual reality based adaptive response technology for children with autism. IEEE Trans Neural Syst Rehabil Eng 2013 Jan;21(1):55-64. [doi: 10.1109/TNSRE.2012.2218618] [Medline: 23033333]
54. Newbutt N, Sung C, Kuo HJ, Leahy MJ, Lin CC, Tong B. Brief report: a pilot study of the use of a virtual reality headset in autism populations. J Autism Dev Disord 2016 Sep;46(9):3166-3176. [doi: 10.1007/s10803-016-2830-5] [Medline: 27272115]
55. Yang X, Wu J, Ma Y, et al. Effectiveness of virtual reality technology interventions in improving the social skills of children and adolescents with autism: systematic review. J Med Internet Res 2025 Feb 5;27:e60845. [doi: 10.2196/60845] [Medline: 39907288]
56. Sandbank M, Bottema-Beutel K, Crowley S, et al. Project AIM: autism intervention meta-analysis for studies of young children. Psychol Bull 2020 Jan;146(1):1-29. [doi: 10.1037/bul0000215] [Medline: 31763860]

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

Edited by S Badawy; submitted 22.Aug.2025; peer-reviewed by Q Zhang, Z Ren; revised version received 16.Feb.2026; accepted 16.Feb.2026; published 30.Apr.2026.

Please cite as:
Wang L, Xu G, Li D, Gao X, Zhao J, He Y, Liu S, Guo H, Bu X
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
JMIR Pediatr Parent 2026;9:e82814
URL: https://pediatrics.jmir.org/2026/1/e82814
doi:10.2196/82814

Screen Time, Child Depression, and Anxiety During the COVID-19 Pandemic: Systematic Review and Meta-Analysis

Marissa Yoshizawa[1], PsyD, MSW; Jennifer Rafeedie[1,2], PsyD; Jasmyn J Tang[3], MPH; Bryan T Lei[4], MS; Ramon Durazo-Arvizu[4], PhD; Danny Azucar[1], PhD, MPH; Sharon Hudson[5], PhD; Sheela Rao[1,2], MD; Karen Kay Imagawa[1,2], MD; Alexis Deavenport-Saman[1,2], DrPH, MPH

[1]Department of Pediatrics, Children's Hospital Los Angeles, 4650 Sunset Blvd MS53, Los Angeles, CA, United States

[2]Department of Pediatrics, Keck School of Medicine, University of Southern California, Los Angeles, CA, United States

[3]Division of General Internal Medicine and Health Services, David Geffen School of Medicine, University of California Los Angeles, Los Angeles, CA, United States

[4]Department of Pediatrics, The Saban Research Institute, Children's Hospital Los Angeles, Los Angeles, CA, United States

[5]AltaMed Institute for Health Equity, Los Angeles, CA, United States

Corresponding Author:
Marissa Yoshizawa, PsyD, MSW
Department of Pediatrics, Children's Hospital Los Angeles, 4650 Sunset Blvd MS53, Los Angeles, CA, United States

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.

(JMIR Pediatr Parent 2026;9:e83228) doi:10.2196/83228

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 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.

Table . STROBE (Strengthening the Reporting of Observational studies in Epidemiology) checklist for bias assessment.

	Introduction		Methods				Results		Discussion		
ID	Background	Objectives	Participants	Variables	Data/measures	Statistical methods	Descriptive data	Outcomes	Results	Limitations	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].

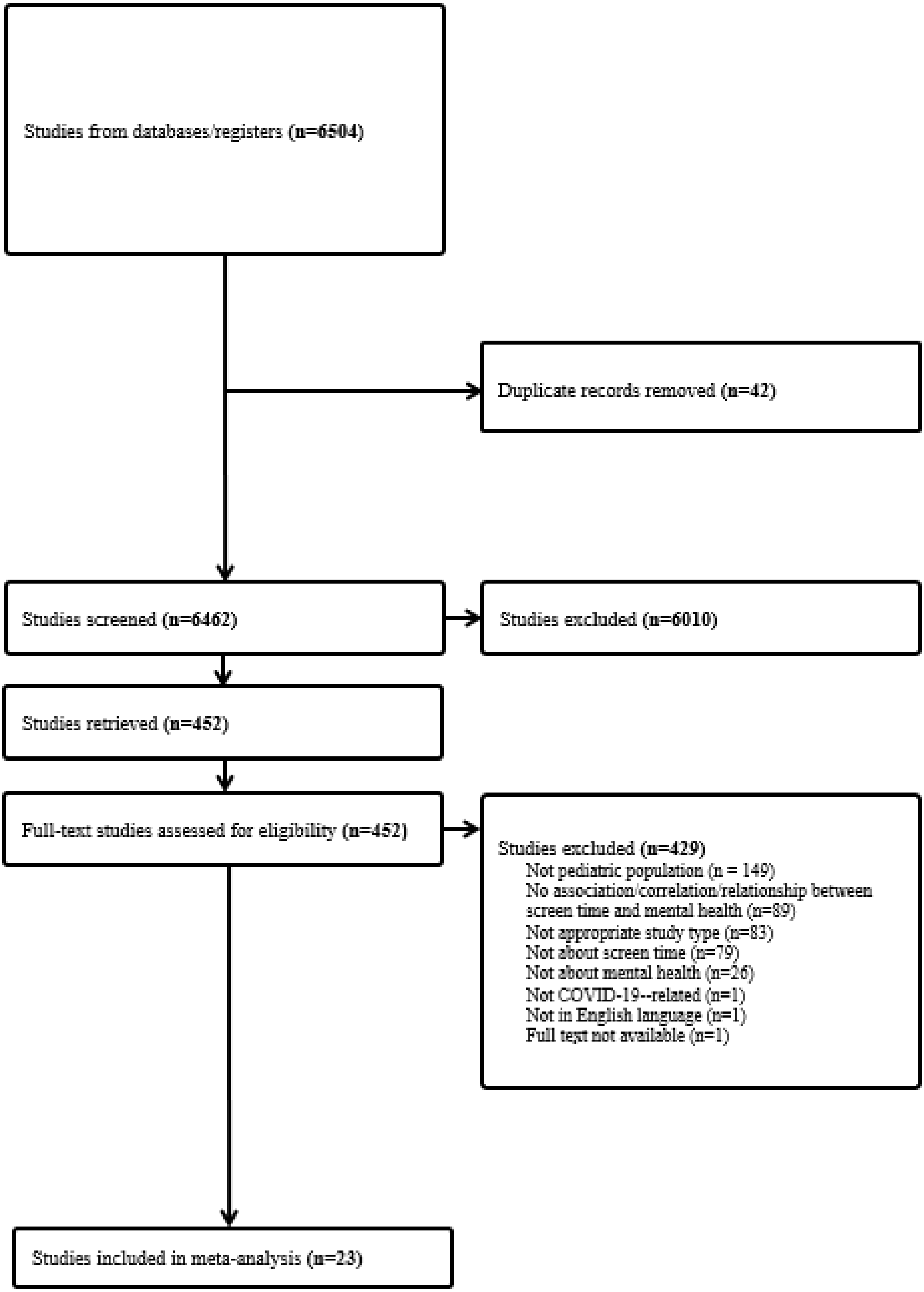
A random-effects model was used for all meta-analysis to account for heterogeneity across studies. Pooled correlations of r=0.10, r=0.30, and r=0.50 were considered as small, medium, and large effect sizes, respectively [37]. Heterogeneity (ie, $\tau 2$) was assessed using the restricted maximum-likelihood 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.

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.



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.

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

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.

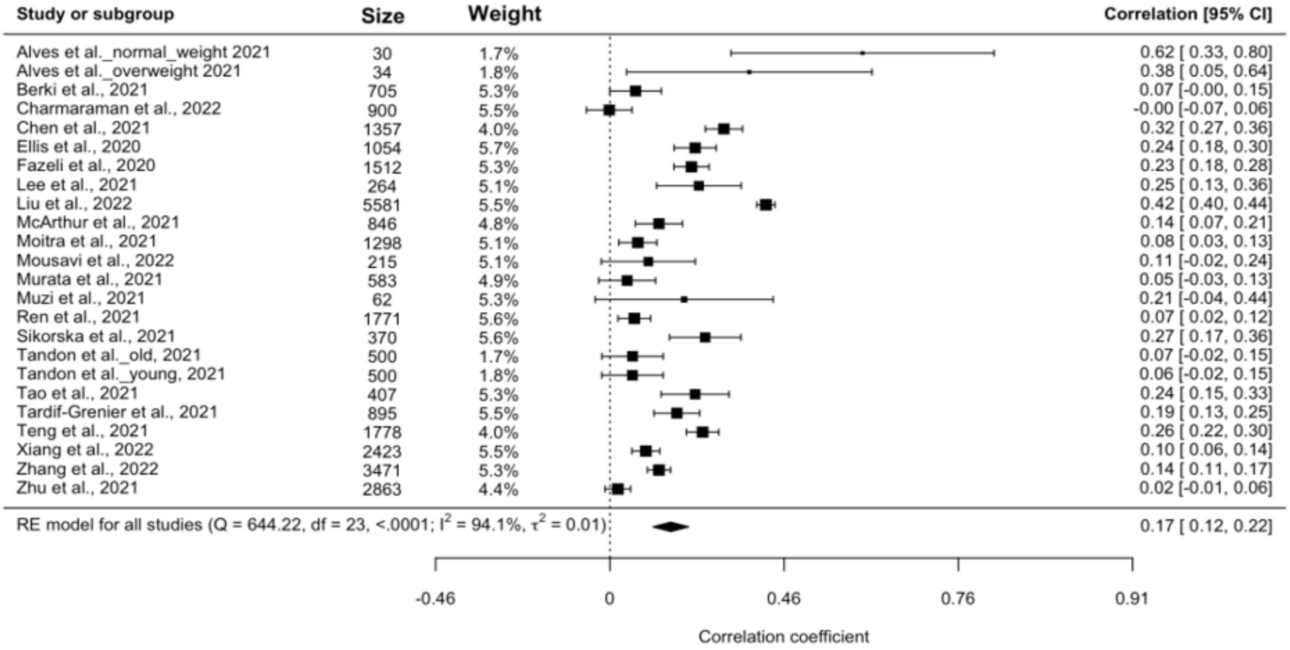
Risk of Bias in Studies

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

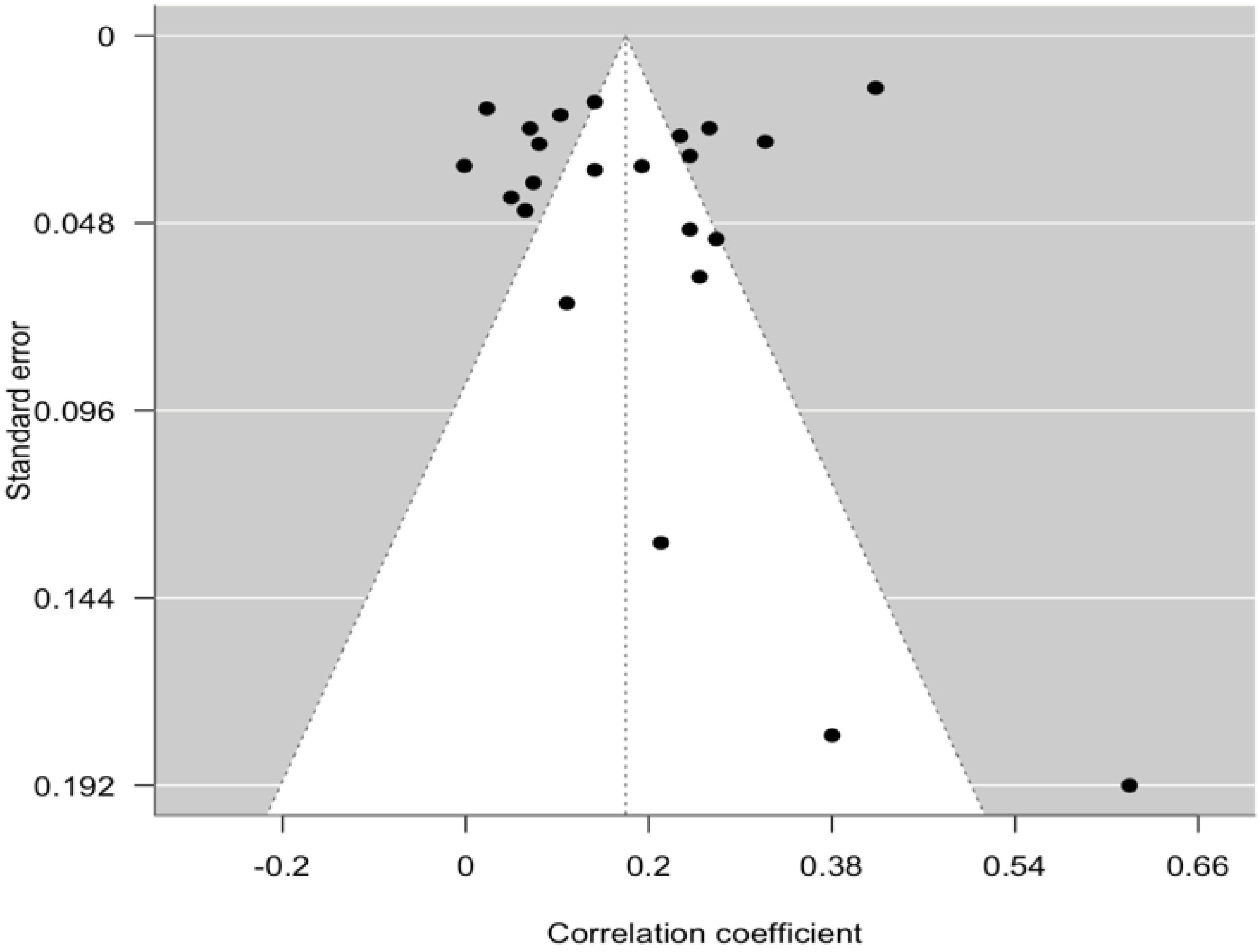
Twenty-two of the 23 included studies (all except [42]) reported comparable effect sizes for screen time and depression. Two studies [15,30] presented results only for stratified subgroups rather than an overall sample. Therefore, we treated the stratified groups as separate studies in the analysis and 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.

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.

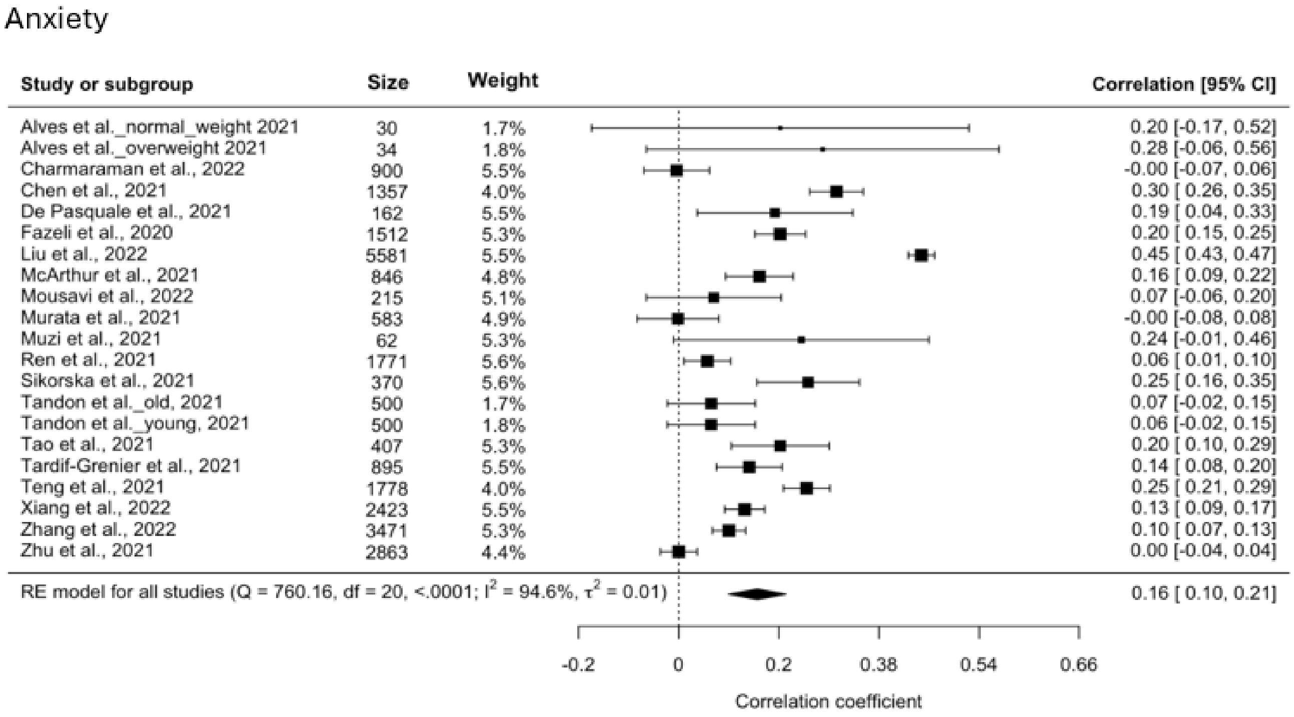
Figure 3. Funnel plot for depression.



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.

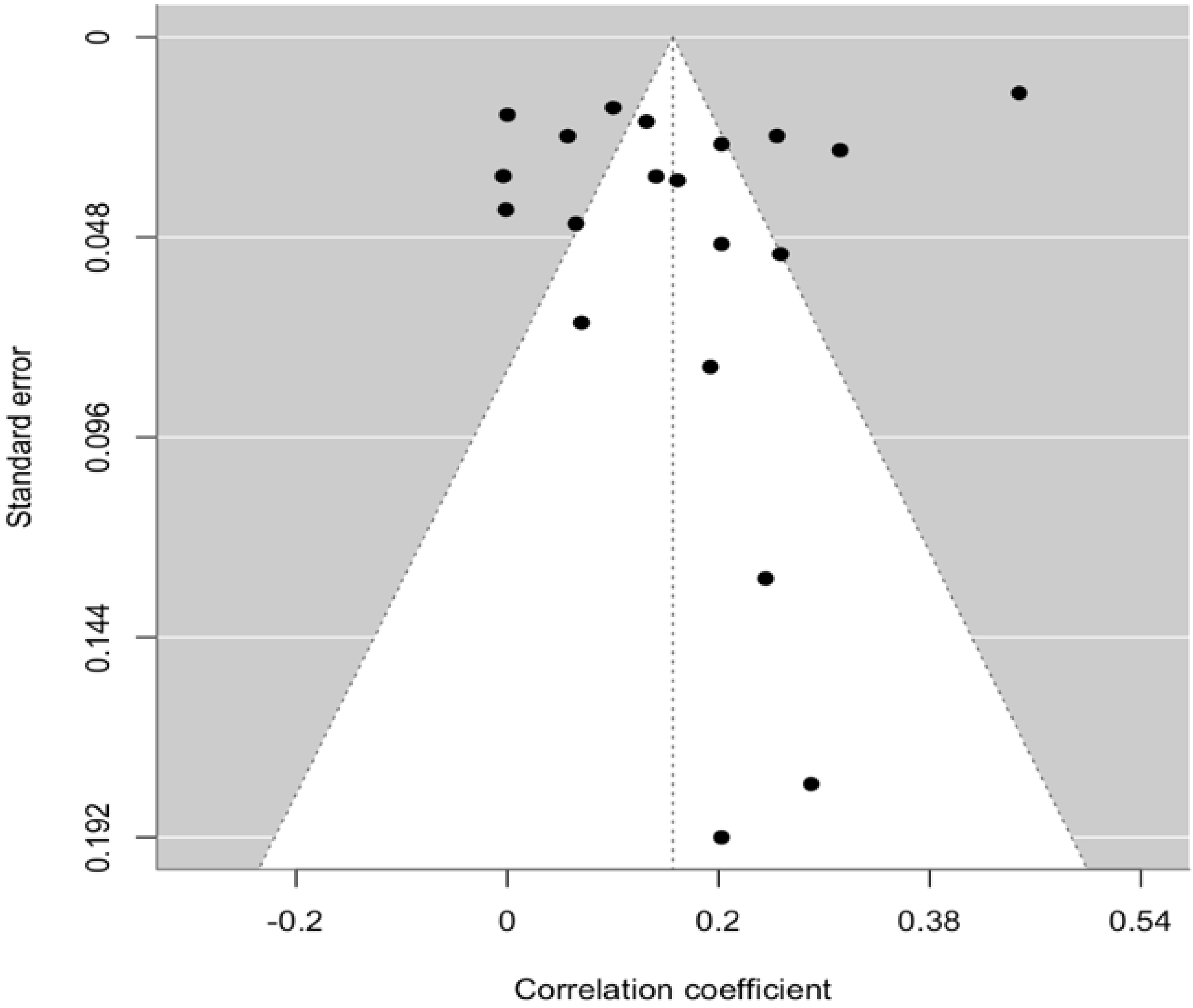
Figure 4. Forest plot for anxiety.



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.

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 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.

Funding

This work was supported by the Biostatistics, Informatics and Data Management Core at The Saban Research Institute, Children's Hospital Los Angeles, and by grant UL1TR001855 from the National Center for Advancing Translational Science (NCATS) of the U.S. National Institutes of Health. The content is solely the authors' responsibility and does not necessarily represent the official views of the National Institutes of Health.

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]

References

1. Madigan S, Eirich R, Pador P, McArthur BA, Neville RD. Assessment of changes in child and adolescent screen time during the COVID-19 pandemic: a systematic review and meta-analysis. JAMA Pediatr 2022 Dec 1;176(12):1188-1198. [doi: 10.1001/jamapediatrics.2022.4116] [Medline: 36342702]
2. Nagata JM, Cortez CA, Cattle CJ, et al. Screen time use among US adolescents during the COVID-19 pandemic: findings from the Adolescent Brain Cognitive Development (ABCD) study. JAMA Pediatr 2022 Jan 1;176(1):94-96. [doi: 10.1001/jamapediatrics.2021.4334] [Medline: 34724543]
3. Vogels E, Rainie L, Nolan H. Teens, social media and technology. Pew Research Center. 2022 Aug. URL: https://www.pewresearch.org/internet/2022/08/10/teens-social-media-and-technology-2022/ [accessed 2026-02-04]
4. McArthur BA, Racine N, McDonald S, Tough S, Madigan S. Child and family factors associated with child mental health and well-being during COVID-19. Eur Child Adolesc Psychiatry 2023 Feb;32(2):223-233. [doi: 10.1007/s00787-021-01849-9] [Medline: 34302530]
5. Protecting youth mental health. US Department of Health and Human Services. 2021. URL: https://www.hhs.gov/surgeongeneral/reports-and-publications/youth-mental-health/index.html [accessed 2025-07-28]
6. Racine N, McArthur BA, Cooke JE, Eirich R, Zhu J, Madigan S. Global prevalence of depressive and anxiety symptoms in children and adolescents during COVID-19: a meta-analysis. JAMA Pediatr 2021 Nov 1;175(11):1142-1150. [doi: 10.1001/jamapediatrics.2021.2482] [Medline: 34369987]
7. Hamatani S, Hiraoka D, Makita K, Tomoda A, Mizuno Y. Longitudinal impact of COVID-19 pandemic on mental health of children in the ABCD study cohort. Sci Rep 2022 Nov 15;12(1):19601. [doi: 10.1038/s41598-022-22694-z] [Medline: 36379997]
8. Ma Z, Idris S, Zhang Y, et al. The impact of COVID-19 pandemic outbreak on education and mental health of Chinese children aged 7-15 years: an online survey. BMC Pediatr 2021 Feb 24;21(1):95. [doi: 10.1186/s12887-021-02550-1] [Medline: 33627089]
9. Marciano L, Ostroumova M, Schulz PJ, Camerini AL. Digital media use and adolescents' mental health during the covid-19 pandemic: a systematic review and meta-analysis. Front Public Health 2021;9:793868. [doi: 10.3389/fpubh.2021.793868] [Medline: 35186872]
10. Social media and youth mental health. : The U.S. Surgeon General's Advisory; 2023 URL: https://www.hhs.gov/sites/default/files/sg-youth-mental-health-social-media-advisory.pdf [accessed 2026-02-04]
11. Tao X, Fisher CB. Exposure to social media racial discrimination and mental health among adolescents of color. J Youth Adolesc 2022 Jan;51(1):30-44. [doi: 10.1007/s10964-021-01514-z] [Medline: 34686952]
12. Li X, Vanderloo LM, Keown-Stoneman CDG, et al. Screen use and mental health symptoms in canadian children and youth during the COVID-19 pandemic. JAMA Netw Open 2021 Dec 1;4(12):e2140875. [doi: 10.1001/jamanetworkopen.2021.40875] [Medline: 34962557]
13. Bramer WM, Giustini D, de Jonge GB, Holland L, Bekhuis T. De-duplication of database search results for systematic reviews in EndNote. J Med Libr Assoc 2016 Jul;104(3):240-243. [doi: 10.3163/1536-5050.104.3.014] [Medline: 27366130]
14. Borenstien M, Hedges LV, Higgins JPT, Rothstein HR. Introduction to Meta-Analysis: John Wiley & Sons Incorporated; 2009.
15. Alves JM, Yunker AG, DeFendis A, Xiang AH, Page KA. BMI status and associations between affect, physical activity and anxiety among U.S. children during COVID-19. Pediatr Obes 2021 Sep;16(9):e12786. [doi: 10.1111/ijpo.12786] [Medline: 33720550]
16. Berki T, F. Pikó B. Sedentary lifestyle may contribute to the risk of depression during the COVID-19 pandemic: a snapshot of Hungarian adolescents. EJMH 2021;16(2):99-119. [doi: 10.5708/EJMH.16.2021.2.5]
17. Charmaraman L, Lynch AD, Richer AM, Zhai E. Examining early adolescent positive and negative social technology behaviors and well-being during the COVID-19 pandemic. Technol Mind Behav 2022;3(1). [doi: 10.1037/tmb0000062] [Medline: 36561093]
18. Chen CY, Chen IH, O'Brien KS, Latner JD, Lin CY. Psychological distress and internet-related behaviors between schoolchildren with and without overweight during the COVID-19 outbreak. Int J Obes (Lond) 2021 Mar;45(3):677-686. [doi: 10.1038/s41366-021-00741-5] [Medline: 33495523]
19. Ellis WE, Dumas TM, Forbes LM. Physically isolated but socially connected: psychological adjustment and stress among adolescents during the initial COVID-19 crisis. Canadian Journal of Behavioural Science / Revue canadienne des sciences du comportement 2020;52(3):177-187. [doi: 10.1037/cbs0000215]
20. Fazeli S, Zeidi IM, Lin CY, et al. Corrigendum to "Depression, anxiety, and stress mediate the associations between internet gaming disorder, insomnia, and quality of life during the COVID-19 outbreak" [Addict. Behav. Rep. 12 (2020) 100307]. Addict Behav Rep 2020 Dec;12:100322. [doi: 10.1016/j.abrep.2020.100322] [Medline: 33364329]
21. Lee J, Lim H, Allen J, Choi G, Jung J. Smartphone addiction and depression among low-income boys since COVID-19: the moderating effect of being an only child. Healthcare (Basel) 2021;9(10):1350. [doi: 10.3390/healthcare9101350]
22. Liu S, Zou S, Zhang D, Wang X, Wu X. Problematic internet use and academic engagement during the COVID-19 lockdown: the indirect effects of depression, anxiety, and insomnia in early, middle, and late adolescence. J Affect Disord 2022 Jul 15;309:9-18. [doi: 10.1016/j.jad.2022.04.043] [Medline: 35439467]

23. McArthur BA, Racine N, Browne D, McDonald S, Tough S, Madigan S. Recreational screen time before and during COVID-19 in school-aged children. Acta Paediatr 2021 Oct;110(10):2805-2807. [doi: 10.1111/apa.15966] [Medline: 34076927]
24. Moitra P, Madan J. Impact of screen time during COVID-19 on eating habits, physical activity, sleep, and depression symptoms: a cross-sectional study in Indian adolescents. PLoS ONE 2022;17(3):e0264951. [doi: 10.1371/journal.pone.0264951] [Medline: 35259203]
25. Mousavi SZ, Barry CT, Halter BM. Relations of adolescent knowledge of COVID-19, social media engagement, and experiences during quarantine/lockdown with well-being. J Child Fam Stud 2023;32(1):110-121. [doi: 10.1007/s10826-022-02465-0] [Medline: 36277326]
26. Murata S, Rezeppa T, Thoma B, et al. The psychiatric sequelae of the COVID-19 pandemic in adolescents, adults, and health care workers. Depress Anxiety 2021 Feb;38(2):233-246. [doi: 10.1002/da.23120] [Medline: 33368805]
27. Muzi S, Sansò A, Pace CS. What's happened to Italian adolescents during the COVID-19 pandemic? A preliminary study on symptoms, problematic social media usage, and attachment: relationships and differences with pre-pandemic peers. Front Psychiatry 2021;12:590543. [doi: 10.3389/fpsyt.2021.590543] [Medline: 33986698]
28. Ren Z, Xin Y, Wang Z, Liu D, Ho RCM, Ho CSH. What factors are most closely associated with mood disorders in adolescents during the COVID-19 pandemic? A cross-sectional study based on 1,771 adolescents in Shandong Province, China. Front Psychiatry 2021;12:728278. [doi: 10.3389/fpsyt.2021.728278] [Medline: 34603106]
29. Sikorska IM, Lipp N, Wróbel P, Wyra M. Adolescent mental health and activities in the period of social isolation caused by the COVID-19 pandemic. Postep Psychiatr Neurol 2021 Jun;30(2):79-95. [doi: 10.5114/ppn.2021.108472] [Medline: 37082432]
30. Tandon PS, Zhou C, Johnson AM, Gonzalez ES, Kroshus E. Association of children's physical activity and screen time with mental health during the COVID-19 pandemic. JAMA Netw Open 2021 Oct 1;4(10):e2127892. [doi: 10.1001/jamanetworkopen.2021.27892] [Medline: 34596669]
31. Tardif-Grenier K, Archambault I, Dupéré V, Marks AK, Olivier E. Canadian adolescents' internalized symptoms in pandemic times: association with sociodemographic characteristics, confinement habits, and support. Psychiatr Q 2021 Sep;92(3):1309-1325. [doi: 10.1007/s11126-021-09895-x] [Medline: 33768414]
32. Teng Z, Pontes HM, Nie Q, Griffiths MD, Guo C. Depression and anxiety symptoms associated with internet gaming disorder before and during the COVID-19 pandemic: a longitudinal study. J Behav Addict 2021 Mar 10;10(1):169-180. [doi: 10.1556/2006.2021.00016] [Medline: 33704085]
33. Xiang M, Liu Y, Yamamoto S, Mizoue T, Kuwahara K. Association of changes of lifestyle behaviors before and during the COVID-19 pandemic with mental health: a longitudinal study in children and adolescents. Int J Behav Nutr Phys Act 2022 Jul 26;19(1):92. [doi: 10.1186/s12966-022-01327-8] [Medline: 35883177]
34. Zhang Y, Zhan N, Zou J, Xie D, Liu M, Geng F. The transmission of psychological distress and lifestyles from parents to children during COVID-19. J Affect Disord 2022 Apr;303:74-81. [doi: 10.1016/j.jad.2022.02.007]
35. Zhu S, Zhuang Y, Lee P, Li JCM, Wong PWC. Leisure and problem gaming behaviors among children and adolescents during school closures caused by COVID-19 in Hong Kong: quantitative cross-sectional survey study. JMIR Serious Games 2021 May 7;9(2):e26808. [doi: 10.2196/26808] [Medline: 33960954]
36. Higgins JPT, Thompson SG. Quantifying heterogeneity in a meta-analysis. Stat Med 2002 Jun 15;21(11):1539-1558. [doi: 10.1002/sim.1186] [Medline: 12111919]
37. Gignac GE, Szodorai ET. Effect size guidelines for individual differences researchers. Pers Individ Dif 2016 Nov;102:74-78. [doi: 10.1016/j.paid.2016.06.069]
38. Rubio-Aparicio M, Sánchez-Meca J, López-López JA, Botella J, Marín-Martínez F. Analysis of categorical moderators in mixed-effects meta-analysis: consequences of using pooled versus separate estimates of the residual between-studies variances. Br J Math Stat Psychol 2017 Nov;70(3):439-456. [doi: 10.1111/bmsp.12092] [Medline: 28164265]
39. Viechtbauer W, Cheung MWL. Outlier and influence diagnostics for meta-analysis. Res Synth Methods 2010 Apr;1(2):112-125. [doi: 10.1002/jrsm.11] [Medline: 26061377]
40. Viechtbauer W. Conducting meta-analyses in R with the metafor package. J Stat Softw 2010;36(3):1-48. [doi: 10.18637/jss.v036.i03]
41. von Elm E, Altman DG, Egger M, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. J Clin Epidemiol 2008 Apr;61(4):344-349. [doi: 10.1016/j.jclinepi.2007.11.008] [Medline: 18313558]
42. De Pasquale C, Chiappedi M, Sciacca F, Martinelli V, Hichy Z. Online videogames use and anxiety in children during the COVID-19 pandemic. Children (Basel) 2021 Mar 8;8(3):205. [doi: 10.3390/children8030205] [Medline: 33800320]
43. Li X, Vanderloo LM, Keown-Stoneman CDG, et al. Screen use and mental health symptoms in Canadian children and youth during the COVID-19 pandemic. JAMA Netw Open 2021 Dec 1;4(12):e2140875. [doi: 10.1001/jamanetworkopen.2021.40875] [Medline: 34962557]
44. Nilsson A, Rosendahl I, Jayaram-Lindström N. Gaming and social media use among adolescents in the midst of the COVID-19 pandemic. Nordisk Alkohol Nark 2022 Aug;39(4):347-361. [doi: 10.1177/14550725221074997] [Medline: 35999947]

45. Perez O, Garza T, Hindera O, et al. Validated assessment tools for screen media use: a systematic review. PLoS One 2023;18(4):e0283714. [doi: 10.1371/journal.pone.0283714] [Medline: 37053175]
46. Byrne R, Terranova CO, Trost SG. Measurement of screen time among young children aged 0-6 years: a systematic review. Obes Rev 2021 Aug;22(8):e13260. [doi: 10.1111/obr.13260] [Medline: 33960616]
47. The 5Cs of media use. American Academy of Pediatrics. 2024 Apr 20. URL: https://www.aap.org/en/patient-care/media-and-children/center-of-excellence-on-social-media-and-youth-mental-health/5cs-of-media-use/ [accessed 2025-04-11]
48. Krug SE, Chung S, Fagbuyi DB, et al. Ensuring the health of children in disasters. Pediatrics 2015 Nov 1;136(5):e1407-e1417. [doi: 10.1542/peds.2015-3112]

Abbreviations

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
STROBE: Strengthening the Reporting of Observational studies in Epidemiology

Edited by S Badawy; submitted 05.Sep.2025; peer-reviewed by H Pratomo, Y Wu; revised version received 12.Jan.2026; accepted 25.Jan.2026; published 01.Apr.2026.

Please cite as:
Yoshizawa M, Rafeedie J, Tang JJ, Lei BT, Durazo-Arvizu R, Azucar D, Hudson S, Rao S, Imagawa KK, Deavenport-Saman A
Screen Time, Child Depression, and Anxiety During the COVID-19 Pandemic: Systematic Review and Meta-Analysis
JMIR Pediatr Parent 2026;9:e83228
URL: https://pediatrics.jmir.org/2026/1/e83228
doi:10.2196/83228

Digital Health Interventions for Sexual Health Education Among Adolescents With Autism Spectrum Disorder: Scoping Review

Elsi Rahmadani[1,2], MKep; Idris Adewale Ahmed[1], PhD

[1]School of Nursing & Applied Science, Lincoln University College, Petailing Jaya, Malaysia
[2]Department of Pediatric Nursing, STIKes Tri Mandiri Sakti Bengkulu, Jl. Raya Hibrida No.3, Sido Mulyo, Gading Cempaka, Bengkulu, Indonesia

Corresponding Author:
Elsi Rahmadani, MKep
School of Nursing & Applied Science, Lincoln University College, Petailing Jaya, Malaysia

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.

(JMIR Pediatr Parent 2026;9:e79009) doi:10.2196/79009

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 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).

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, 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.

Data Analysis and Synthesis

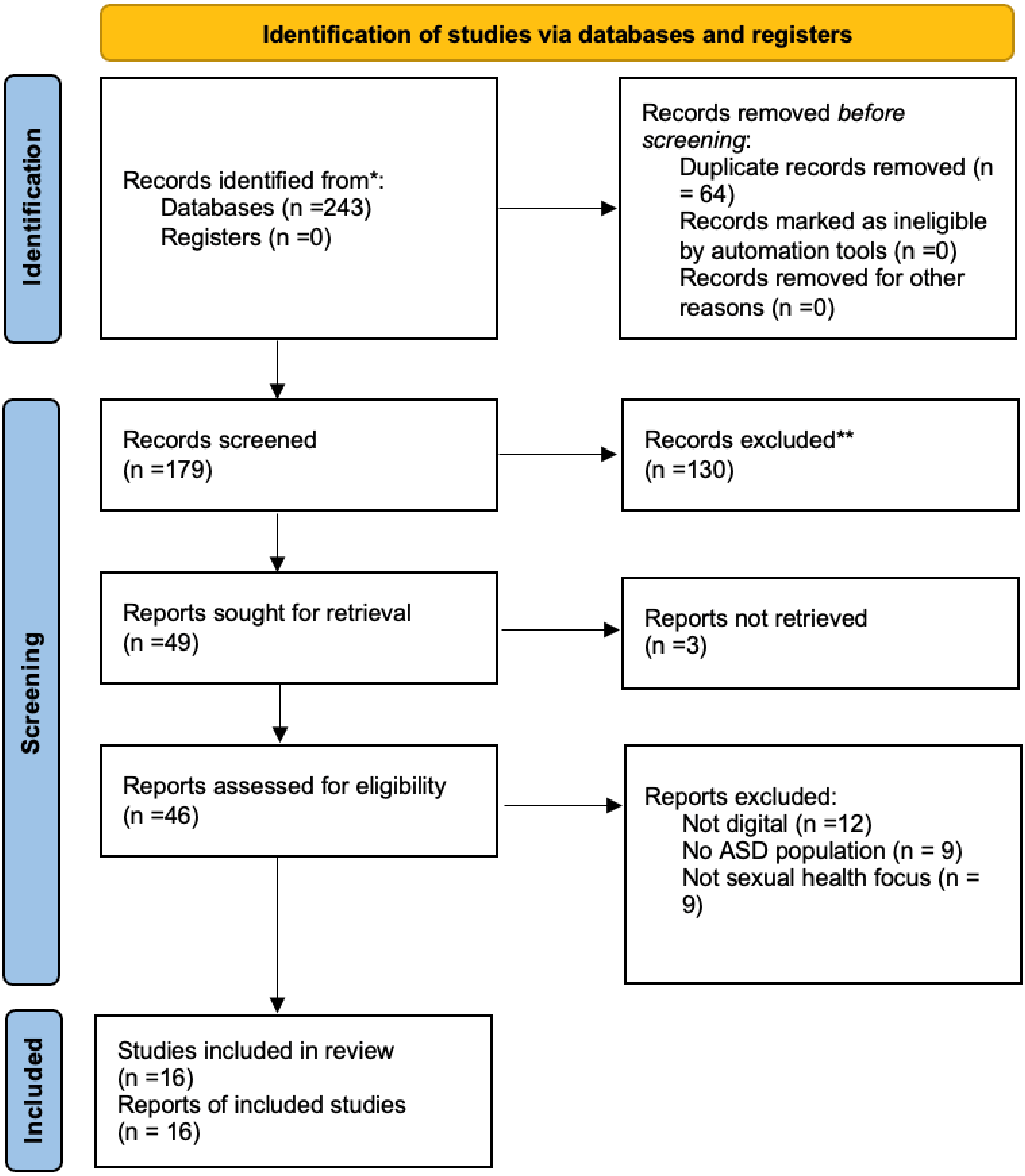
Extracted data were organized into structured summary tables capturing key study features, intervention characteristics, and reported outcomes. A narrative synthesis was then conducted using a combined inductive-deductive thematic approach. Deductive coding was informed by the review objectives and a 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).

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.

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

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.

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.

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 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.

Acknowledgments

The authors would like to express their gratitude to all individuals and institutions that contributed to the completion of this study.

Funding

The authors declared no financial support was received for this work.

Conflicts of Interest

None declared.

Checklist 1
PRISMA-ScR Checklist.
[DOCX File, 67 KB - pediatrics_v9i1e79009_app1.docx]

References

1. Zeidan J, Fombonne E, Scorah J, et al. Global prevalence of autism: a systematic review update. Autism Res 2022 May;15(5):778-790. [doi: 10.1002/aur.2696] [Medline: 35238171]
2. WHO guidelines on mental health at work. : World Health Organization; 2022 URL: https://iris.who.int/server/api/core/bitstreams/6152a556-6893-4c4e-9ed8-094478bb25eb/content [accessed 2026-01-13]
3. Gil-Llario MD, Fernández-García O, Morell-Mengual V, Estruch-García V, Ruiz-Palomino E. Effectiveness of an affective-sexual intervention for adolescents with autism spectrum disorder and their parents: a randomized trial. Research in Autism 2025 May;123:202541. [doi: 10.1016/j.reia.2025.202541]
4. Weiss JA, Fardella MA. Victimization and perpetration experiences of adults with autism. Front Psychiatry 2018;9:203. [doi: 10.3389/fpsyt.2018.00203] [Medline: 29887806]
5. Cooke K, Ridgway K, Westrupp E, Hedley D, Hooley M, Stokes MA. The prevalence and risk factors of autistic experiences of interpersonal violence: a systematic review and meta-analysis. In Review. Preprint posted online on Nov 23, 2022 URL: https://doi.org/10.21203/rs.3.rs-2286120/v1 [accessed 2026-01-13] [doi: 10.21203/rs.3.rs-2286120/v1]
6. Ngo AM, Donaghue A, Weng KH, Crehan ET. Barriers and facilitators for addressing sex education for autistic individuals: a systematic review. J Spec Educ 2025 Aug;59(2):71-80. [doi: 10.1177/00224669241292045]
7. Greene A, Simić Stanojević I, Sherwood-Laughlin C, et al. Teachers' perceptions of barriers to implementing school-based sexual health education for students with intellectual and developmental disabilities. Am J Sex Educ 2025 Oct 2;20(4):536-558. [doi: 10.1080/15546128.2024.2429432]
8. Motamed M, Hajikarim-Hamedani A, Fakhrian A, Alaghband-Rad J. A systematic review of sexual health, knowledge, and behavior in autism spectrum disorder. BMC Psychiatry 2025 Apr 22;25(1):410. [doi: 10.1186/s12888-025-06836-x] [Medline: 40264093]
9. Kennedy RS. A meta-analysis of the outcomes of bullying prevention programs on subtypes of traditional bullying victimization: verbal, relational, and physical. Aggress Violent Behav 2020 Nov;55:101485. [doi: 10.1016/j.avb.2020.101485]
10. Chin PS, Ramachandram S. Effectiveness of sexual health training to parents with children of autism spectrum disorder. Med J Malaysia 2024 Jul;79(4):464-469. [Medline: 39086345]
11. Ballan MS, Freyer MB. Autism spectrum disorder, adolescence, and sexuality education: suggested interventions for mental health professionals. Sex Disabil 2017 Jun;35(2):261-273. [doi: 10.1007/s11195-017-9477-9]
12. Ayuningtyas F, Genilo JWR, Intyaswati D, et al. Enhancing sex education for children with autism: a comparative analysis of phenomenology. . Retracted inCogent Social Sciences. 2024;10(1):2350132. [doi: 10.1080/23311886.2024.2350132]

13. Estruch-García V, Gil-Llario MD, Ruiz-Palomino E, Fernández-García O, Morell-Mengual V, Anastácio ZFC. Systematic integrative review: sex education for people with autism spectrum disorder. Sex Disabil 2025 Mar;43(1):6. [doi: 10.1007/s11195-025-09890-1]
14. Tan-MacNeill KM, Smith IM, Corkum PV. Acceptability of an online intervention for insomnia in children with neurodevelopmental disorders. Res Dev Disabil 2023 Mar;134:104423. [doi: 10.1016/j.ridd.2023.104423] [Medline: 36640741]
15. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci 2010 Sep 20;5:69. [doi: 10.1186/1748-5908-5-69] [Medline: 20854677]
16. Peters MDJ, Godfrey C, McInerney P, Munn Z, Tricco AC, Khalil H. Scoping reviews. JBI Manual for Evidence Synthesis 2020. [doi: 10.46658/JBIMES-24-09]
17. Tricco AC, Lillie E, Zarin W, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med 2018 Oct 2;169(7):467-473. [doi: 10.7326/M18-0850] [Medline: 30178033]
18. Chan J, John RM. Sexuality and sexual health in children and adolescents with autism. J Nurse Pract 2012 Apr;8(4):306-315. [doi: 10.1016/j.nurpra.2012.01.020]
19. Strauss C, Bibby-Jones AM, Jones F, et al. Clinical effectiveness and cost-effectiveness of supported mindfulness-based cognitive therapy self-help compared with supported cognitive behavioral therapy self-help for adults experiencing depression: the Low-Intensity Guided Help Through Mindfulness (LIGHTMind) randomized clinical trial. JAMA Psychiatry 2023 May 1;80(5):415-424. [doi: 10.1001/jamapsychiatry.2023.0222] [Medline: 36947058]
20. Lou C, Arriaga RI. eLIFE: social network based digital support for individuals with ASD. 2019 Presented at: CSCW '19 Companion: Companion Publication of the 2019 Conference on Computer Supported Cooperative Work and Social Computing; Nov 9-3, 2019; Austin, TX, USA p. 293-298. [doi: 10.1145/3311957.3359494]
21. Teti M, Cheak-Zamora N, Bauerband LA, Maurer-Batjer A. A qualitative comparison of caregiver and youth with autism perceptions of sexuality and relationship experiences. J Dev Behav Pediatr 2019 Jan;40(1):12-19. [doi: 10.1097/DBP.0000000000000620] [Medline: 30444737]
22. Drozdowicz L, Gordon E, Shapiro D, et al. Sexual health in child and adolescent psychiatry: multi-site implementation through synchronized videoconferencing of an educational resource using standardized patients. Front Psychiatry 2020;11:593101. [doi: 10.3389/fpsyt.2020.593101] [Medline: 33329142]
23. Pugliese CE, Ratto AB, Granader Y, et al. Feasibility and preliminary efficacy of a parent-mediated sexual education curriculum for youth with autism spectrum disorders. Autism 2020 Jan;24(1):64-79. [doi: 10.1177/1362361319842978] [Medline: 31096780]
24. Zervogianni V, Fletcher-Watson S, Herrera G, et al. A framework of evidence-based practice for digital support, co-developed with and for the autism community. Autism 2020 Aug;24(6):1411-1422. [doi: 10.1177/1362361319898331] [Medline: 32026715]
25. Shakuri MA, Alzahrani HM. Challenges of sex education for adolescents with autism spectrum disorder from the Saudi family's perspective. Front Educ 2023;8:1150531. [doi: 10.3389/feduc.2023.1150531]
26. Camilleri LJ, Maras K, Brosnan M. Supporting autistic communities through parent-led and child/young person-led digital social story interventions: an exploratory study. Front Digit Health 2024;6:1355795. [doi: 10.3389/fdgth.2024.1355795] [Medline: 38545445]
27. Panagiotakopoulou A, Vasileiou I, Katsarou DV. Investigation of sexual education programs for adolescents with autism and the role of parents in providing support. Mater Sociomed 2024;36(2):155-159. [doi: 10.5455/msm.2024.36.155-159] [Medline: 39712329]
28. Quayle E, Schwannauer M, Varese F, et al. What are practitioners' views of how digital health interventions may play a role in online child sexual abuse service delivery? Front Digit Health 2024;6:1325385. [doi: 10.3389/fdgth.2024.1325385] [Medline: 38572144]
29. Oğur Ç, Olçay S. The effectiveness of video visual scene display-assisted behavioral skills training in the instruction of skills to prevent online sexual abuse among adults with autism spectrum disorder. Arch Sex Behav 2025 Jun;54(6):2373-2386. [doi: 10.1007/s10508-025-03152-z] [Medline: 40447919]
30. Wang T, Ma Y, Du X, et al. Digital interventions for autism spectrum disorders: a systematic review and meta-analysis. Pediatr Investig 2024 Sep;8(3):224-236. [doi: 10.1002/ped4.12417] [Medline: 39347529]
31. Pownall M, Talbot CV, Henschel A, et al. Navigating open science as early career feminist researchers. Psychol Women Q 2021 Dec;45(4):526-539. [doi: 10.1177/03616843211029255]
32. Dewinter J, De Graaf H, Begeer S. Sexual orientation, gender identity, and romantic relationships in adolescents and adults with autism spectrum disorder. J Autism Dev Disord 2017 Sep;47(9):2927-2934. [doi: 10.1007/s10803-017-3199-9] [Medline: 28597143]

Abbreviations

ASD: autism spectrum disorder
LMIC: low- and middle-income country

MeSH: Medical Subject Headings
PCC : population-concept-context
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews

Edited by S Badawy; submitted 13.Jun.2025; peer-reviewed by A Olanlesi-Aliu, C Campoy-Guerrero; revised version received 05.Nov.2025; accepted 24.Dec.2025; published 19.Mar.2026.

Please cite as:
Rahmadani E, Ahmed IA
Digital Health Interventions for Sexual Health Education Among Adolescents With Autism Spectrum Disorder: Scoping Review
JMIR Pediatr Parent 2026;9:e79009
URL: https://pediatrics.jmir.org/2026/1/e79009
doi:10.2196/79009

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org